Activating Illness:

Tactics from Patient Activism and the Politics of

Thalassaemia in Cyprus

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Abstract

Thalassaemia is a blood disorder prevalent amongst the Cypriot population because of genetic, ecological, and social reasons. Although a successful prevention system has been in place since the early 1980s, approximately 650 thalassaemia patients still live on the island whose births preceded the given system. For my fieldwork I spent a year in Cyprus with the PanCyprian Thalassaemia Association (PTA) – a patients group which acts as the main channel of politicisation for thalassaemia patients in Cyprus. By organising events such as conferences, fundraisers and workshops, the PTA strives to maintain the awareness of thalassaemia in the Cypriot public sphere. The association also maintains an agonistic yet healthy relationship with the Cypriot state. Thalassaemia treatment in Cyprus is provided by public healthcare and, since its foundation in 1973, the PTA has won several skirmishes against the state on issues such as a more reliable blood supply, better provision of medicines, and more hospital space for patients. In addition, the PTA has forged numerous alliances with national and international organisations, patient associations and scientific research bodies which have a decisive say in how thalassaemia comes to be enacted on a Cypriot and global level. Throughout the thesis I focus on the tactics the PTA uses to politically activate thalassaemia. As I argue, activating illness entails making discernible political dimensions of illness which previously evaded, or were left unaccounted, by public and governmental perceptions. In addition, through the anthropological analysis of PTA case studies, I develop tactics of my own by which patient associations can activate illness. Through an ethnography and at the same time conceptual development of tactics, the thesis aims to fruitfully reconcile the ontology and politics of illness.
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Declaration: no portion of the work referred to in the thesis has been submitted in support of an application for another degree or qualification of this or any other university or other institute of learning.

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Introduction

Thalassaemia is one of the most common blood disorders worldwide (Dyson and Atkin, 2011). The name of the illness comes from *thalassa*, meaning “sea” in Greek and *aima* for “blood”. This name derives from the distribution of the illness, which is particularly prevalent in areas situated around the Mediterranean basin. Thalassaemia is a recessive illness and is not contagious but genetically inherited. If both the mother and father of a newborn are carriers of the mutation, then the newborn has a 25% chance of being a patient of thalassaemia, a 50% chance of being a carrier of the thalassaemia mutation, and a 25% chance of being neither of the above. The transmission pattern of thalassaemia is detailed below in Figure 1. Being born with thalassaemia means that one’s red blood cells are unable to produce sufficient haemoglobin, thus restricting oxygen circulation in the body, and causing tiredness, asphyxiation, and ultimately, if left untreated, death. Thalassaemia patients require weekly to bi-weekly blood transfusions to restore their haemoglobin to normal levels. The side effect of blood transfusions is that, because of these influxes of blood, excess iron accumulates in the body, which can also prove deadly over time. Thus, in addition to transfusions, thalassaemia patients also use deferoxamine - a chelating agent - on a daily basis in order to remove excess iron from their organism. Deferoxamine is either injected in the body using dialysis pumps or ingested orally in the form of tablets. Deferoxamine leads to physiological side effects, such as nausea and drowsiness, which are detailed in the second chapter of the thesis.

Cyprus is one of the countries with the highest percentage of the thalassaemia mutation in proportion to its total population. More specifically, 16% of the population - 1 out of 8 Cypriots - carries the thalassaemia mutation, second only to the Maldives which has a prevalence of 18% (Agarwal et al. 2014). When I first started my PhD in September of 2011, my objective was to explore the workings of the Cypriot thalassaemia prevention
system which I detail in the first chapter of the thesis. I found this topic interesting because it presents a really impressive example of biopolitical governance and public understanding and uptake of science in relation to existing cultural logics and practices. As mentioned, Cyprus is one of the countries in the world with the highest prevalence of thalassaemia. Nevertheless, through the given scheme births of children suffering from thalassaemia were minimised in the short span of ten years. In this respect, the small population (just under 600 thousand in 1960 and currently 1.1 million) and isolated island ecology of Cyprus acted as a double-edged sword. While it allowed the recessive disorder to freely circulate and spread within the Cypriot population in previous years, it also made it easier to control, once the proper legislative, technological and medical arrangements were put into place. Nowadays no accidental births of infants with thalassaemia happen. Cypriots are regularly tested and given certificates on their status as carriers of the thalassaemia mutation, either shortly after birth or as young adults (see Figure 2 for the author’s certificate that he is not a carrier of the thalassaemia mutation). In addition, since 1983, newlywed couples to-be have had to acknowledge that they have been genetically tested for the disorder by presenting a premarital certificate to the wedding authorities (see Figure 3). While the certificate declares that both are aware of their status as a carrier or not, it does not divulge the results of the tests. Genetic counselling arrangements are also in place, which provide guidance for couples should they both prove to be carriers of the mutation.

The result of such arrangements is that thalassaemia, an illness which even up to the early 1980s carried connotations of social discrimination in Cyprus, is now liberally talked about. Discourses on thalassaemia are not only communicated from the Cypriot state to the public, in order to maintain awareness of getting screened, but also amongst the public itself – discussed between friends, families, newly-wed couples, and between men and
women who have just met each other. Such discussions usually revolve around the notion of “the stigma”. The stigma is the idiomatic name given to the thalassaemia mutation by the Cypriot population.

![Figure 1: Recessive transmission pattern of thalassaemia.](image)

Images reproduced from (Hadjiminas, 2008: 44-46)
It is undeniably a spectre of the illness’ problematic past, a time when those suffering from thalassaemia, or even those simply carrying the mutation, were indeed stigmatised by Cypriot society (see Chapter 1). Yet, over the years, through intense public sensitisation and more developed understanding of thalassaemia by the Cypriot public, a peculiar inversion in the definition of the stigma occurred. On occasions of imminent marriage or child-birth, or even when people feel unwell, Cypriot people freely discuss whether one carries the stigma. The stigma does not refer to the figure and personal condition of the carrier as much as it does the general condition of the mutation itself. In short, although its name has not changed, the stigma no longer causes social withdrawal, but rather connection.  

Fig. 2. Certificate of the author denoting that he does not have the thalassaemia “stigma”. The second image, carrying the doctor’s signature, says “lab exam showed nothing pathological. 

I was drawn by the particularity with which the Cypriot government and public faced its problem of thalassaemia, and decided to write about it. I was further provoked by the fact that most anthropological work that happens in Cyprus nowadays, in accordance with a general impression most people have of the island, is preoccupied with its political landscape: the 1974 Turkish invasion, the splitting of the island in two and the current climate of reconciliation between the two parts. These are elements which do appear in
the thesis, but do not form its core. The political history of Cyprus is undoubtedly entangled with the history of thalassaemia on the island. The short history of Cyprus is a turbulent one, and this is a trajectory paralleled by the history of Cypriot thalassaemia – one likewise permeated by rupture and unpredictability. The social processes which occurred in the period 1940-1959, when the island was still under British administration, its declaration of independence in 1960 and the post-1974 rebuilding of Cypriot society and economy were catalytic in terms of how thalassaemia circulated and was understood in the Cypriot population. This was reflected in terms of population movement, urbanisation and a more general trajectory of democratisation and modernisation which took place in the aftermath of the invasion, and which changed how the illness was spread, transmitted, and perceived in the island. One can understand plenty about the history of Cyprus through the prism of thalassaemia.

When writing my first year PhD proposal I drafted a hypothesis, using theories from complexity theory, that the Cypriot thalassaemia prevention system was successful because it acted as an “attractor” which, through genetic counselling and public discourses on thalassaemia, managed to accommodate the specificity of individual circumstances within overarching institutional, legislative and healthcare arrangements. Through such accommodation of the particular and the general, individual circumstances and biopolitical governance were both affirmed, while thalassaemia as a space of knowledge and practice persevered. My impression was that, akin to what Roy Wagner wrote of incest amongst the Daribi (Wagner, 2011), this was an arrangement according to which both, prohibition (or prevention in this case) and the object prohibited, were co-produced. The objective of the project was to pinpoint the mechanisms through which such accommodation and co-production of illness and prevention is achieved. Another objective was to pinpoint the mediums and media channels through which the Cypriot state communicat-
ed information to the public. Finally, I was also interested in the public reception of such information, and wanted to find out to what extent the Cypriot population was morally aligned with the prevention system. Did Cypriot people share the sentiment promoted by legislative arrangements of having “the right to know?” How did they negotiate bioethical dilemmas of “choice” and “free will” (Prainsack and Siegal, 2006) through genetic counselling and governmental discourses on thalassaemia? What was their impression of the premarital certificate, which, of all institutional authorities, was introduced by the Cypriot Christian Orthodox Church?

![Certificate](image.png)

Fig. 3: Scan of the premarital certificate given to Cypriot couples. Image reproduced from (Hadjiminas, 2008: 159)
Most of these objectives were cast away in the initial months of fieldwork. This was due to the blend of circumstances I found myself in, as well as personal choice. For one, I wasn’t able to get access to the counselling sessions conducted by clinicians to newly-wed couples who both carried the thalassaemia mutation. Asking for the names of couples in order to talk to them in my own time was of course out of the question as this would endanger their privacy. Furthermore, the counsellors did not agree to ask couples if they were willing to be interviewed. All in all, the counsellors were adamant in protecting the anonymity and emotionally fragile circumstances of couples. These were ethnographic indications in themselves, but not ones I could do much with.

In addition, I was put off by the overwhelming approval by which the Cypriot public handled governmental discourses and regulations on thalassaemia. My issue was not that a widespread sense of agreement between state officials and the public was unworthy of doing a project on. After all consistency, much like denial is an ethnographic question in itself. Rather, I felt that such discussions and agreement did not present itself as a bounded topic of inquiry. Although the legislative arrangements of the Cypriot thalassaemia prevention system have been inciting discussion amongst the annals of bioethicists on issues of morality, life and choice for years (e.g. Cousens et al. 2010; Cowan, 2009; Hoesdemaakers and ten Have, 1998), this has not been the case amongst the Cypriot population. The premarital certificate is readily and unproblematically accepted by the overwhelming majority of newly-wed couples. In all of the initial interviews I conducted with couples, the premarital certificate always proved to be trivially mentioned – it was treated as instrumental to having children, having a family and getting married. As previously mentioned, this is certainly a topic of inquiry in itself, but I did not want to devote my thesis to exploring a ubiquitously accepted “obligatory point of passage” (Law and Callon, 1988) which, nevertheless, led to a myriad other trajectories of life.
The decisive factor which changed the focus of my inquiry was my set of initial conversations with existing thalassaemia patients. I first made contact with patients when I started piecing together the historical trajectory by which the prevention system emerged, which is presented in the first chapter of the thesis. Although a rudimentary treatment system was put in place in 1970, it did not attain consistency until 1981, when the technology of foetoscopy was introduced in Cypriot healthcare. The vast majority of thalassaemia patients were born before the prevention system was fully put into effect. Between 1970 and 1981 the existing parents of thalassaemia patients and, as time passed, the patients themselves, advocated intensely for more public sensitisation of thalassaemia. They did so for two reasons. First, better awareness of the illness amongst the Cypriot public would mean better conditions for patients and their families, who up until that point had been stigmatised and ostracised from villages and communities. Second, if the state provided better guidance regarding screening and prevention of thalassaemia to couples, and hence minimised the births of infants with thalassaemia, then existing patients would have a greater supply of blood transfusions and deferoxamine – the two basic methods which even today are used to treat thalassaemia. This second factor was of particular importance since the newly formed Cypriot economy was in its infancy, and thalassaemia treatment is expensive. The lobbying of the Cypriot state by patients intensified with the founding of the PanCyprian Thalassaemia Association in 1973. This is the political entity my thesis largely focuses on.

In talking to patients, it became apparent that while nowadays the Cypriot prevention system of thalassaemia functions well, this is not the case on the treatment side of things. This is in contrast to the early years of treating thalassaemia in Cyprus when the treatment system was considered to be internationally pioneering and successful. This lack in treatment aspects for thalassaemia patients in Cyprus can be traced back an overall lack-
ing and aging healthcare system, some features of which date back to British colonial rule (Antoniadou, 2005). Cyprus is currently the only EU country which does not have a national health system in place. Even though a parliamentary law was passed in 2002 dictating that plans move forward for a nationwide health system, these are yet to materialize. In addition, what little progress has been made in implementing a Cypriot NHS is being derailed by an increasing austerity measures imposed after the 2012 IMF bailout. Because of these insufficiencies the Cypriot population is becoming increasingly dependent on private-sector healthcare for quality treatment. Yet, due to lack transparency and regulation, private healthcare in Cyprus promotes inequality to access and provision of medication and therapy (Cylus, et al., 2013). It is currently estimated that private healthcare currently constitutes 50% of healthcare consumption in Cyprus (Samoutis and Paschalides, 2011).

Nevertheless, private treatment is not feasible for the overwhelming majority of thalassemia patients due to the chronic nature of their illness and the expensive prices of their medication. This leaves them no other option but to depend on current governmental healthcare arrangements for their treatment. Patients would repeatedly give me evaluations of the Cypriot thalassaemia treatment as remaining “static” and becoming increasingly inattentive to their needs. Although the prevention system receives considerable publicity in international circles of medical policy and bioethics, this is not the case for the treatment system. The relation between the two goes beyond international recognition. The prevention system is geared towards a long-term cause, namely the prevention of a prevalent recessive disorder amongst a small island population. This is a relatively inexpensive task achieved through a sedimanted public understanding of thalassaemia and a genetic counselling system comprised of a handful of counsellors island-wide. On the other hand, since the prevention system has proved really successful, the treatment
system is only relevant to a static and ageing population of about 650 thalassaemia patients (this is 2013 figure provided to me during one of my interviews by a thalassaemia patient). In addition, thalassaemia treatment is costly due to its chronic dimension, a fact which as I mentioned before was the impetus for introducing a prevention system in the first place. Thus, for the Cypriot state, priority, and also ease of execution, is on the side of prevention rather than treatment.

*Politics and the political*

The relation between a self-organised prevention system and a malfunctioning treatment system has put patients in the difficult position of trying to maintain relevance amid governmental agendas and budget cuts – a condition which has only been intensified by the politics of austerity implemented on the Cypriot economy ever since March 2012. On the one hand, the PTA maintain their goal of keeping the Cypriot public aware of thalassaemia and encouraging people to get screened so as to facilitate better treatment for existing patients. On the other hand, the association constantly tries to maintain pressure and convey to the Cypriot state that the treatment system is operating according to an older paradigm of mortality, when thalassaemia was considered to be a deadly rather than chronic condition. The ontological leap from mortality to chronicity, achieved through advances in therapy and social integration, means that for patients thalassaemia is no longer a telos but a process. In other words, unlike in its earlier manifestations when treatment was sparse and rudimentary, thalassaemia is no longer perceived in relation to the anticipation of imminent death, but rather in accordance with the multiplicity of practices by which thalassaemia is enacted in everyday life, as well as by how such practices change over time.
Ontology, generally put, is the study what entities exist in the world and how these affect each other. The emphasis I put on everyday practices of thalassaemia patients and how these transform, or have the potential to transform, means that the ontological perspective through which thalassaemia is explored in this thesis is processual. In other words, I do not perceive the ontology of thalassaemia to be static, but rather a process, changing through time. As I will repeatedly argue, this change in the ontology of thalassaemia stems from social, economic, technological and most importantly political factors. My treatment of ontology throughout the thesis, although potentially relevant to it, does not explicitly subscribe to the ontological turn in anthropology (see Pedersen, 2012 for an overview). Rather, my understanding and treatment of the term comes from Science and Technology Studies. This because I find the understanding of ontology provided by STS to be more attuned to the processual perspective I want to adopt, than its anthropological counterpart. More specifically, following Annemarie Mol’s work on the ontology of atherosclerosis, I think of ontology as that which is “brought into being, sustained, or allowed to wither away in common, day-to-day, sociomaterial practices” (Mol, 2002: 6). Throughout the thesis the ontologically and praxeologically processual nature of thalassaemia is explored on several fronts: policy making, patient activism, the organisation of medical conferences, subjectivity, and technology.

The main concern of thalassaemia patients in Cyprus is that the state-led healthcare system is becoming increasingly ignorant of this developing, processual nature of thalassaemia in its interconnected experiential, techno-therapeutic and socio-political registers. Patients constantly try – through several channels such as governmental organisations, media outlets and public appearances – to convey to the Cypriot state that thalassaemia is no longer a matter of life and death, but rather of living. Throughout the thesis, I call this extended milieu of society, politics and technology where illness is enacted an extra-
pathological space. This “extra” suffix denotes relations, forces and processes which, despite not being pathological in nature, nevertheless affect how thalassaemia is practiced and understood in Cyprus.

After hearing patient narratives of the growing inconsistencies in the Cypriot healthcare system I switched the focus of my research to the treatment (rather than prevention) of thalassaemia in Cyprus. This was a decision based on the understanding and perhaps the intuition that an anthropological approach could ethnographically and conceptually do justice to the political struggles of thalassaemia patients in Cyprus. Anaemic subjectivities have a lot to tell (Chatjouli, 2013). Thalassaemia patients experience sensations which non-anaemics do not: primarily the awareness and necessity of blood as life, a fact which is often taken for granted. Their experience of everyday life is different: the weight of the dialysis pump on their hip, the side effects from medication, their intimate relationships with the practicality of blood and the almost familial bonds developed with clinicians who treat them once or twice a week. These are relationally and affectively rich worlds. Nevertheless, focusing on the politics rather than subjectivity of illness means I prioritise the former over the latter.

Yet, the subjective element of illness cannot be completely ignored. On the contrary, one could say it forms the foundations out which my inquiry into the politics of illness is deployed. As Julie Livingston (2012: 126) makes clear through her ethnography of cancer treatment in Botswana, the overarching bureaucratic parameters by which health systems operate often display lack of connection with the everyday enactment of illness. The task then, for patients, policy makers, and medical practitioners alike, is to find the means by which the subjective, experiential aspect of illness can inform its more general conditions of treatment. More specifically, my interest in this thesis is in locating how the subjective and, moreover, ontological dimension of illness can be intentionally connected with, and
inform its politics. As I argue elsewhere in the thesis, this connection is required insofar as politics of illness can affect the subjective, ontological register, but not vice versa. In other words, there is an affective hierarchy, which demands that the only way for the ontological and subjective of illness to inform the political one is through collective action from patients.

Thus, while illness is always enacted according to a political dimension, in order for patient associations to gain leverage amid an extra-pathological space, they must flesh out such political dimensions of illness and make these explicit in governmental logic and processes of decision-making. This, then, is the distinction between the political and politics which I develop throughout the thesis. While the term “political” can be understood as part of the ontological realm of the affective forces according to which illness comes to be enacted and subjectively experienced by patients, the term “politics” can be understood as the means and collective practices through which such political forces can be rendered perceptible, negotiated and contested on a publicly visible scale. Everything might be political, but not everything is politics. The purpose of doing politics for patient associations is to render visible the political dimension of illness which might otherwise go unnoticed. In such a sense, the distinction of the term “politics” from “the political” is “not ‘a transcript of reality’, but a tool that we can assess with regard to how well it serves a particular purpose” (Brown, 2015: 4). Unlike the omnipresent political dimension of being, I do not perceive politics to be an ontological given but an intentional practice which might, or might not work – a practice which, if successful, then acquires ontological relevance.

The distinction between politics and the political might initially appear as dichotomous. Yet, if such an initial dualism between the two terms is posed, it is not to claim an irreconcilable gap between the two, but the potential of the connection. It is, as Isabelle Sten-
gers writes, a matter of “thinking through the middle” (Stengers, 2005: 187) of the terms proposed, trying to figure out the means and channels by which the two can be connected, as well as evaluating the effects such amalgamations give way to. The name given to these practices used by patients, capable of achieving a connection between the ontology of illness and its politics, is tactics.

_A note on method, theory and purpose_

Before a literature review and overview of the chapters, I would like to provide a short note on the methodological and theoretical foundations of the thesis, as I feel its purpose is anthropologically distinct. Illness gives way to a particular form of conducting politics. As a result of their connection to life and death, the politics of illness are permeated and driven by an urgency which one does not encounter in traditional forms of politics. More than informing the governance of life and everyday practice - Foucault’s initial formulation (Foucault, 2008) - biopolitics is a modality of doing politics which does not merely inform but rather _stems_ from life, or, as in the case of thalassaemia patients in Cyprus, from the collective perseverance and desire to prolong and improve life. The perpetual relation of the anaemic body to blood, medication and therapy constitutes a modality of subjectivation which gives way to the political pursuit of life par excellence.

These, then, are the central questions of the thesis: What kind of politics can illness in its widespread manifestation mobilise and make possible? Through what means can such politics take place? A thesis is not only on something, but also results from and is of something. I regard my thesis as emergent from the urgency which characterises the political efforts of the PTA. When I was writing, my purpose was to try to grasp and feed this political urgency of Cypriot thalassaemia patients into my work, on both an ethno-
graphic and conceptual register. On an ethnographic level, the thesis aims to analyse the main actors by which thalassaemia is politically negotiated in Cyprus and to pinpoint the tactics by which the PTA accrues political leverage. On a conceptual level, and through analysis of the activities of the PTA, the thesis aims to develop relational tactics of its own by which patient groups can make explicit the political dimension of illness. While the descriptive aspect of the thesis showcases how tactics used by the PTA succeeded in granting it political momentum, the conceptual part of the thesis involves the analysis of case studies as springboards for anthropological concept-work. The notion of tactics throughout the thesis thus oscillates between these two modalities: tactics as ethnographic objects and tactics as conceptual, that is to say potent and pragmatic, devices.

Relevant to this above objective, there is something to be said about conducting fieldwork with a political entity like a patient organisation – namely that the focus of your inquiry is something which is intangible which does not materially exist. And yet, its immateriality does not imply its lack of reality. The PTA is indeed a socially and politically concrete entity, whose activities have considerable effects on the politics of thalassaemia in Cyprus. Yet, the robust ontological standing of the PTA was not always apparent for me to examine and document. Its ontological standing, or that of any political entity, should not be received as ready-made in ethnographic imaginings, but as requiring effort - an effort so great that the PTA only manifested itself under particular circumstances. The manner of achieving such organisational “essence” (Latour, 2013: 41) is thus a task in itself, and requires its own tactics. While interviews I conducted with PTA members alluded to the organisational essence of the association, this essence would only unfold for me to witness at specific occasions of exceptional political activity. In such a way the focus of my analysis, namely the PTA, disappeared and appeared, de-assembled and reassembled at the stroke of circumstance. Without exception, these circumstances were
characterised by an intense event which denoted and made publicly explicit a problematic entanglement of illness, society and politics; in other words, they were characterised by tactics.

One can see how such tactical modus operandi can be problematic for an ethnographic endeavour, in the strict sense of the term. The PTA, as a political entity, and also illness as a social and political matter of concern, became apparent in specific events and circumstances. This means that my field was not always there for me to explore. As such, one can regard the mode of ethnographic analysis presented in the thesis as one of nodal ethnography. In other words, in my ethnography, I did not take the relation between illness, society and politics as a given. Rather, I always tried to pinpoint locales, events and occasions where nodes of pathological, social and political relations manifested themselves in the perception of those with whom I worked, as well as mine. There were considerable spells of time between nodal recurrence, mediated by archival research and patient interviews. One can say that, unlike most ethnographic accounts, the singular, particular and ephemeral, rather than the recurrence of the event and encounter, ended up being my unit of analysis. I maintain that the involvement of the ethnographer with brief, transient conditions is necessary when conducting research with political entities such as the PTA. The singularity and particularity of the event of politics should not be a constraint, but rather an enablement for the ethnographer. The exceptionally powerful and important occurrences of nodal events of activation should be precisely attended to in terms of their infrequent nature. The thesis is mostly comprised of the observation, narration and analysis of events such as conferences, public and media appearances, demonstrations, and skirmishes between the Cypriot state and the PTA, as well as archival material such as newspaper articles detailing events which brought forth the explicitly social and political dimension of illness.
Borrowing from the title of the thesis, we can refer to such events, technologies and tactics as processes of *activation*. The demarcation of illness not simply as a pathological condition of one person, but as an ethical, social and political project of many, entails that patients and ethnographers create a relational and conceptual excess which takes illness beyond its archetypical medical definition. The purpose of tactics and the practice of activation thus works on this shift: to activate illness means disrupting its static biomedical façade, pinpointing knots of illness, society and politics according to which the ontology of illness comes to be, unravelling and examining them, and putting them back together in different configuration. Activating illness is thus predicated on a primary distinction of medical anthropology, namely that between disease and illness as is as made by Arthur Kleinman:

*Disease* refers to a malfunctioning of biological and/or psychological processes, while the term *illness* refers to the psychosocial experience and meaning of perceived illness…Viewed from this perspective, illness is the shaping of disease into behavior and experience. It is created by personal, social and cultural reactions to disease (Kleinman, 1980: 72).

And yet, much like the connections between illness, politics and society, or between the ontology of illness and its politics, the distinction between disease and illness should, likewise, not be assumed. This because the distinction between disease and illness, and the need to distinguish it, is exactly predicated upon a lack of understanding and awareness between the two. In other words, the distinction between disease and illness is not merely analytical, but rather emerges out of actual practices, understandings and values of an extra-pathological space which do not account for the socio-political dimensions of illness. Tactics as means of activating illness serve the purpose of rendering visible such socio-political facets of illness. The event of activation signals the unfolding of previously
imperceptible forces of an extra-pathological space, renders these forces perceptible in public and governmental consciousness, and effectuates a shift in understanding that moves from disease as a biological condition of one, to illness as a social and political condition of many. This is exactly the main concern of patient activism: to shift public understanding and attention of their condition, from its idealised biomedical definition, to its extra-pathological dimensions, and from its field of static medical symptomatology to the turbulent socio-political space where such symptoms are daily experienced and enacted. In short and as further elaborated in Chapter 3, the event of activation transforms illness from a matter of fact, to “a matter of concern” (Latour, 2008).

I do not treat such events of activation as social representations or patterns, since such analytical treatment would dissolve the exceptionality of the event into the functioning of society and its politics. The success of ethnomethodology was to achieve taking the event as the starting point of inquiry, but its mistake was to treat the event as representing the entire society from where it emerges. But the event does not represent anything. Rather, the questions are: In its short-lived duration and exceptional strength, where does the event of activation stem from, and to what is it able to connect? What were the relational arrangements which gave way to the event, but also, in what ways does the event bear the potency to inform and alter such relational arrangements? In such a sense, my definition and treatment of the event stems from that of Max Gluckman’s Manchester school of ethnography. As Bruce Kapferer writes in a succinct overview of the Manchester School’s methodology of analysing events, “the events or situated practices attended to by Manchester anthropologists were atypical, even unique, and their close investigation would reveal dimensions of the potentialities of the realities within which they irrupted” (Kapferer, 2010: 2). Relevantly, as Claire Colebrook points out in her analysis of Michel Foucault and Michel de Certeau - one of the few texts which directly attend to the con-
ceptual importance of tactics – tactics are practices irreducible to the milieu out of which they emerge. As she writes, “a tactical economy is generated…by generating a different point of view, a different way of viewing.” (Colebrook, 2001: 557) While the deployment of a tactic stems from certain conditions of an extra-pathological space, is not indicative of this conditions but rather, through its “structural causality” (Colebrok, 2001: 553) creates a new dimension of movement and register of thought, and is hence capable of enriching the space of possibility from where it was initially deployed.

The purpose of the event of politics as means of activation is to rearrange the conditions which gave way to it. The main theoretical objective of the thesis, that of documenting and developing tactics as political technology, stems from the collective dimension and, connected to this, the importance and ability of the event of politics to partake in how illness is socially understood. In addition, the need for tactics arises from the fact that, while the emergence of the event of activation might be unpredictable in its manifestation, the directions by which the event unfolds and develops can be informed through planning and intentionality. Or, even better, the event of activation can be arranged so as to be frequent and anticipated in its manifestation. To “activate”, rather than trigger, exactly extracts from the unpredictability of circumstance the connotation of a well thought out and strategic practice, as opposed to one of reckless abandon. The terms tactics thus denotes that the relations between the ontology of illness and politics are not given but must be achieved and that can, over time, be severed. In other words, the purpose of tactics is not only to connect the ontology of illness to the political landscape of an extra-pathological space, but also to carefully maintain and manage this connection. In order to maintain such connection, patient associations must likewise maintain the relations and alliances which make the deployment of a given tactic possible – they must, in other
words, maintain an infrastructure which allows for the deployment of tactics in time of need.

Moreover, my focus on the description and construction of political tactics is intended to emphasise the increasingly uncertain environment in which politics of thalassaemia take place in Cyprus. The historical narrative provided in the first chapter showcases how thalassaemia in Cyprus has always been negotiated in uncertain milieus of colonial governance, war and financial hardship. In the wake of a fragile European economy, such conditions have not subsided but have attained contemporary form, especially in terms of publicly provided healthcare (Petrou, 2015). Such uncertain conditions for patients are also reflected in terms of technological and therapeutic potential, in Cyprus and also elsewhere. On a global scale, illness is constantly being reconfigured according to both techno-therapeutic breakthroughs as well as the epistemological and financial uncertainty leading up to them. As detailed in Chapter 5, attempts are being made by scientific bodies to find a final cure for thalassaemia through gene therapy. If this is done, then thalassaemia will once again be transformed from a process to a telos. Yet, these attempts are taking place in ambivalent spaces of scientific experimentation and financial flow. How can patient organisations best handle this cloudy horizon? How can financial and therapeutic uncertainty not be defeated, but transformed from a hindrance to a political tool? These are questions which both thalassaemia patients in Cyprus and I grapple with and which I explore in the thesis.

Tactics, in their ethnographic or conceptual guise, do not attain power through a definitive definition of their practical possibility, but through their potential connections to other practices and concepts. Tactics as a form of doing politics gesture to the potential of movement, manoeuvring and alliance formation which exists between the socio-political relations which constitute an extra-pathological space. The formulation and de-
ployment of concepts and tactics is the strategic element by which political possibility is navigated and fruitfully deployed amid such spaces. Neither the formulation nor use of these concepts is reserved for the anthropological imagination. It becomes evident throughout the thesis that patients themselves are also aware of the need for strategy and careful planning in how they politicise. Anthropological terms and research methods such as “relation” and “comparison” become formidable tools of conducting politics in the hands of patients. It is at this intersection, of relational understanding and deployment from patients on the one hand, and anthropological conceptualisation on the other, that this project takes place. It is also at this intersection where theory and ethnography become reconciled, and where anthropological concept-work attains pragmatic efficacy.

Before moving on, I want to briefly attend to the connection of this thesis to the PTA. One can imagine how an ethnographic description of a political and organisational entity can adopt a deconstructive character by unveiling the internal discontent which takes place between members of the given entity. This is not the intent of this thesis: although I perceive such internal discontent to exemplify political vigour and purpose, one can imagine how it could also negatively affect the public perception of the PTA. The thesis strives to ally itself to the PTA. When writing, I felt it was important to not merely think of, or like thalassaemia patients but, most importantly, “with them” (Pignarre and Stengers, 2011: 12). Such collective essence bears an ethnographic character precisely because it is indicative of, arises through and is driven by an urgency characteristic of the politics of illness. If the event of activation of illness signals the unravelling of an extra-pathological space, it also signals the manifestation of the political essence of those who kick-start the process of activation and as such must be also affirmed by the ethnographer. Insofar as one of the prerequisites of the PTA in times of turmoil is to affirm its organisational and political essence, then so too will the thesis.
In the next section I provide a literature review of how the figure of the patient is currently implicated in medical anthropology. More than amassing a collection of writings, my intent in this next part was to denote why medical anthropologists should attend to patients through their attempts at politicisation and their tactics of doing so, rather than through their marginalisation by the state or a healthcare system. An overview of the thesis chapters then follows.

**The place of the patient in medical anthropology**

Anthropologists, ethnographers and social theorists, utilising various analytic lenses, have consistently documented how patients become embroiled in clusters of bio-governance, neoliberal ideologies, considerations of risk, medical experimentation, infrastructural failure, pharma-financialisation and, more recently, biosecurity (Petersen and Lupton, 1996; Farmer, 2003; Ong and Collier, 2005; Sunder Rajan, 2006; Rose, 2006; Rose and Rabinow, 2006; Petryna, 2009; Lakoff and Collier, 2013). Though such conceptual heuristics do well in documenting the historically and increasingly complex and turbulent fabric of pathological constitution, they also present the problem that through such descriptions patient agency and subjectivity often dissipates amid political agendas, scientific research objectives, capitalist imperatives and socio-cultural categories. Although people are undeniably affected by such clusters of culture, power, and knowledge, their existence cannot be reduced to the effects of these (Good, 2012; Biehl and Locke, 2012; Whyte, 2009; Gibbon and Novas, 2008; Biehl et al. 2007; Callon and Rabeharisoa, 2004). At stake is the anthropological production of knowledge of how patient agency exceeds and exists beyond such difficult arrangements.
One can also pinpoint a related problematic in work showcasing resistance to dominant socio-medical agendas, insofar as such acts of resistance relate to, and thus maintain, that which they resist. As Caroline Humphrey writes, “Theories which subordi-
nate the identification of the subject to the recogni-
tion by the evil done to her or him (e.g. by the state, capitalism, and so on) tend to reduce the subject also to sufferer, recursively ‘subjectified’ by what he or she opposes.” (2008: 361) The issue here is not that patient agency is sub-
verted or resisted by medical expertise. After all, refusal or opposition is often not in re-
gard to medical treatment itself, but to cultural, social and familial dimensions of illness which a given medical regime is unaware and inattentive of (Rapp, 1999; Lock, 2001; Lewando-Hundt et al., 2001; Ivry et al., 2011). Rather, what is problematic in such cases of ethnographic engagement is that patient agency is always perceived and documented in relation to a reactive act of clinical negation and opposition. Consequently, patient agency and subjectivity is always negative and deductive, rather than positive and creative; its causes and effects depend on and are maintained by that which it resists and opposes at a specific time and place. Such relegation of patient agency can be identified, in inverted form, in ethnographic literature of therapeutic care (Mol 2008; Kleinman and van der Geest, 2009). Albeit often positive and beneficial on the patient body, care as an interac-
tive modality of engagement similarly reduces patients to a proponent of a medical rela-
tionship; in such a way, subjectivity and agency are once again relative and locked, and enacted according to a patient-doctor dialectic of care. Of importance, in this regard, is extending patient existence and ethnographic engagement outside of the caressing setting of clinical therapy. Although philosophical reflection has the capacity to problematise and improve clinical care as concept and practice it is also important to situate and explore pathology beyond such conditions.
The risk is that, by thinking of patients through their relations to medical regimes of care or healthcare systems, anthropologists risk reducing them to proxies of these regimes and systems. On such occasions of anthropological thinking, ethics, as a mode of acting and thinking in the world is attended to and critiqued on the level of governmental officials and medical practitioners as something problematic and lacking, yet it is altogether suspended at the level of the patient. In other words, while anthropological accounts of faulty healthcare systems and medical regimes of practice gesture to their problematic functioning, and propose ways of improvement, they tend to disregard the figure of the patient in such narratives of improvement. On the other hand, attending to patients through their attempts at politicisation and activism procures an ethnographic image of the world which anthropological discourses on marginalisation, resistance and care cannot - namely, a portrayal of patients as collectives and political entities implicated in crucial efforts of reconfiguring governmental and international agendas of which directly have an impact in how illness is experienced in everyday life. In the next part I further explore how patient activism has developed through the years and how it has become an anthropological field of inquiry.

The rise of patient associations

Patient associations (from now on referred to as PAs) of chronic disorders are becoming increasingly implicated in national and international politics of healthcare and research agendas of biomedicine and techno-science. Such accumulating political gravitas of PAs explains the accompanying interest by social scientists and emerging literature linked to the activities of such organisations. Although no particular time or context was catalytic to their emergence as political actors, patient organisations first became discernible to the public eye in the 1950s (Aymé et al., 2008). In their recent, succinct literature review Ko-
Ay and Sharp note the ambivalent and diverse factors and social processes which gave way to the creation of PAs. Such geographically and politically varied and complex origins include: “grassroots health organizations”, “environmentalist and consumer-rights movements” and “self-help groups” (Koay and Sharp, 2013: 582). In another comprehensive review of the history of PAs, Steven Epstein similarly traces the existence of such “proto-” rudimentary forms of patient activism in the US back to the early twentieth century, in organisations such as the National Tuberculosis Association and the American Cancer Society (Epstein, 2008: 500). For their part, Rabeharisoa et al. attribute the increasing interest social scientists show to PAs to factors such as the advent of medical and diagnostic technologies, the increasing liability for radical treatment such technological progress carries regarding the future lives of chronic patients, as well as the recognition and participation of such patients as stakeholders in the formulation of biomedical research and the formulation of health policies (Rabeharisoa et al., 2013: 3).

The emergence of PAs in diverse socio-cultural settings has also been consistently accompanied by a related rhetoric of patient “empowerment”, (Ayme et al., 2008) allowing patients of chronic disorder to enter the political arena. The bid for political representation initially entails that groupings of individual patients gather in order to construct a collective identity, which they can then use to politicise and express their demands to state and public alike. As Epstein points out, “Patient groups and health movements have been pivotal actors in the making and the unmaking of so-called biological, biomedical, biopolitical, or genetic citizenship” (Epstein, 2007: 503). The collective potential of patients and their politicisation through associations allows them to mobilise their pathological identity as chronic sufferers in order to stake a claim in governmental decisions regarding healthcare policy and decision-making, as well as access to medical provision. In such a sense, as Adriana Petryna aptly puts it in her fieldwork of radioactivity exposed
patients in Ukraine, “Sufferers have turned suffering and disability into a resource” (Petryna, 2003: 84). Identity formation does not remain static and unchanging but is constantly revised in light of technological ruptures and socio-economic developments. Accordingly, the political relevance and potency of a collective pathological identity oscillates between fixity and fluidity, and between “framing” (Clarke et al. 208) and “negotiation and contestation” (Wehling, 2011: 80). On the one hand, patients try to ascribe and even “perform” (Hacking, 2006) a collective identity that, through the political potency of representation, will allow them to have a say in governmental processes, while, on the other hand, they constantly try to reconfigure such collective identity in relation to social, political and technological changes.

Thus, besides documenting the means by which pathological identity becomes collective and politicised, it is also important for ethnographers to note the shifting forces, objectives and prerogatives at work which serve to constantly (re)fix the collective identities of patient associations. As Epstein writes, “Collective illness identities are rarely stable over long periods of time. Not only do identities often evolve as groups embark on different biomedical and political projects, but the group’s definition may itself be at stake in health controversies” (Epstein, 2007: 511). Such an objective of reconfiguring their identity might stem from several reasons; patients might want to disrupt widespread perceptions the public has of them, or they might want to stake a claim in light of advancing political, economic and biotechnological developments, such as upcoming gene and stem-cell therapies (Langstrup, 2011).

In addition, their congregation in associations allows patients, through their very experiences as sufferers, to construct and utilise alternative regimes of knowledge in order to claim a political stake and inform policy decisions. Famously, Callon and Rabeharisoa’s “research in the wild” (Callon and Rabeharisoa, 2003) is a term coined to denote the in-
volvement of patients with scientists in the production of scientific knowledge. As the
two write, the implication of patients with scientific practice serves in simultaneously
constructing their identities as well as their future access to medical provision and tech-
nology. The implication of knowledge as a tool for PAs implies that not only knowledge
per se but also its production is a political enterprise in itself. As Akrich at al. write, “Ra-
ther than contemplating knowledge as a mere resource ‘out there’ which patients’ organi-
zations and groups of activists rely upon for defending their causes, knowledge (and what
counts as such) should be considered as ‘something’ to be produced and discussed”
(2013:2).

Elsewhere, Rabeharisoa et al. (2014) utilise the term “evidence-based activism” to de-
scribe the manner by which patients, through their everyday experiences of their illness,
construct regimes of knowledge which run counter to the faulty healthcare policies and
misinformed perceptions of experts, and therefore aim to adjust and reconfigure these.
Rather than succumbing to the opinions of medical experts and policy makers, using
their claims as “experts of experience” (Rabeharisoa, 2008) patients deploy their “experi-
ential knowledge” (Borkman, 1976; Caron-Flinterman, 2011) to inform and adjust such
policies and perceptions. As O’Donovan et al. write, “The coordination of evidence and
experience seems to be a recurrent problem in contemporary healthcare” (O’Donovan et
al., 2013: 325); it is thus often the case that patients, through the political momentum
they gain by politicising into an association, are able to bridge the gap between experience
and evidence through the making visible of their experience and knowledge as chronic
sufferers. Conceptualising the deployment and production of knowledge as politically
potent entails that one recognises such successful connections between experience and
evidence as acts of epeidixis (demonstration) and apodeixis (proof) (Latour, 1997; Callon,
2007): acts which proceed through a certain communicative, performative, and ultimate
political vigour but which also serve in providing proof that such claims are indeed valid. In such a sense, it is not only the production of experiential knowledge that is important to patient associations, but also the ways in which such knowledge can be produced and documented, and the mediums and channels by which it can be deployed in the political arena. Through acts of epideixis and apodeixis patient organisations increase their visibility in the public eye and solidify their stake as political interlocutors.

The participation of patient groups in aspects of health policy and scientific research agendas has also led to the reformulation of political practice as a whole. Conceptualising as a form of practice and skill entails looking at politics not in terms of representation, but according to the ways and means – what this thesis refers to as tactics - by which parties claim and achieve representation. Representation as articulation and alliance, rather than as opposition to existing governmental and healthcare arrangements, entails looking at political practice as a means of putting the parties involved in a given matter of concern in fruitful conversation and deliberation. As Rabeharisoa and O’Donovan point out, the scientific and political input of PAs “have removed politics from a classic partisan fight to an extended multifaceted collective experimentation” (2013: 29). Such process of experimentation results in the creation of new collectives and assemblies between all those involved in the enactment of a certain illness. As Michel Callon writes, “several patient organisations …have become members of highly competent collectives…communities like these, developed around the design of open sourcesm have demonstrated the limits of existing rules and the possibility of imagining new ones” (Callon, 2005: 312).

Similarly conceptualising politics as a process of relational and political experimentation, Bruno Latour provokes governments and policy makers alike to be aware of the limit and partiality of their experience and knowledge, and instead turn to patients themselves in
order to formulate sound policies and decisions. As he writes, “It is well known from the development, of example, patient organisations that many more people are formulating research questions, insisting on research agendas, than those who have a PhD or wear a white coat” (Latour, 2011: 3). Such accumulating political gravitas of patient associations increasingly blurs the division and distinction between doctor and patient, and expert and lay person, and instead directs us to the shifting positions between experts and patients and the reconfiguration of the position of patients in the politics of their illness: from “passive exclusion to active inclusion” (Callon and Rabeharisoa, 2008: 235).

The proliferation of patient associations around the world implies such processes of negotiation and efforts at political relevance and inclusion take place in increasingly diverse conditions and settings. Constant ethnographic engagement with patient associations is capable of showing that such a feat of inclusion is not a singular act, but rather a constantly negotiated and reformulated process, subject to technological progress and socio-economic fluctuations. The milieus inhabited by and interacting with PAs are differentiated by the ways in which institutions operate in their respective milieus as well as differences in economic states and other cultural norms. The result of such mushrooming of PAs is that it often makes it difficult to put singular case studies of patient activism on a common plane of reference. As Koay and Sharp point out, such difficulty also arises from the fact that there is no one succinct, universally accepted definition as to what constitutes a patient group, and what its composition and activities should entail. As the two write, “Given the substantial diversity of both formal organizations and informal patient networks, there may be no choice but to use ad hoc, study-specific definitions of the relevant groups. An unfortunate result of this terminological plurality is the difficult of comparing studies of PAOs [patient associations and organisations] with one another...the diversity of these organizations limits the ability to provide generalizations about
them as a collective category” (2013: 581). Perhaps, regarding their diverse origins, PAs around the world can be seen as associated since they similarly direct us to their increasing implication in governmental decisions and healthcare policy making, or at least their efforts in this regard. The present influence PAs have in governmental processes, a phenomenon Epstein does not hesitate in calling “global” in scale (Epstein, 2007: 501), provides the diverse contexts of their operation with a connecting commonality: their political relevance, or struggle to attain this.

**Overview of chapters**

The development of relational tactics of activating illness is what I perceive to be my conceptual debt (Viveiros de Castro, 2014: 39) to the PTA. My “debt”, in this case, comes from my evaluation of the PTA as a successful political entity whose past and present activities, if addressed on a conceptual level, can produce broader conclusions about how patients can be politically active. Thus, while they provide an ethnographic narrative of how thalassaemia is socially and politically enacted in Cyprus, each chapter also attempts to extract a useful conceptual thread from how patients, in Cyprus but also elsewhere, effectively conduct a politics of illness. Although the chapters are not linked together by a linear chronology or by a particular spatial locale, they are linked by the purpose of attending to PTA tactics and, from there, devising anthropological concepts which can in return be fed back into political activities of the PTA as well as other patient associations.

My premature, for now, claim that these concepts carry broader implications in how politics of illness can be enacted – that they can be used by entities besides the PTA, which originally developed them – does not stem from the generality of thalassaemia as a condi-
tion. Undeniably, thalassaemia differs in its ontological constitution according to the extra-pathological space in which it is enacted. Thalassaemia for a Cypriot patient is not the same as it is for a Greek or Lebanese patient since it is enacted under different social, cultural, technological and political dimensions. Rather, as I further argue in Chapter 3, such a claim stems from the necessity of relations and alliances between PAs situated in different cultural milieus. As the thesis showcases, alliances and the formation of international organisations between patient associations is a formidable tool in accruing tactical and political gravitas.

Chapter 1 provides a trajectory of the history of thalassaemia in Cyprus. It traces thalassaemia from its rudimentary form to its initial stages of birth as an object of knowledge and practice amongst the international medical community, and thereafter Cyprus. The chapter then traces the formation of the Cypriot thalassaemia treatment and prevention system from its infant stages in 1960 up to 1983, when the premarital certificate was introduced by the Cypriot Orthodox Church. Although the PTA figures in it, it is perhaps the chapter which attends to the activities of the association the least. The chapter rather focuses on a group of medical practitioners and their participation in events which were catalytic to the formation of the Cypriot thalassaemia programme. I decided to include this chapter in order to provide the reader with an introduction to both thalassaemia and Cyprus and to provide the rest of the thesis with a historical background. I make the case that in the trajectory of the formation of the thalassaemia programme one can discern an ethic of conducting policy corresponding to what philosopher of science Isabelle Stengers conceptualises as “slow science” (Stengers, 2011). Following Stengers, I make the case for a “slow” form of conducting policy, which does not do away with the uncertainty intrinsic to a socio-political field in order to implement a template form of policy. Ra-
ther, slow policy weaves through such uncertainty as a mode of relational articulation and decision making.

Chapter 2, in contrast with the first one, brings the reader up to date with the deterioration of the Cypriot thalassaemia treatment programme. It connects insufficiencies developed by the Cypriot treatment programme to an understanding of illness as process. By using Byron Good’s theory of narrative as a “network of perspectives” (Good, 1994: 162), narratives of thalassaemia patients are assessed to show how experiences of thalassaemia patients in Cyprus have been consistently entangled with national politics and social perceptions and practices. Through such narratives, I make the case that, by perceiving illness in its archetypical biomedical form, and by operating according to a paradigm of life and death, rather than living, the Cypriot thalassaemia programme proves to be increasingly ignorant of the developing symptoms and needs of thalassaemia patients. The chapter thus focuses on illness in its interconnected experiential, social and political registers. It revisits Margaret Lock and Nancy Scheper-Hughes’s seminal The Mindful Body (1987) and makes the case that links between illness, society and politics should not be received as ready-made in the anthropological imagination, but as a challenge to be achieved. In relation to this, the chapter also suggests a re-organisation and a hierarchy of the three registers and advocates for the primacy of the political over the other two bodies.

Chapter 3 introduces the reader to the PTA and its activities. It provides a short history of the association, detailing changes in its structure and organisation, and proceeds to examine its political involvement in a medical rationing scheme implemented by the Cypriot government in light of austerity politics. Following from the previous chapter, and using Bruno Latour’s concept of “matters of concern” (Latour, 2004, 2008) I make the case that patient activism has as its purpose the explication and connection of relations between illness, society and politics, and the presentation of these to a wider public. “Doing
politics”, in such a sense, entails connecting achieving and maintaining a connection between the ontology of illness and its politics. I present five tactics through which the PTA was able to do so in the case of the rationing scheme.

Chapter 4 ethnographically and theoretically focuses on the importance of medical conferences as events of organisational revision. Unlike its widespread philosophical treatment as an unpredictable moment of rupture, here the event is conceptualised as an artificial and in many ways arranged and programmatic setting. On a basic level, medical conferences provide a space where all those involved in the enactment of an illness, and who belong to the same medical associations and organisations, get to interact and engage in conversation. Using Edwin Ardener’s theory of “world structures” (Ardener, 1989) the chapter argues that such encounters provide opportunities for these actors to deliberate over certain political dimensions of illness and to revise these through updating organisational agendas, parameters and objectives. At the same time, the argument can be made that, on certain occasions, the structure of the conference does not allow for such encounters and deliberative processes to occur. In such circumstances, the conference is not an event of revision and deliberation, but rather a reinforcement of rigid and disproportional arrangements of power and knowledge production between medical practitioners and patients. Another question the chapter tackles, therefore, is: what arrangements – relational, material and social – must be in place in order for the event of the conference to prove politically meaningful and productive when it comes to bettering the lives of patients?

Chapter 5 focuses on the alliances of the PTA with national and international scientific research bodies, and situates such alliances in ongoing research on gene therapy. Gene therapy is a therapeutic method utilising the manipulation and insertion of viral-vectors in the human organism in order to replace faulty genes with therapeutic ones. Gene therapy
is still in a preliminary, experimental stage yet, if successful, carries the potential of
providing a permanent cure for thalassaemia. By engaging with literature on ethnographic
explorations of potentiality, expectation, hope, and imagination, the chapter critically ex-
plores the relevance of such biomedical promises as enacted in the political scene of Cyp-
riot thalassaemia patients. I make the case that imagination and expectation acquire polit-
ical relevance and potency insofar as they are disseminated into an institutional infrastruc-
ture of heterogeneous actors (which I call techno-collectives) capable of upholding pa-
tient expectations and hopes of techno-therapeutic finality as issues of collective concern,
to be deliberated and contested by many.
Chapter 1: The formation of the Cypriot thalassaemia system

This chapter focuses on the formation of the Cypriot thalassaemia treatment and prevention programme. It begins by providing a history of thalassaemia in Cyprus, detailing how thalassaemia entered the medical and public sphere while the island was still under British administration. It then traces the formation of the system from its early stages of inception in the early 60s, when Cyprus became an independent republic, up to 1984 when a premarital certificate was introduced and the thalassaemia prevention system achieved a 100% prevention rate. The chapter consists of sources I located through archival research and also of life narratives of individuals implicated with the coming together of the programme. Archival sources vary. I initially located around fifty newspaper articles on thalassaemia in Cyprus, the oldest one dating back to 1954. As fieldwork progressed historical data slowly accumulated; I had already collected some articles and books which documented the struggle of Cyprus with thalassaemia (Beck and Niewöhner, 2009; Bornik and Dowlatabadi, 2008; Prainsack and Siegal, 2006; Cowan, 2008). In addition I got my hands on a PhD thesis written by medical anthropologist Patricia Book. Commissioned by the Cypriot Ministry of Health, she had conducted fieldwork in Cyprus in 1977 regarding the psychosocial aspects of thalassaemia patients (Book, 1980). After being tipped off by a friend, I bought a tome entitled “Cyprus and Thalassaemia”, inside of which several medical practitioners - including one who would become my faithful interlocutor, Dr. Angastiniotis - provide early accounts of thalassaemia in Cyprus (Hadjiminas et al., 2008).

There are two main points of the chapter and they are connected. The first has to do with the process of thalassaemia as an “object” and also “space” of knowledge (Hagner and Rheinberger, 2003). Perceiving thalassaemia as an object and space of knowledge entails that illness supersedes medical, biological and scientific foci, and overflows to in-
clude dimensions of civil society, social discourse and governmental practice. Social understandings of illness and advances in therapeutic technology provided a political, techno-discursive space, where thalassaemia as a pathological disorder came to be produced. To quote STS scholar David Turnbull, “Knowledge production is not simply an idealistic linking of ideas; it is also a social process of linking people, practices and places - of creating a knowledge space. All knowledge is produced by particular groups of people at particular sites with particular skills, techniques and technologies” (Turnbull, 2004: 209). To denote a pathological disorder as an object and space of knowledge serves in breaking down unproductive dichotomies between the biological and the social, the natural and the cultural, the private and the public, and the material and the discursive. Instead, perceiving thalassaemia as object and space requires one to attend to entanglements and hybridisations of the aforementioned modalities, and how they serve in differentiating illness as it unfolds along time.

The importance of attending to such entanglements is that, by doing so, one can also denote the complexity and uncertainty by which the thalassaemia programme attained consistency. This is the second main point of the chapter. I will make the case that this experimental dimension, driven by uncertainty and also urgency, made the Cypriot thalassaemia paradigm successful, insofar as it accounted for and worked through the obstacles met in the social field, rather than disregarding them in favour of actualising a predetermined plan conceived in the imagination of policy makers, bureaucrats and technocrats. Thus, and to use a term by Isabelle Stengers which will be further attended to later on, the construction of the Cypriot thalassaemia scheme was slow (Stengers, 2011). Stengers uses the term slow to denote a method, an ethos of acting and orientating one’s self in the world which embraces the open-endedness of uncertainty in order to foster new connections and alliances. Such an ethos does not abide by predetermined trajectories
but by careful instances of deliberation and connection – creation, but also evaluation. This is an apt way to conceptualise the trajectory of the Cypriot thalassaemia programme insofar as it did not strive to realise a predetermined blueprint or form, but was rather the result of a piecemeal construction of careful thinking, planning and also experimentation. The trajectory by which the Cypriot thalassaemia system was formed was one marked by social complexity, technological rupture and political contingency. Such processes involved the coming together of several actors who entertained divergent yet at the same time interrelated interests, and whose personal trajectories started and unfolded contiguously, before entering into causal relations at later moments in time.

As the narrative unfolds, it will become apparent that out of all the actors involved – institutions, governmental officials and the public - I have placed emphasis on the actions and importance of particular medical practitioners involved in the construction of the thalassaemia programme. These individuals played an important part in the given process. Although largely responsible for setting the Cypriot thalassaemia system in motion, they did not do as their heads and hearts desired; their process of construction was often met by obstacles, blockages, periods of stasis and deliberation, as well as unpredictable events. In the historical narrative which follows, events and facets are evident which evade and supersede human intentionality. Hence, the process by which the thalassaemia system was put together was not predetermined; its process did not anticipate its genesis. Rather, such process was one of experimentation, in the relational and organisational sense of the term: it was a process of testing the waters, of entering new domains, and of succeeding but also failing.

The linear, one-dimensional mannerism by which written text operates often made it hard for me to capture the erratic and entangled nature of these interactions. This was a problem I encountered with the historical sources I collected, as well as with certain in-
terviews I conducted, which would similarly oscillate between different periods in time and jump across personal and institutional narratives and trajectories; these were occasions where the plural and complex nature of history could not be restrained and accommodated by a singular narrative; the presence of relational excess was undeniable. To once again quote Rheinberger, “The difficulty for the historian arises that the linearizations of what he calls history are altogether fictions created for the sake satisfying the desire for a logos-driven process” (1994: 70). And it is here, according to this discrepancy between mono-dimensional logos and multi-plural becoming, where we locate another difference: the objective of historical historiography is to reduce and singularise; that of anthropological historiography is to pluralise and complexify (Jensen, 2005a). And because of this, much like a slow modality of conducting science and policy, it is a modality of examining history which feeds off and is driven by the relational complexity of a social field, rather than by reducing it to an all-encompassing trajectory. This chapter is thus not an attempt to synthesise, or categorise, but rather to conceptually make sense of and apprehend the mass of historical information I collected through primary and secondary research; not to account and present a linear sequence of events and facts, but to extract from these a temporal narrative of conceptual and anthropological relevance; to construct from these a “dynamic lens” (Petryna, 2002: 25) which can account for social entanglements of biology, pathology, culture and politics in the context of how the Cypriot thalassaemia system was brought together in time, as well as what lessons can one can learn from this process. Let’s begin with malaria.

Thalassaemia as an early object and space of knowledge and practice (1944-1960)

According to Dr. Hadjiminas, a founding member of the Cypriot thalassaemia system, the high prevalence of beta-thalassaemia in Cyprus can be attributed to a previously,
equally high prevalence of malaria distributed over the island (Hadjiminas, 2008: 77-90). As with other cases of thalassaemia prevalence around the world, it is thought that local population developed the thalassaemia mutation as an antibody against the spread of malaria. Although not contested and mostly accepted as plausible for a while now (Angel, 1964; Clegg and Weatherall, 1999), this assumption is yet to be verified, and the spatial distributions of malaria and thalassaemia in Cyprus and elsewhere do display certain discrepancies. In his account Dr. Hadjiminas attributes such discrepancies to the lack of research done regarding the factors which led to the emergence of thalassaemia in Cyprus and also to the movement of the Cypriot population during periods of unrest: the 1955-1960 war of liberation against the British and the 1974 Turkish invasion. The high prevalence of malaria at the time is attributed to the wide expanses of marshlands which covered the island, which provided a home to the Anopheles mosquito, the primary vector of malaria. As Dr. Hadjiminas writes, “Malaria was prevalent in Cyprus for centuries, [as it offered] an ideal home to the various [p]lasmodia that cause the disease. Stagnant waters, mud, marshes and lack of proper irrigation, together with ignorance, also suited the carrier of the plasmodia, the Anopheles mosquito” (Hadjiminas, 2008: 77).

The first steps to counter the epidemic of malaria in Cyprus took place in 1878, when the British took over administration of the island from the Ottomans. A series of studies was done by British medical practitioners, which denoted the Anopheles mosquito as the main method by which malaria spread in the island, and also mapped the hotspots where the mosquito bred. Decisive action against malaria came into effect in 1935. The national policy implemented by the British to purge Cyprus of malaria is in its own right fascinating and complex, but we cannot but skim over it in the present time. The policy included three objectives: to drain the marshlands where the Anopheles mosquito bred, to use DDT to counter the mosquito from villages, and finally to set up educational workshops
communicating information to the locals on how to recognise and avoid the mosquito. The policy was successful, and a drop from 18,273 cases of malaria in 1937 to 10,950 in 1938 was recorded. Malaria rates increased during World War II, when the priorities of the British government were reconfigured. The scheme came back into effect after the war ended, and by 1948 Cyprus was clear of malaria (Shelley and Aziz, 1949).

As mentioned earlier, although the relation of malaria to the emergence of thalassaemia hotspots has yet to be clarified, for his part Dr. Hadjiminas writes:

Our considerable knowledge of thalassaemia in Cyprus enables us to say with certainty that the incidence of thalassaemia genes is correlated with the frequency of malaria. In the plains and hills where malaria was at high levels, so too was the incidence of the genes for thalassaemia. In contrast, in the mountainous areas where malaria was rare, the incidence of thalassaemia was also lower. (Hadjiminas, 2008: 87).

The ambiguity and discussions regarding the origins of thalassaemia in Cyprus shows how the emergence of the disorder preceded the knowledge Cypriot medical practitioners had of it. Taking his cue from Lawrence Angel’s work, Dr. Hadjiminas posits that thalassaemia can be traced as far back as the second millennium BC. Hence, the social and epistemological construction of thalassaemia this chapter focuses on does not equal the genesis of thalassaemia. Rather, it describes the process by which the existence of thalassaemia entered the human sphere of perception. Albeit identified in the mid-20th century, and akin to Pasteur’s bacteria (Latour, 1988), thalassaemia had been there all along. The problem, however, was that Cypriot medical practitioners were not aware of thalassaemia as a disease, and thus did not make a distinction between it and malaria, or other illnesses. To once again refer to Hadjiminas, “Until the mid-1940s, thalassaemia was routinely diagnosed as chronic malaria, leishmaniasis or congenital syphilis amongst others”
Much like the Cypriot public, medical practitioners, too, had to undergo a process of multiplying perspectives and acknowledging the gap which existed between biomedical and public understandings of thalassaemia.

Such process of multiplication started with the publication of Dr. Alan Fawdry’s “Erythroplastic anaemia of childhood in Cyprus” (Fawdry, 1944). According to Dr. Hadjiminas:

Fawdry’s work on thalassaemia in Cyprus not only provided the first in-depth programme of treatment for patients, but was also the first to lay out a programme of treatment for patients … the publication of his findings played a key role in raising awareness of the disease within the island’s medical community. (Hadjiminas, 2008: 92).

Following Fawdry’s publication a number of other studies by foreign medical practitioners followed, attempting to map the percentage of the thalassaemia mutation amid the Cypriot population. The conclusions of these studies varied according to the sample size used, the geographical area they attended to, and year they took place. They provided diverging results according to such discrepancies: 20% (Banton, 1951), 6-8% (Plato et al., 1964) and 13% (Bate, 1975). A study conducted by Cypriot doctors showed that the percentage of the mutation was 17.2%. This last study concluded as such:

Considering the severity of thalassaemia major these figures demonstrate its seriousness as a public health problem in Cyprus. Since at present there is no other way of reducing the birth rate of patients with thalassaemia major except by genetic counselling, it is suggested that the whole population at risk should be screened for the thalassaemia trait and careful genetic counselling provided to all prospective couples whenever both the prospective father and mother are heterozygous. (Kattamis et al., 1972: 417)
These were attempts at trying to frame thalassaemia in numerical terms. My impression is that what is important here is not the fact that certain studies diverged in their results, but that they all had the same objective, which further intensified interest in thalassaemia amid the Cypriot and international medical community; these studies did not oppose one another, but rather set up a terrain of conversation, as it were, according to which doctors attempting to tackle the illness could think and take further action. Such discursive terrain was essential to the further construction of thalassaemia as an object of medical knowledge and also of practice.

Following Fawdry’s study, and his suggestion that patients of thalassaemia could benefit from blood transfusions, a section devoted to the treatment of thalassaemia was introduced in the Nicosia General Hospital. According to Dr. Hadjiminas this section was run by Dr. Jack Gillespie, an Irish medical practitioner who showed keen interest in thalassaemia. Apart from Dr. Hadjiminas’s account, the work of Dr. Gillespie is absent from historical accounts of how thalassaemia was handled in Cyprus. Although his name appears in scientific papers of the time, the only historical and ethnographic trace of Dr. Gillespie that I have found is a mysterious novel I uncovered on archive.org, entitled The Impartial Knife and written by one Peter Paris (Paris, 1962).
The book starts off as follows: “Peter Paris is the pseudonym for a young aspiring doctor just graduated from a London hospital who decided to start practice where he was most needed in the Nicosia General Hospital in Cyprus” (Paris, 1962: ii). The book begins on St. Patrick’s Day, 1958. Throughout the book Paris refers to thalassaemia as Cooley’s anaemia or Mediterranean anaemia. Paris vividly captures the uncertainty and unravelling epistemological trajectory of thalassaemia as well as its implication in the Cypriot context amid an unstable political climate. The first mention of thalassaemia comes twenty pages into the book. I will quote this at length; albeit perhaps dramatised, it presents a vivid image of medical perceptions and practices of thalassaemia, as well as Dr. Gillespie’s knowledge and authority at the time:

In the next bed was a pathetic small boy with a beautiful Murillo face. He had large brown eyes fringed with very long lashes showing against the pallor of his skin. Somehow the head looked a bit too big for his body. “Here you are,” said Dr. Gillespie. “Do you know what this disease is? If you don’t you will soon find out; we have more of it here, I think, than anywhere else in the world. Have a look. You can almost diagnose it on sight.”

The boy was the colour of straw, with brown patches on his face like those of pregnancy. He had buck teeth and prominent cheekbones. I remembered the chief’s trick and pulled down the lower eyelid. Also pale. Anemia. Suddenly I realized.

"Mediterranean anemia, sir. This is Cooley’s anemia."

"Right also called thalassaemia - thalassa is the Greek for sea. I now diagnose it on the look of the face, although I always confirm that diagnosis in the laboratory. Now, look at him. The blood breaks down so he is pale; it breaks into iron and pigment; the pigment makes him yellow and the iron probably causes those brown
patches in the skin. So, the skin is pale, jaundiced and bronzed. Also he is underdeveloped - the body is too small for the head. How old do you think he is?"

"About seven."

"Actually he is thirteen years old, but his body and his mind are indeed those of a child of six or seven.

"Feel his abdomen. Note that large tender liver and enormous spleen. Later on listen in to the heart you find various murmurs. If we take that spleen out he should do well, but we are still investigating to make sure. I think I have seen more cases of this condition than anyone else in the world and the surgeon here has the record for operating on them. He is very good at it."

"Does taking the spleen out help much?"

"Not in all cases; you have to select your patients. Of course it does not affect the basic cause, which is constitutional - fragile red cells and abnormal haemoglobins. The spleen is just one of the factors contributing to the breakdown of the red cells, but it is the one factor you can do something about. If you remove it they have that much more chance of leading a better life, although never, I am afraid, a normal one. If there is no chance, then of course you must not subject them to the pain and the risk of an operation. (Paris, 1962: 14-15)."

The above passage serves in conveying the ambivalence which characterised thalassaemia as a pathological and epistemological entity at the time, as well as its widespread distribution within the Cypriot population. As one can tell from Paris’s careful diagnosis of the child, such epistemological ambiguity was a sober awareness that one does not know much at this point of time; a careful consideration that facets of thalassaemia existed at the time which could not yet be accounted for. As shown by Paris’s hesitancy and incomplete knowledge regarding the treatment methods of thalassaemia, as well the bene-
fits of removing the spleen, such pathological and epistemological ambiguity also defined the medical and therapeutic imagination, and influenced the retrospectively diagnostic and treatment methods available at the time. Elsewhere, Paris describes the manner by which he would go about diagnosing patients:

The first job that next morning was again the Cooley’s anemia boy, Charalambros Kyprou. I had to take blood from him. I found a nice fat vein in the crook of his arm and pushed in the needle; blood came running out, not the thick sticky red of normal blood, but fast and thin like raspberry wine. I sent this in a small bottle to the laboratory and after an hour the first result came back: "Kyprou, Charalambros, male medical ward. Hemoglobin 15 per cent."

He had less than one-sixth the amount of blood that he should have. I went over and he smiled at me.

"Ime endaxi kyr’iatre?" [“Am I OK Doctor?” – author’s translation]

"Endaxi, Charalambros, telia endaxi". I had learnt some.

"I am all right, Mr. Doctor?"

"All right, Sotiris, quite all right."

I examined him while we were waiting for the result. His breathing was deep and rapid. On his chest one could see where the tip of his heart, trying to make what blood he had do six times as much as it should, banged against the wall of the chest. It lifted the ribs with each beat. Through a stethoscope one could hear a soft murmur all over the front of the heart.

I undid the pajama cord. His belly was tense and swollen. I ran my hand over it and felt, on his left side, a large smooth mass inside the abdomen which moved up and down with his breathing. It ran from the ribs to below the navel, filling all the left
flank. The lump was the boy's spleen which, as Dr. Gillespie had said, would have to be removed. On his right-hand side below the ribs I could also feel something which moved with breathing. As I touched it he gasped; it was tender. This mass must be an enlarged liver, but there would be no operation to take that out. No one can live without a liver.

I listened in to his chest again but the lungs, at least, were all right. There were no unusual noises. Air was passing back and forth in the tubes and tissues of his lungs top and bottom, front and back, both sides no wheezes, no crackling or bubbles, but the breathing was very fast (Paris, 1961, 39-40).

One can thus notice the tactile, dermatic and sensorial dimensions according to which diagnosis of thalassaemia was enacted at the time. Rather than taking place on the molecular level, like nowadays, diagnosis was carried out according to the phenomenal facets displayed by the human body, such as protruding ribs, a swollen belly and yellow skin, as well as the connection and evaluation of such symptoms by medical practitioners through sensorial experience: running a hand over the ribs, checking the colour of the skin, and listening to the breathing of the patient through the stethoscope. At the same time, the blissful ignorance and naivety with which the little boy perceived his condition conveys how experiences of pain and suffering exceeded medical understandings and knowledge of the time. These were the beginning stages of thalassaemia as an object and space of knowledge for both medical practitioners and Cypriot people alike. If this ambivalence was evident in the international medical community, it was one which was explicit amongst the Cypriot population at the time. As Dr. Angastiniotis told me during an interview, although everyone in Cyprus at the time had an experience with thalassaemia, their knowledge and understanding of it was minimal:
The social fabric of Cyprus was different back then. The island was not urbanised and was comprised of small communities and villages. Everyone had an experience with thalassaemia. They might not have known how to call it, but everyone knew of a woman or a family whose newborns would die. People would try to rationalise these things through religious or biological explanations: they would say that it was punishment from God, or that a woman’s milk was ‘bad’. It was their way of making sense of things.8

Dr. Hadjiminas joined Dr. Gillespie in 1952 following his studies in England, six years prior to Paris’s arrival. Hadjiminas prominently figures in Paris’s book under the name of Dr. Hadiji, and is presented as a jovial figure who enjoyed a drink or two and whose desk was well stocked with citrus fruits and nuts (when I sent the book to Dr. Angastiniotis to read he said that Paris provides a perfect caricature of Dr. Hadjiminas). To once again revert to Hadjiminas’s account, the initial steps introduced by Dr. Gillespie to treat thalassaemia included transfusions, splenectomy and counselling for patients and their relatives which focused on the psychosocial dimensions of thalassaemia. Despite the breakthrough of these treatment methods, which were, after all, the first means available by which thalassaemics could live beyond adolescence, their uptake was low. As said, although thalassaemia might have begun being constructed in the minds of medical practitioners, this was not the case with the public. To once again quote Dr. Hadjiminas:

The clinic faced formidable challenges. The majority of Cypriots at the time knew nothing about thalassaemia - a disease whose correct management and prevention was overshadowed by social stigma. The shame associated with thalassaemia was such that families would often leave an affected child untreated rather than bring him or her to the clinic and face the rejection of a positive test. As a result, many children died unnecessarily early and painful deaths, usually at around the age of two.
This fear of opprobrium from the relatives and the community at large was also a major obstacle to efforts to introduce premarital testing. (Hadjiminas, 2008: 96).\(^9\)

Cypriot medical practitioners were, at that point, hindered in their project of treating thalassaemia by two factors. For one, in this initial stage of thalassaemia treatment the fear of prejudice and social exclusion exceeded the collective desire for treatment and social integration. At the same time, one can notice how medical and scientific knowledge was segregated from public perceptions of thalassaemia; despite being enacted on the same spatial locale, medical and social regimes of knowledge were “distributed” (Mol, 2002) and enacted according to different networks and relations. A leap had to be made in order to connect the medical regimes of knowledge and practice with the public ones.

*Thalassaemia under Cypriot rule (1960-1969)*

After 1960, when Cyprus became a Republic, the responsibility for thalassaemia treatment was passed from Gillespie to Hadjiminas. The clinic remained at Nicosia General Hospital but the programme was moved from the Department of Medicine to the Department of Paediatrics. Although not explicitly stated by Hadjiminas in his account, the fact that thalassaemia treatment was relocated to the Department of Paediatrics implies that emphasis was still given to the treatment of young patients; the realisation that a shift to prevention was needed had not yet taken place. In 1964 deferoxamine-, an iron chelating agent used to rid the body of excess iron resulting from blood transfusions, was introduced into Cypriot healthcare. This meant that patients could now have more regular transfusions; before Desferal became available transfusions were kept at a minimum and haemoglobin levels were kept as low as possible so as not to burden the body with high
levels of iron which could result in death. Desferal was the catalyst for transforming the
disease from deadly to chronic and is, even today, the most popular thalassaemia treat-
ment, although its delivery method is being improved. Nevertheless, the initial introd- 
tion of Desferal into the treatment of thalassaemia, much like transfusions and splene-
tomies before it, was not met with widespread use. Hadjiminas attributes this to the 
cumbersome and painful methods of delivering Desferal into the body at the time. To 
quote Hadjiminas:

The introduction of Desferioxamine, while essential for improving patients’ quality 
and length of life, was not immediately successful. Desferal was initially administered 
both intramuscularly and intravenously, in quantities determined according to patient 
age. Patients disliked the intramuscular route and a number refused to continue 
treatment, preferring to receive Desferal via blood transfusions. (Hadjiminas, 2008: 
99).

The use of Desferal, as well as transfusions, also failed to take off for reasons which ex-
tended beyond medical technicalities. Such reasons included dominant social-cultural 
perceptions and structural insufficiencies, and one can very well assert that the gravity of 
these was greater than the technological handicaps of the treatment methods. Ruth Cow-
an points out that “a study of hospital admissions for b-thalassaemia on Cyprus in the 
early 1970s concluded that some parents were still refusing treatment for their children 
and that only 18 percent of the known Greek Cypriot patients were receiving regular 
transfusions” (Cowan, 2008: 199). In addition, the fact that Cypriot marriage patterns of 
the time involved the exchange of property and carried connotations of prestige and sta-
tus (Loizos, 1975; Sant Cassia 1982) made people avoid having themselves or their chil-
dren tested for the mutation, for fear of sullying the family name if testing positive. If a 
child was diagnosed as thalassaemic, parents would keep the condition a secret for fear of
social stigmatisation, and the ruining of marriage opportunities. Such perceptions and practices would carry on into the early 70s, and remain evident in Patricia Book’s ethnography, conducted in the period of 1976-1977. To quote Book, these were “culture-specific problems stemming from values such as the desirability of producing normal children, and the preferential sacrificing of abnormal children through non treatment” (Book, 1980: 33).

As Cowan describes,

In the 1960s Cyprus was still a very traditional, agricultural society; most marriages were arranged by parents. Most people were fatalistic about the results of their sexual relations; they also believed that a young person’s value on the marriage market would plummet if anyone in his or her family was known to carry ‘the stigma.’ (2008: 203)

Returning to Patricia Book, concerning the psychosocial dimensions of thalassaemia patients:

In Cyprus, the birth of a thalassemic child reflects adversely on the entire family and jeopardizes future alliances. The ill child represents a failure for the young couple attempting to establish itself it-self in Cypriot society. In the truest sense of the word, the Cypriot thalassemic child is unwanted - unwanted by a family which is tainted by the child’s very existence and unwanted by a medical system which is unprepared and probably unable in the long run to bear the burden of maintaining these children at an optimal level. The thalassemic child is a new phenomenon in Cyprus, reluctantly given years by medical intervention in what would otherwise have been a short course.” (Book, 1980: 135)

Book’s research also showcases how theological conceptions of thalassaemia were still in effect, even in the mid-70s. Commissioned by the Cyprus Ministry of Health at the time,
Book conducted regular interviews and visits to houses of couples with thalassaemic children. Regarding these she writes, “In a few instances parents were slightly ill at ease. There were several idiosyncratic reasons for this - the extended family may not have known that there was an ill child and it was feared that grandparents might be alerted by our visit” (Book, 1980: 123). In another instance Book writes, “The parents have also kept the disease a secret from relatives and friends. A cousin of the mother only found out because she met the mother at the treatment clinic with her own newly diagnosed child” (Book, 1980: 144). In addition to the secrecy with which Cypriot couples dealt with thalassaemia at the time, Book’s interviews also convey the widespread theological perceptions according to which Cypriots regarded thalassaemia at the time:

One woman reported that though counselled about risks, her husband loved and wanted children so they ‘trusted in God.’ All of their children (four thalassemics) were unplanned … There was considerable range of variation among parents as far as their level of understanding of the genetics of this disease was concerned … a few parents seemed totally unaware of the genetics of the disease and tended to attribute its existence to God’s will or poor natal care at the hospital. (Book, 180: 230-231)

Elsewhere, she writes: “Two women felt the birth of an ill child was punishment from God” (Book, 180: 240).

Cowan directs us to the inequalities of access people had to the drug, as well as the structural problems Cypriot healthcare faced at the time Desferal was first introduced. As she writes, “Many people recall that, in the first few years, the children of affluent families had the easiest access to the drug, second only to the children who lived near to the naval bases, where the physicians were sometimes able to requisition it as part of their ‘necessary’ supplies” (Cowan, 2008: 200). The Cypriot population also faced infrastructural and political challenges at the time:
The obstacles to this treatment regimen were numerous. Much of the population of Cyprus was rural, transportation was poor, and there was no blood bank. Many children, parents, and donors had to travel long distances to clinics, overnight stays were often required, and blood donors asked for payments in lieu of lost wages. On top of all this, civil unrest was endemic, starting in the 1950s. (Cowan, 2008: 199)

This lack of blood extended back to the days of the British administration. No regulated system existed, and blood was collected sporadically. As Paris writes, “There were a few voluntary blood donors amongst Cypriots, I had been told; the doctor [Gillespie] has to browbeat friends and relations” (Paris, 1962: 40). Book also reports that, “In 1976, the centre for Thalassaemia treatment and prevention was Nicosia General Hospital. The facilities were centrally located, but access was complicated by poor road conditions, occasional inclement weather and irregularity of bus schedules and other transportation” (Book, 1980: 96). Thus, on the one hand, theological and superstitious perceptions of thalassaemia made parents leave their children untreated. On the other hand, lacklustre transport and healthcare infrastructure made it hard for patients to get access to existing treatment arrangements.

Hence, although, because of the high prevalence it displayed, Cyprus was a country which remained in the vanguard of implementing new medical technologies on the treatment of thalassaemia, the acceptance rate of these was low due to the aforementioned reasons: fear of social stigmatisation, lack of blood, as well as the rural segregation of villages and long distances from the clinics. Finally, one must mention the political and nationalistic tension permeating everyday life at the time. Cyprus may have gained independence from the British and become a Republic, but inter-communal conflict and tension with the Turkish population was still taking place. These were factors which in their generality prevented the social integration of thalassaemia patients in Cyprus, as well as
the opening up of thalassaemia as an object of politicisation and knowledge production. This was a point in time where the breakthrough and potency of new medical technologies was restrained by fossilised socio-cultural arrangements, as well as a fragile political climate and national economic instability.


Concern was growing amongst Cypriot medical practitioners and politicians alike, regarding how to prevent new cases of thalassaemia from taking place. Thalassaemia was an expensive illness to treat, and the addition of new patients hindered attempts at providing adequate treatment to existing ones. At the same time, the costly nature of treatment was impacting on the Cypriot economy as a whole. Desferal might have provided a lifeline to thalassaemia patients, but at the same time the extended lifespan of patients meant that treatment also was prolonged. If medical costs had risen, it would have put the lives of even the few patients able to afford treatment at the time into jeopardy. To quote Angastiniotis et al.:

> Deferoxamine is expensive and it was difficult to find enough blood donors to sustain a high transfusion regimen … Resources were clearly going to be severely strained if new cases were added year by year. The prevention of further homozygote births therefore became necessary to ensure the survival of existing patients. (Angastiniotis et al., 1986: 292)

Hadjiminas writes:

> A full scale, five-year programme for the management of thalassaemia was launched in 1969 … Support was sought from the World Health Organization, which agreed
to send an adviser on thalassaemia to lend his expertise to the programme. Prof. George Stamatoyiannopoulos of the University of Washington in Seattle duly arrived in Cyprus in November 1971. (Hadjiminas, 2008: 103).

Developing from the involvement of the World Health Organization the Cypriot struggle against thalassaemia acquired and benefited from global connections; it had been almost 50 years since Cooley first presented his findings on anaemia to the American Medical Association. Knowledge and expertise regarding thalassaemia around the world had been accumulating and changing. Such enrichment, however, was globally disuniform and disconnected. Knowledge, and the practices deriving from it, are interactively enacted and sustained according to relational regimes which are nevertheless local in scope and thus potency. The decision by Cypriot medical practitioners and politicians to recruit the help of the WHO and Prof. Stamatoyiannopoulos was thus an act which managed to foster a connection between previously segregated localities of knowledge and practice regarding thalassaemia.

The report drafted by Dr. Stamatoyiannopoulos for the Cypriot government acted as an impetus for a shift to take place, regarding the national policy of thalassaemia, from treatment to prevention. To once again quote Dr. Angastiniotis:

The report of a consultant from the World Health Organization demonstrated that the resources of the health services were going to be severely strained as the curative services improved. Given an annual increase of 60-70 cases [of thalassaemia], it was doubtful if adequate amounts of deferoxamine and blood would be found to ensure adequate treatment and survival of existing patients. Increased survival rates could have led to a rise in prevalence from 1:1000 to 1:138 in about 50 years, causing a 300-400% increase in blood requirements and a 600-700% rise in the cost of treat-
A prevention programme was thus regarded as imperative. (Angastiniotis et al., 1986: 292)

The report drafted by Stamatoyiannopoulos was an instance where, through a process of numerisation and calculation, a process of problematisation was triggered regarding the position of thalassaemia in Cypriot national policy, which not only caused the transformation of the state from a passive one into an “activist” one (Biehl, 2004), but also the transformation of thalassaemia from a matter of fact to “a matter of concern” (Latour, 2008). As Hadjiminas writes, “A growing awareness of the social, financial and logistical cost of thalassaemia in Cyprus lent the programme a sense of urgency … From the outset my team was given as free a rein as possible, including permission from the Minister of Health to seek support as needed, avoiding bureaucratic delays” (Hadjiminas, 2008: 119). According to such authority, the Cypriot government granted Hadjiminas and his co-workers with passageways and mediums by which they could perform speedy leaps and mediate between previously contiguous domains. Such implication of local governing authorities, as well as global health organisations, meant that thalassaemia became, as it were, the “country’s disease” (Biehl, 2008: 12) – at least in the eyes of medical practitioners and politicians. One should notice how the need to attain medical and financial security forced a shift in how thalassaemia was to be dealt with; illness would now be dealt with, not only *in-esse*, but also *in-potentia*, not only in its present actuality (treatment), but also in its future possibility (prevention) or, rather, in the very present presence of such future possibility.

Due to these events, thalassaemia, and the field of knowledge according to which it was enacted, assumed a problematic character in relation to the Cypriot context, not in the sense of posing or being a problem, but rather in the sense of assembling and construct-
ing one. We must not confuse the two; the assembly and construction of a problem are two very different things, insofar as the non-intentional assembly of a problem defines the parameters for and gives way to the intentional construction of a problem. On the one hand, thalassaemia as an object of knowledge and practice parallels the assembling trajectory of thalassaemia as a problem: the coming to life of new thalassaemia patients, the dominant perceptions of the Cypriot people, the drafting of the WHO report, the need to secure economic stability, and the newly achieved democratisation of Cyprus; these were the elements according to which thalassaemia was deemed problematic – the process by which “a problem ‘gathers together’” (Stengers and Pignarre, 2011: 112). On the other hand, the construction of a problem out of these aforementioned elements was an intentional project, aimed at situating thalassaemia within policy-making processes of local government and global organisations alike.

This is thus the “double articulation” (Deleuze and Guattari, 1987) of problematisation; while the process of assembly of a problem is non-intentional and emerges out of the gathering of the elements according to which a problem makes itself apparent to human perception, the construction of a problem is an intentional process of organisation which traces the contours of a potential field of action and possibility with regard to the previously assembled problematic elements, apprehends and serialises these, and actively situates them in political and institutional agendas. The political predicament in such processes is who has a claim and is able to partake in such intentional processes of serialised problematisation, as well as how the process of serialisation is conducted by those involved. To once again quote Stengers and Pignarre, “There is nothing more demanding, intellectually, affectively and imaginatively as the process of creating a problem” (2011: 144).
It soon became evident that in order for thalassaemia treatment and prevention to take place, the existing dominant perceptions the Cypriot population had about the illness had to be countered. Thalassaemia had to be grounded. The following quotation by Hadjiminas does well to convey the infliction of suffering and discrimination such perceptions caused, even in the early 70s when the prevention initiative was put into effect:

The challenge of preventing thalassaemia in Cyprus was huge - and the main obstacle was not medical or scientific but social. Couples resisted being tested for the trait for fear that a positive result would mean ostracism. By extension the birth of a child with thalassaemia was often believed to be God’s punishment, forcing affected families to live in isolation in order to hide their child’s illness and avoid the scathing remarks of family and friends. In extreme cases, father demanded divorce, mother committed suicide, children were killed. (Hadjiminas, 2003: 108).

The construction of the Cypriot thalassaemia programme first and foremost required emptying the perceptions of Cypriots of superstitious beliefs. As previously mentioned, prior to the dissemination of medical knowledge and practice, Cypriot people by and large were oblivious of the pathological dimensions of thalassaemia; on an epistemological level, thalassaemia did not exist - or, rather, it existed, but according to faulty understandings and knowledge. On an ontological level, however, thalassaemia as a recessive mutation and disorder kept making its way through the Cypriot population through marriage patterns and childbirth. A change was thus required in order to align public epistemology and pathological ontology, to evaluate pathology not according to sclerotic perceptions, but to a spirit of practicality and pragmatism. To situate thalassaemia not in a judgemental theological doctrine, but in bodies, social relations and interactions such as genes, blood, meeting new people and getting married. One could say that in these initial stages, the programme did not have as its objective the prevention of thalassaemia per se, but rather its construction. The objective of the system was not only to prevent and do
away with thalassaemia, but also to fully affirm and acknowledge the given pathology as one unavoidably imbricated with the Cypriot population: to openly and loudly declare and accept that this is what had to be dealt with.

For such a shift in perceptions to be achieved another leap had to be made. Thalassaemia as an open-ended object of knowledge and practice might have entered the medical sphere of perception, but not the public one. Even though situated on the same spatiality, these two regimes of knowledge and practice were largely disconnected and enacted separately; a reconciliation or, rather, cross fertilisation and connection between the two had to be achieved. When the programme was first put into effect, such a process of medical and cultural connection was achieved through two initiatives which were parallelly and relatedly triggered: the need to provide better treatment to existing thalassaemia patients, and the need to sensitise and educate the public through the dissemination of scientific and medical knowledge regarding thalassaemia so as to facilitate its social acceptance and prevention.

The first task in achieving such a two-pronged approach was to set up a network of clinics in the main cities of the island. These would not only increase the level of treatment for existing thalassaemia patients, but would also act in disseminating information of thalassaemia as a genetic disorder and provide genetic counselling to the parents of patients, as well as existing couples who might be implicated with the disease in the future. As mentioned before, the previously sole clinic in Nicosia could not cope with the entirety of the patient population, and in addition its transport connections were poor and lengthy. It was thus considered essential to the progress of the programme that a proper infrastructure was set up. Clinics staffed with appropriate medical personnel were thus set up around the island. Besides the existing one in Nicosia, clinics were established in Limmassol in 1970, in Larnaca in 1972, in Famagusta in 1972 and Paphos in 1973. In addi-
tion, a sensitisation campaign was put into motion in order to educate the Cypriot population on aspects of thalassaemia. This sensitisation campaign included the genetic counselling of families at risk, the inclusion of classes on thalassaemia in the high school curriculum, public lectures, as well as the dissemination of information through mediums such as posters, leaflets, and television and radio shows.

If not the gravity, the intentionality of the medical regime of knowledge superseded the public one amid such initiatives. In other words, it was largely up to the medical practitioners, not the public, to attempt to reconcile the two regimes. This statement of mine is not meant to downplay the role or power of the public at the time, but rather to consider the movements and leaps of certain individuals as especially important; we all mediate between others, in one way or another, but what distinguishes the specific individuals involved in the bringing together of the Cypriot thalassaemia programme is the fact that they displayed an exceptional vitality and speed which allowed them to traverse a social field in its extremity; they forged novel connections, and facilitated unprecedented constructions. At the same time, we must acknowledge that the power to make such leaps was granted to such individuals through governmental authority.

In the case of the Cypriot prevention programme, the passageways and channels by which medical practitioners could traverse the social were provided by governmental authority. Such an intentional stance by the medical practitioners did not entail that public and cultural perceptions of thalassaemia were cast aside in favour of the introduction of a scientistic regime of knowledge and practice. On the contrary such public and socio-cultural perceptions were treated as facets which had to be accounted for, and not cut through; they acted as points of problem construction, and were included in such processes of serialisation and problem construction. Such obstacles were not reduced, internalised or consolidated in the unfolding trajectory of policy implementation. Rather,
these obstacles acted as points of reference and connection; they acted as articulations rather than negations – points of reference according to which the trajectory of the thalassaemia system was determined and constructed. As we will see later, the dissemination of medical knowledge did not result in the complete rationalisation of Cypriot culture. To put it another way, newly introduced medical knowledge did not override Cypriot customs of marriage and matchmaking, but rather deepened and complemented them.

*The Turkish invasion, a two year hiatus, and a turnaround (1974-1983)*

Two years after the national programme was put into effect the Turkish invasion took place, which threw the island into disarray. The thalassaemia programme was unavoidably halted and the Famagusta clinic was now defunct since it was situated in the land taken over by Turkish forces. Thousands of people abandoned houses in the north of Cyprus and made their way down to the south of the island to relocate to main urban areas there. The invasion took place in July of 1974, and the national thalassaemia programme was not put back into full effect until 1976. According to Hadjiminas:

As a result the programme was restricted to testing couples who were about to get married, following-up on the care of patients and providing blood transfusions - a particular challenge … after several months the decision was taken to reactivate the Thalassaemia Programme in full. In the event, however, the programme was not fully restored until 1976. (Hadjiminas, 2008: 120).

My impression is that because of the chaotic state the island was in following the invasion, as well as because it was in its infant stage, no data was gathered regarding the success of these early stages of the thalassaemia system from 1972 until 1974. I could not locate any statistics as to the achieved prevention rate of the programme, nor could an
interviewee provide me with some sort of figure; this was an instance where the intentional process of problem construction was upset by a contingent event.

The earliest figures pointing out the efficiency of the prevention programme appear in a joint article by Angastiniotis et al. (1986). The figures cover the period 1974 to 1984. The lack of efficiency of the prevention system in its early stages is apparent. In the year 1974, 8,594 births were expected in the Cypriot population as a whole. Given the estimations of the prevalence of the thalassaemia mutation in the population 54 births of thalassaemic children were expected. 53 thalassaemic children were born. In 1975, 51 births of thalassaemic children were expected, and 48 came into being. It is evident from these early figures that the prevention system was not as efficient as it was hoped it would be.

However, the statistics show a dramatic change in the rate of prevention in the next year of 1976; 59 thalassaemic births were expected, but only 37 took place. This was still a long way from the 100% prevention rate target set, but the change from previous years was striking. 59 thalassaemic births were expected in 1977, and once again only 37 took place. By 1983 the prevention percentage had reached 88%; 69 thalassaemic births were expected in that year, and 8 took place (see Figure 5 for statistics).

To what factors can the dramatic change of 1976 be attributed to? I am not sure, and following Ruth Cowan’s conclusion on this matter, I am also under the impression that “no one who was involved can fully account for the magnitude of that change” (Cowan, 2008: 205-206). Much like Cowan, I have heard several speculations, but no definitive answers as to why such a change took place. I interpret this ambiguity and uncertainty surrounding the turnaround of the Cypriot thalassaemia programme as indicative of the complex relationality according to which the space of thalassaemia at the time was enacted. Social processes of change and rupture are often non-intentional and unexpected. Nevertheless, although we cannot pinpoint such progress to a specific actor or process
within the Cypriot thalassaemia system, we can attend to the multiple operations which unfolded in parallel, and which similarly strived towards improving the prevention rate at the time. Such initiatives collectively aided in overcoming the discrimination and superstition by which thalassaemia was previously considered.

<table>
<thead>
<tr>
<th>Methods Used</th>
<th>Year</th>
<th>Births</th>
<th>Expected births of thalassaemias</th>
<th>Actual number of thalassaemias born</th>
<th>Difference</th>
<th>Prevention</th>
</tr>
</thead>
<tbody>
<tr>
<td>Introduction of genetic counselling</td>
<td>1974</td>
<td>8594</td>
<td>54</td>
<td>53</td>
<td>1</td>
<td>1.8</td>
</tr>
<tr>
<td></td>
<td>1975</td>
<td>8039</td>
<td>51</td>
<td>48</td>
<td>3</td>
<td>6.0</td>
</tr>
<tr>
<td></td>
<td>1976</td>
<td>9259</td>
<td>59</td>
<td>37</td>
<td>22</td>
<td>37.0</td>
</tr>
<tr>
<td>Introduction of prenatal diagnosis, in UK, Greece and Israel</td>
<td>1977</td>
<td>9188</td>
<td>58</td>
<td>37</td>
<td>21</td>
<td>36.0</td>
</tr>
<tr>
<td></td>
<td>1978</td>
<td>9644</td>
<td>61</td>
<td>27</td>
<td>34</td>
<td>56.0</td>
</tr>
<tr>
<td></td>
<td>1979</td>
<td>10372</td>
<td>66</td>
<td>25</td>
<td>41</td>
<td>62.0</td>
</tr>
<tr>
<td></td>
<td>1980</td>
<td>11087</td>
<td>70</td>
<td>20</td>
<td>50</td>
<td>71.0</td>
</tr>
<tr>
<td></td>
<td>1981</td>
<td>10780</td>
<td>66</td>
<td>10</td>
<td>58</td>
<td>85.0</td>
</tr>
<tr>
<td>Introduction of prenatal diagnosis in Cyprus</td>
<td>1982</td>
<td>11578</td>
<td>73</td>
<td>8</td>
<td>65</td>
<td>89.0</td>
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<tr>
<td></td>
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<td>10900</td>
<td>69</td>
<td>8</td>
<td>61</td>
<td>88.0</td>
</tr>
<tr>
<td>Introduction of Premarital Certificate</td>
<td>1984</td>
<td>11200</td>
<td>71</td>
<td>4</td>
<td>67</td>
<td>94.0</td>
</tr>
<tr>
<td></td>
<td>1985</td>
<td>10421</td>
<td>66</td>
<td>2</td>
<td>64</td>
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<tr>
<td></td>
<td>1986</td>
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<tr>
<td></td>
<td>1987</td>
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<td>65</td>
<td>2</td>
<td>63</td>
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</tr>
<tr>
<td></td>
<td>1988</td>
<td>10752</td>
<td>68</td>
<td>0</td>
<td>68</td>
<td>100.0</td>
</tr>
<tr>
<td></td>
<td>1989</td>
<td>10372</td>
<td>66</td>
<td>0</td>
<td>66</td>
<td>100.0</td>
</tr>
</tbody>
</table>

Fig. 5: Results of the Cypriot thalassaemia prevention programme. Table reproduced from (Hadjiminas, 2008: 132).

Let me go a bit more into detail about these multiple processes. As mentioned earlier, written text does not help me in denoting the processually pluralistic interactions by which thalassaemia as an object of knowledge was enacted at the time.

1) In 1977 the Co-Ordinating Committee of Blood Donation and Enlightenment was founded by another Cypriot medical practitioner, Dr. Nicos Pavlides. The task of the committee was two-fold. For one, it aimed to tackle the problem of the lack of blood which the Cypriot healthcare system faced at the time. In addi-
tion, it aimed to inform and enlighten Cypriots as to voluntary blood giving. As Dr. Pavlides mentioned when I interviewed him, before the committee was set up the blood collected amounted only to 3% of the amount required. Acquiring the required amount of blood was integral to setting up a well-functioning blood donation and banking system for thalassaemia patients at the time. At the same time, the blood bank would be used for other purposes, such as emergency transfusions in the case of accidents and other forms of surgery. The blood required for thalassaemia patients was gathered through a vigorous schedule of blood donation events organised by the Committee in villages and towns around the whole of Cyprus, an exercise which persists even today.

As was the case with the entirety of the Cypriot thalassaemia programme, the blood donation committee was organised and enacted according to the cultural dimensions of the Cypriot polity. To quote Dr. Pavlides, “The programme introduced was organized in a way to meet the Cypriot mentality, religious beliefs and culture. There was no copying from similar systems in other countries. Everything done had the earmark of the Cypriot mentality” (Pavlides, 2008: 312, my translation from Greek). An example of this cultural adjustment was provided to me by Dr. Pavlides himself during our interview. As he said to me

In order to get people to donate blood we would go to villages and I would go and sit with people in coffee shops. At first they would be hesitant to give blood because they feared they would be frowned upon by the rest of the village. As we kept playing cards I would explain to them that thalassaemia wasn’t this terrible thing they thought but just an illness. Some of them agreed to give to blood, some didn’t – but back then every single donour counted.
Once again then, one can see how practices to acquire blood as well to as to socially integrate thalassaemia were adjusted to Cypriot culture, values and beliefs. As made evident by Dr. Pavlides’ narration, such cultural adjustment did not only take place on the macro-level of policy and governmental decision-making, but also on the micro-level of everyday life.

2) 1977 was also the year when foetoscopy became available. This was a radical at the time technological breakthrough which allowed prenatal diagnoses to take place. In other words infants could be tested for the disease while still in the mother’s womb. The technology would not be integrated in Cypriot healthcare until 1981, but in the period 1977-1981 Cypriot pregnant women at-risk were sent to the UK, Greece or Israel to be tested. As was the case with previous technological advancements, such as blood transfusion and Desferal, the potential benefit of foetal diagnosis for the Cypriot thalassaemia system was recognised from early on. Couples at-risk would be sponsored by the Cypriot government to travel abroad and be tested. The first woman to be sent from Cyprus to the UK to be tested was the 13th worldwide. The introduction of prenatal diagnosis was important in rearranging the perceptions and practices of Cypriots regarding thalassaemia. Previously, potential carriers would not be tested for the trait for fear of ruining marriage opportunities. However, the introduction of prenatal diagnosis meant that couples now had a way to treat thalassaemia even after the event of marriage. Nevertheless, even considering the change in medical capacity brought by the technology of foetal diagnosis, we must be careful in translating such change in social and cultural terms. Although it offered unprecedented opportunities, such technological advancement did not entail a radical break with previously existing Cypriot cultural norms. On the contrary, the technology of
prenatal diagnosis was integrated into already existing marriage practices; in this regard, the coming of foetal testing technology did not entail the rationalisation (Beck and Niewöhner, 2009) or technological determinism of Cypriot norms (Bornik and Dowlatabadi, 2008), but rather their enrichment (Edwards, 2005).

3) The improvement of the prevention rate can also be attributed to the sensitisation and educational campaign which had started gaining momentum by 1976. The campaign was put on halt following the Turkish invasion but was restarted once the Cypriot population had resettled in the south part of the island. The dissemination of scientific knowledge made Cypriots reconsider their perceptions of thalassaemia, and acknowledge its biological dimensions. Such an epistemological shift was especially evident in high school students attending classes focusing on the pathological dimensions of thalassaemia, which were then introduced into the school curriculum.

4) Another scenario is that the rupture of the Turkish invasion and the internal migration which followed was a process which upset the previously rigid social hierarchies and marriage patterns of the island. The movement of population following the invasion caused a process of intense urbanisation, as people previously living in villages resettled in the more urban and densely populated cities of the island. As Dr. Angastiniotis mentioned in one of our conversations, a potential factor which emerged out of these movements of the Cypriot population is that young people leaving the village and moving to more urban areas were not under the influence of hierarchical norms and the gerontocracies of villages. As such, interaction between partners was more liberal, shifting away from the sclerotic perceptions surrounding thalassaemia in villages.
Finally, the transformation of thalassaemia into a matter of concern can be attributed to the formation of the Pan-Cyprian Anti-anaemia Society. Although it only has a small part in this chapter, the patient’s association becomes the focus of the thesis in chapter three. This group was formed in 1973 by the parents of thalassaemia patients. The group played an important role in politicising and lobbying in order to demand better healthcare from the Cypriot State. The association did not only have as its purpose the improvement of treatment facilities for existing patients, but also the prevention of future patients. This was because it recognised that better treatment entailed prevention, since the birth of more thalassaemia patients implied that existing patients would receive less funds and medical attention. Such a process of politicisation and lobbying was epitomised in 1977 when, after a series of demonstrations, the Cypriot government agreed to supply all thalassaemic patients with their regular Desferal supply for free.

The introduction of the premarital certificate and a 100% prevention rate (1984-present)

1984 was the year in which the premarital-certificate was introduced. Although by that year the Cypriot thalassaemia programme had achieved a consistent yearly prevention rate between 85% and 89%, the introduction of the certificate was implemented because it was thought it would result in a 100% prevention rate. The reason for implementing the certificate was because almost all of the births of thalassaemic children at that point in time took place due to women asking for a foetal diagnostic test at a late stage of pregnancy, when it was too late to consider the possibility of an abortion. A way was thus required to get couples tested before they conceived. For its part, the Church apprehended this as means of couples being aware of their carrier status, and thus preventing future abortions of thalassaemia babies from taking place.
The suggestion of implementing a premarital certificate had been mentioned twice more before this: once by Dr. Gillespie in 1957 when Cyprus was still under British rule, and once more by Dr. Stamatoyiannopoulos, the WHO expert who conducted the report in 1972. Although the idea of a premarital certificate eventually came to fruition, the implementation of the idea was, like the rest of the decisions by which the programme had been constructed up to that point, met by deliberation. I will quote Dr. Hadjiminas at length on this point, because I believe his memory and reflection of the given situation conveys the complexity and novelty of the matter at hand:

I tried hard to find a less painful solution that could be acceptable to all interested parties. We had to find a way to convince couples to come forward early to be tested for thalassaemia. We had to convince them that doing the test was in their best interest, while helping them surmount their fear of rejection. The problem was complicated and immensely human. Ethical, social, religious and medical issues had to be taken into consideration before the right solution could be found. And whatever the solution was, it must not interfere with the human rights and freedom of the individual. For that reason I rejected a proposal of having the Premarital Certificate under the control of the State … I arranged a meeting with Archbishop Chrysostomos, and soon found myself in front of the Archbishop and the Holy Synod to present the case on behalf of the Thalassaemia Centre. (Hadjiminas, 2008: 142).

The introduction of the certificate incrementally increased the prevention rate, and by 1988 no accidental births of thalassaemic children were taking place. The implication of thalassaemia with religious and theological beliefs has been attended to throughout this chapter. As previously mentioned, in order for thalassaemia to be accepted as an acceptable pathological entity it had to first be emptied of its theological and superstitious connotations. In this regard, the involvement of the Cypriot Church with the thalassaemia programme might come as a surprise. Yet, the introduction of the premarital certifi-
cate was not meant to reinstate thalassaemia’s religious dimensions. Rather, this was an instant where religion, much like thalassaemia, was relegated from a transcendent entity into an actor of deliberative capacity. To put it another way, the Cypriot Church as an organisation and religious doctrine did not assume the transcendent role of a central authority regulating the social field, but was actively and productively involved with the enactment of thalassaemia as an object of knowledge; it did not rule over such object, but was rather part of the object itself. Through its implication in bureaucratic dimensions of marriage, the Cypriot Church assumed a practical and pragmatic stance; it introduced an “obligatory passage point” (Beck and Niewöhner, 2009: 81; Callon, 1986) which served to promote awareness regarding one’s status as a thalassaemia carrier.

It is worthwhile, at this point, to also mention that the certificate does not promote and have as its objective the abortion of thalassaemic children, but rather its objective is that potential parents are informed as to whether they are carriers of the thalassaemia mutation or not. With this in mind I would like to recount a vignette from my fieldwork: I believe it was my second conversation with Dr. Angastiniotis, an important figure in the construction of the prevention system and a present medical advisor to the Thalassaemia International Federation. While we were speaking, his phone rang. We interrupted our conversation so he could take the call and five minutes later he hung up and told me that they told him that the birth of a thalassaemic baby had taken place in Larnaca – a city of Cyprus. I was confused by this because, as can be seen above, the tables show that the prevention rate has been 100% ever since 1988. I told the doctor this but he dismissed my assumption, and told me that, on average, five to six thalassaemic babies are born every year. It would later occur to me that the statistics and prevention rates refer to non-intentional births. In other words, five to six children with thalassaemia are born every
year, but these births are not included in the prevention rate because they take place with parental consent; they are not prevented, but rather accepted.

**Slow vs. fast policy making**

Throughout this chapter I have been making the claim that the movements of Cypriot medical practitioners traced the contours and created a space according to which thalassaemia came to be collectively enacted as a social object of knowledge and practice. This was achieved through the deployment of relational regimes which served in disseminating medical and scientific knowledge and practice. Relational regimes were set up on several interacting levels, such as the bureaucratic, governmental, technological and socio-cultural, through different means, such as public sensitisation, the forging of alliances with international bodies and organisations and the procurement of emerging technologies such as Desferal and foetoscopy. Such newly established regimes of relations not only served in providing public forums where thalassaemia could be discussed and thus emptied of its theological connotations and misinformed assumptions, but also succeed in transforming thalassaemia in a collective matter of societal deliberation and mutual co-construction. Through such spaces of deliberation, thalassaemia morphed from a static relational arrangement determined and maintained by sclerotic cultural perceptions, into an open-ended, unfolding arrangement of socio-political constitution.

I would like to connect such conclusions to Isabelle Stenger’s concept of “slow science”. My concluding assertion is that the Cypriot thalassaemia system proved to be effective due to the policy making by which the Cypriot thalassaemia programme weaved in and accounted for the obstacles and affections met in its course, rather than disregarding them in favour of a fast, predetermined trajectory. Stengers uses the concept of slow sci-
ence to denote a form of conducting science and producing scientific knowledge which does not proceed through and strive to achieve an anticipated end, but rather, works through the obstacles met in the course of doing research; slow science does not treat deviations from a perfect form as void static noise, but as the very substance research must attend to. As she writes, the form of slow science involves “active lucidity about what is actually known, avoiding any confusion between the questions that are actually answered and the questions that will arise in the wider inevitably messy environment.” As she writes elsewhere, slow science seeks “to enable scientists to accept that what is messy not as a defect, but as what we have to learn to think in and with” (Stengers, 2011). More recently Adams et al. (2014) explored what an ethic of “slow research” would entail for global health. As they write, “Slow research takes the local as a starting point. It calls attention to and focuses on the importance of particularity and specificity. It assumes that the particulars which makes one place or project differ from another cannot be set aside in favor of those qualities that makes places and projects appear to be similar” (Adams et al., 2014: 181).

With these sayings in mind, and in relation to the trajectory by which the Cypriot thalassaemia system was constructed, I would like to pose the following questions: How would a slow modality of policy making proceed? How can policy making acknowledge the messiness of everyday life? And, on a more general level, how can the relationship between techno-science and polity be conceptualised as beneficial and productive? It is my impression that a slow form of conducting policy would work through the obstacles and affections met in the field and polity which any policy-making decisions will address and ultimately influence. In the case of the Cypriot medical practitioners, the construction of the thalassaemia system was not a fast trajectory of implementing a predetermined template solution; it was, on the contrary, a slow process of working through existing cultur-
al, social and religious categories. It was slow, albeit not in the sense that it took a long time for it to produce results. In fact, the Cypriot thalassaemia system produced remarkable results in a relatively short amount of time, if one considers the magnitude of the challenge faced and the unstable socio-economic conditions at the time. Rather, it was slow that in the sense that it was constructed through processes of deliberation and problematisation, and according to uncertainties met in its process of construction. Such uncertainties did not constitute obstacles which had to be negated and overcome, but rather as points of connection and further construction of the programme.

I would like to return to a specific key instance, namely the 1972 WHO report, which I perceive exemplified what Stengers calls “slow thinking”. Besides predicting that the exponential growth of thalassaemia patients would place an unbearable burden on the island’s financial resources, the report also concluded with some recommendations as to how such an outcome could be avoided. Nevertheless, rather than taking the report and recommendations of the WHO official for granted, as a “magic bullet” approach – or what Bruno Latour would call a “double click” approach (Latour, 2003), an action which happens automatically when you double click on your computer – Cypriot medical practitioners used the report as means for problematisation. To once again quote Hadjiminas:

Prof. Stamatoyiannopoulos delivered his report to the Minister of Health in 1972, outlining the key principles on which a thalassaemia prevention programme should be based as well as recommendations for the treatment and follow-up of thalassaemia patient … Prof. Stamatoyiannopoulos’ report was of great help to me, but it was necessary to carry out a number of changes to the text to make the Programme to be in line with the needs, culture and mentality of the Cypriots who were the people to benefit from the programme. (Hadjiminas, 2008: 104).
Thus, rather than acting as instrumental to the setting up of the prevention programme, as a blueprint or ideal form, the report was used as a tool for deliberation. The WHO report did not serve in definitively defining the problem of thalassaemia. Rather, it was one element amongst many by which the problem of thalassaemia was assembled, but not necessarily determined. Put the above passage in conversation with a snippet of my discussion with Dr. Angastiniotis. As he said to me:

We didn’t have targets. People think that our target was to minimise births but that wasn’t true. Our purpose was to get a response from the Cypriot population. When we started providing people with information about thalassaemia we had some who said that they didn’t want to abort their thalassaemic children. So that was our goal; to make people aware of thalassaemia, not minimise births.

Cypriot medical practitioners, while acknowledging the usefulness and gravity of the WHO report, also recognised that a process of cultural and organisational adjustment had to take place in order for the thalassaemia programme to prove successful. The report did not speak in the name of a situation, but was rather part of the situation. Following the report, a governmental programme was put into effect in order to provide the infrastructure for a national thalassaemia treatment and prevention system. At the same time, however, such a system had to account for the specificities of Cypriot culture and society. On the one hand thalassaemia was perceived through faulty superstitious and folk beliefs which were to be countered, but, on the other hand, thalassaemia was also implicated with marriage patterns and rituals of the Cypriot population. It was evident that the latter could not be simply cast aside regarding policy implementation. Thus, as Hadjiminas writes:

A programme that aims to combine the highest possible level of care to patients with a significant reduction in, or no, new births, requires the co-ordination of spe-
cific clinical and administrative services. At the same time, considerable care must be
taken to enlist the support and active participation of the community as a whole,
through information campaigns aimed at explaining the disease and the services
available to patients. (Hadjiminas, 2008: 110).

Such an agenda, as described by Hadjiminas, entailed that the construction of thalassaemia as a problem and as a system had to account for the specificities of the Cypriot context, itself being pluralistic and heterogeneous. It entailed that the setting up of the treatment and prevention system had to account for the obstacles and uncertainties met in the course of its construction - which presented themselves in the form of religious, social and cultural dimensions of the Cypriot polity - rather than disregard these in favour of the template solution offered by the WHO report.

To once again quote Hadjiminas, “Religious, ethical and legal issues all stand to be challenged by a far-reaching prevention system. The Cypriot prevention programme took account of these potential sticking points from the outset, ensuring that the programme addressed key issues of concern and supported individuals and the community through the process” (Hadjiminas, 2008: 110). The way by which the system was set up was thus determined according to a process of experimentation and “tinkering” (Mol et al., 2010). This process paralleled the construction of a problem which did not anticipate its end; it did not presume a trajectory starting from an essential problem and final solution. Rather, problem and solution were both subjects of a process of differentiation unfolding across time, which paralleled the attempt of medical practitioners to adjust to the needs and wants of the Cypriot population; the solution was not determined, but was to be found; it was not to be imposed, but was to emerge. Or, rather, problem and solution were enacted in parallel and dialectically, and morphed according to the obstacles met in the field and the piece-meal trajectory by which the thalassaemia system was constructed. The
process was not always intentional, and included unpredictable events of technological breakthrough and war. In contrast with examples of fast policy making, where the specificities and particularities of a certain cultural milieu are cast aside in favour of a predetermined trajectory whose finality acts as the “solution” to a problem, policy making in the case of the Cypriot thalassaemia programme was slow and accounted for the challenges met, and although it had an anticipated end, the means to such an end were not set.

A slow process of policy making does not proceed according to transcendent values (since that would make it fast) but rather through pragmatic instances of deliberation and evaluation. To once again borrow from Stengers, processes of deliberation cause a slowing down, which cause previously thought certainties and assumptions to “stutter”. (Stengers, 2005b) One can contrast an such ethos of slow governance and policy making to fast examples, which did not account for the socio-cultural arrangements they attempted to inform. Take James Scott’s analysis of the building of a Brazilian city, Brasilia, which was enacted according to the vision of legendary architect and policy planner Le Corbusier. As Scott writes, Le Corbusier’s blueprints acted as “transcendent negations” (Scott, 1998: 119), and furthermore, “The goal of making over Brazil and Brazilians necessarily implied a disdain for what Brazil had been” (Scott, 1998: 119). In this regard, the existing socio-cultural dimensions of the Brazilian people did not act as points of articulation and building blocks for productive planning, but as aspects to be disregarded and altered. As Scott writes elsewhere, “Although it was surely a rational, healthy, rather egalitarian, state-crest city, its plans made not the slightest concession to the desires, history and practices of its residents” (Scott, 1998: 125).

What is worrying about such failed schemes is not that they are thought of, but that they happen. That is to say, if they are granted the proper authority and power, such fast poli-
cy schemes can supersede their blueprint and come to be realised. Not only that, but such schemes can bear results and in such a sense be validated as fruitful and “correct.” Such results, however, are only successful in the statistical and numerical sense of the term. In order to achieve such results, fast policies disregard the milieus they cast a net over in favour of a predetermined trajectory of “success”, the very notion of which being subject to construction by a select few. Fast schemes do not arrive at a solution through the milieus they work with, but rather they blanket milieus with a predetermined solution conceived in the imagination of the few.

A good policy connects. A bad policy blankets. In my case, a good prevention system is not only evaluated by the results it bears in terms of statistics and percentages, but also according to the feelings and passions it evokes, and the potential for joy, differentiation and creation it provides. It must not only prevent pathology, but also consider the cultural and emotional attachment a certain public has to the given pathology. Take, for example, the case of Dor Yesharim, the sickle cell prevention system set up by the Ashkenazim Ultra-Orthodox Church. Although, like the Cypriot prevention system, it was able to attain a 100% prevention rate, it did so by relating pathology to a theological doctrine of judgement, operating according to a fast trajectory of matchmaking decided by a board of elders. This resulted in the breaking up of marriages, the delegation of power to the hands of a select gerontocracy, and the perpetuation of social stigmatisation for those diagnosed as carriers of the sickle cell mutation (Raz and Vizner, 2008). In such relational arrangement pathology operates within a zone of exclusion, external and divergent to dominant perceptions of normality.

A slow ethos of policy making is made all the more urgent and timely if one considers the accelerating conditions and milieus of globalisation, migration and techno-scientific advancement that contemporary governance becomes entangled with. To this list one can
also add global in scale economic degradation, and an intensifying method of conducting governance that we can deem as a politics of austerity, which makes itself particularly visible in Europe. This is particularly evident within Cypriot healthcare where health provision is publicly provided (Petrou, 2015). Such conditions increasingly situate policy making and planning in unstable, uncertain and contingent environments. As Hajer and Wagenaar write, the rise of “network societies” entails that “practitioners of very different plumage wrestle with conflict, power, uncertainty and unpredictability. Solutions are not so much formulated as arrived at, haltingly, tentatively, through acting upon the situation at hand and through the application of practical wisdom in negotiating concrete situations” (Hajer and Wagenaar, 2003: 19; see also Castells, 1996). A slow method of conducting governance implies that one “thinks with care” (Bellacasa, 2012) when it comes to fragile therapeutic and political contexts. To stop and think before acting entails that a certain meticulousness and attentiveness is displayed in relation to existing and newly forming socio-cultural arrangements of peoples.

At the same time, one must attend to such an ethos of slowness as rooted and emergent of a dimension of uncertainty intrinsic to being. Even in the 18th century Voltaire declared that, “Uncertainty is an uncomfortable position. But certainty is an absurd one.” Uncertainty might be a perennial buzzword of modernity, but at the same time, and following Latour (1993), one can assert that “we have never been certain”. That is, uncertainty cannot be reduced to being derivative of a specific epoch and its socio-economic conditions. It is that, yes, but it much more; on a broader level, uncertainly is the result of a relational arrangement, whatever that might be, operating according to a slow ethic - unsure, yet ready of its next step. Uncertainty as a metaphysical category, and also as a guiding ethos, entails that one displays a certain sensitivity to one’s relational milieu – an appraisal of the realisation that one’s consciousness and practice does not rule over the
world like a transcendent entity but, like many other things, is immanently and productively implicated with it.
Chapter 2: Illness as process

If the first chapter attended to the rise and construction of the Cypriot thalassaemia programme, this chapter will deal with the continuous deterioration and insufficiency. This task is accomplished through patient narratives. Once I started talking to thalassaemia patients, a recurring evaluation I would get is that the Cypriot thalassaemia programme was, at its time of inception, a pioneer in the treatment of chronic haemoglobinopathies. Yet, as all patients quickly went on to add, for all its initial success, the Cypriot healthcare system has failed to attend to the developing needs and circumstances of the approximately 650 thalassaemia patients currently living in Cyprus. This chapter focuses on the reasons behind this decline in therapy and care.

By exploring the narratives of thalassaemia patients, and connecting these to Byron Good’s theory of narrative as a “network of perspectives” (1994: 162), the argument I pursue in this chapter is that the Cypriot healthcare system developed these insufficiencies because it does not account for the processual dimension of thalassaemia in its interconnected pathological, social and political registers. In relation to this, I also suggest that the state healthcare system treats thalassaemia in its static, idealised biomedical form, and not in its everyday, social and experiential iteration. Since it treats thalassaemia in its archetypical medical definition, rather than in its everyday messy enactment and changing nature, the healthcare system, much like its idealised perception of thalassaemia, likewise remains static. As Byron Good writes:

Disease as represented in biomedicine is localized in the body, in discrete sites or physiological processes. The narratives of those who are subjects of suffering represent illness, by contrast, as present in a life. Illness is grounded in human historicity, in the temporality of individuals and families and communities.

(Good, 1994: 157)
The gap which emerges out of governmental perceptions of thalassaemia and the actual experiences of patients has resulted in a healthcare system which is ignorant of several of the predicaments faced by thalassaemia patients in Cyprus.

In addition they also make evident two more points which are the focus of this chapter. While narrative depictions of patients unveil problematic knots of disease, society and politics, they also unveil tactics of improvisation, play and perseverance which patients employ in their everyday lives in order to displace such problems. Such tactics employed by patients in order to cope with their own pathology, the insufficiency of the state to attend to their illness, as well as social discrimination, show how patient agency is not always enacted in relation to medical regimes, but also outside of them. Nevertheless, as I finally argue, such narratives, although they make evident and affirm patient agency, also manifest the urgency and necessity for constant politicisation by patients. This is because play might displace pathological predicaments on an individual and existential level, but not on a collective and political one. With this in mind, and using Nancy Scheper-Hughes and Margaret Lock’s *The Mindful Body* (1987) I conclude that the political register of illness holds an affective superiority over the social and experiential one.

*Narrative as method*

Before I proceed with the ethnographic material of the chapter, I believe my method of choice merits a small introduction. Thalassaemia, or any other form of pathology, does not exist in a vacuum void of interaction. The purpose of medical anthropology at all times is to denote how illness is not simply a matter of biology, but also something imbricated with elements of social and political life. Yet, the socio-political dimensions of illness are not always apparent to the ethnographic eye. Rather, they manifest at specific
periods of time, according to specific events and occurrences. One ethnographic predicament is that one cannot always be present during the manifestation of these events. For example, such events may have already taken place, or they might occur in spaces which the ethnographer cannot access or is ignorant of. With this in mind, narrative proves itself as a versatile tool for the medical anthropologist, since it is capable of describing and grounding illness in its historicity, everyday enactment, and political dimension. To borrow a quote from Annemarie Mol, even if the ethnographer is not able to access the lives of patients in their entirety, “It is still possible for us to get to know some things if we had followed [a patient] in his daily routine. We can listen to [a patient] as if he were his own ethnographer. Not an ethnographer of feelings, meanings or perspectives. But someone who tells how living with an impaired body is done in practice” (Mol, 2002: 14). Thus, narratives of illness lend the ethnographer a patient point of view through which illness becomes diffracted through everyday happening and activities which would otherwise evade ethnographic description.

As I write later on, narrative is not meant to align the perspective of the patient with that of the ethnographer, but to allow the latter to discern the relational multiplicities the former entertains. Patient narratives thus have the capacity to situate and expand pathology beyond its narrow medical definition and clinical setting. They not only attest to how illness is not simply a closed field of symptoms to be routinely diagnosed and treated, but also to how such pathological symptoms and treatments constitute dimensions of living which come to interact with and be propagated by national politics, localised aetiologies and symptomatologies, social obligations and responsibilities, and also individual anxieties and desires (Good and Good, 1981; Lock, 1984a; Kleinman and Kleinman, 1994; Martin, 1994; Petryna, 2002; Biehl, 2007; Cueto, 2007; Nguyen, 2010). Narrative can thus connect to and inform the extra-pathological terrains and practices where illness comes
to be enacted; such terrains are constituted by factors and take place in settings which, albeit not demarcated as clinical, biological or pathological in nature, nevertheless affect how illness comes to be practiced and understood.

In addition, one must not perceive such narratives as simply descriptive and communicative. More than describing to the ethnographer the lives of patients, narratives also unveil emotional spectres of future aspiration and present anguish. As Good writes, “Narratives are organized as predicament and striving and as an unfolding of human desire” (Good, 1994: 164). Thus, more than being descriptive, narratives carry an emotional dimension of anxiety, urgency and will. All these are emotional and affective elements which characterise and even produce the politics of thalassaemia in Cyprus. Narratives of illness are an oscillation of rhythmic qualities. Conversation would sometimes be energetic: it would be passionate and vibrant. At other times – “I am tired today, it’s been a week since my last transfusion” – talk would be lethargic, slow and sorrowful. It would proceed through careful gestures of thought, breaks of eye contact, ellipses and other such languid acts of sociality. There was always something to be said every time. Through patient narratives, the ethnographer can connect to these ambivalent inner words, undoubtedly themselves connected to the social and political field out of which they emerge. In this regard, more than what one says, of equal importance to the ethnographer is where one speaks from: in other words, what social relations does a patient entertain while engaged in the act of narrative, and how is he or she affected by these relations? The collective dimension of individual narrative is indeed made explicit in the snippets which follow. As the reader will see, my conceptual and ontological treatment of thalassaemia as processual is first and foremost informed by these given narratives.
The changing nature of thalassaemia: “We are the first and last of our kind”

I met D for the first time in a cafe of his choice. I arrived fifteen minutes early to wait for him. I recognised him when he arrived because he told me beforehand he would be wearing a bright blue sweater and khaki trousers. Once he entered the establishment he spent fifteen minutes talking with the barista before making any discernible effort to locate me. D did not show any phenomenal signs of illness. He was around 1.80m tall, with fair skin and hair, and a well-proportioned and well-built body; if not for his sartorial give away I wouldn’t have been able to tell he was a thalassaemia patient. I walked up to him and introduced myself. We shook hands and he offered to buy me a coffee. I thanked him and asked for a black filter coffee, and then occupied a table near the corner of the establishment where the music was not as loud and my recorder would pick up our voices better.

“We used to be good, but not anymore” was the first thing he told me related to my research when he sat down. He went on:

Ten or fifteen years ago Cyprus was leading the way regarding the treatment of thalassaemia, especially with regards to blood supply. The campaign to promote voluntary blood donation in Cyprus must have been one of the most successful of its kind. But now we fell behind. This of course has to do with whom you want to compare Cyprus to. If you compare it to China then we’re pretty much an advanced healthcare system. But China only now started tackling the prevalence it has in thalassaemia, and I don’t think it’s fair to compare ourselves to them. We should be compared to our peers. And in relation to treatment systems of the likes of England, Italy, France and Spain, Cyprus falls short – there’s stagnation to how the treatment of thalassaemia in Cyprus works. In some aspects I would even say that we have backtracked – we are now facing problems with the blood supply, a lot of our transfusions have to be rescheduled because of lack of blood.
That is something I often heard when I first started doing fieldwork with thalassaemia patients in Cyprus. Namely, that the Cypriot thalassaemia programme was, at its time of inception, a pioneer in the treatment of thalassaemia. This is indeed true, and many countries around the world facing a high prevalence of anaemia use the initial steps taken in Cyprus as a case study even today, in order to take further action in aspects of treatment and prevention of various forms of anaemia. Yet, as several patients quickly went on to add when I talked to them, for all its initial success, over time the Cypriot healthcare system has failed to attend to the developing needs and circumstances of the approximately 650 thalassaemia patients presently living in Cyprus. Such insufficiencies do not only pertain to a lack of therapeutic technologies such as deferoxamine tablets and dialysis pumps, but also to infrastructural problems, such as an inadequate blood supply and, related to this, the constant rescheduling of blood transfusions and routine check-ups.

While the treatment programme in the 1970s proved very successful, when treatment in terms of life expectancy was about mortality – patients now believe that, while the current arrangement does allow them to stay alive, as it did back in the 1970s, it nevertheless does not strive to improve their quality of life. In other words, the state system operates according to an older paradigm of two general extremes: it oscillates between the two poles of life and death while it leaves everything in middle - life and its discontents - unaccounted for. To frame the problem in relational and temporal terms, and in accordance with the overarching argument of this chapter, the Cypriot healthcare system does not attend to thalassaemia in its processual iteration but instead operates on an older paradigm of life and death which cannot account for the specificity of living and the changes which took place in the space of the extra-pathological enactment of thalassaemia in Cyprus ever since the 1970s. The inability of state healthcare to attend to illness in its developing, processual register, entails that medical understandings of an idealised version of
illness become segregated from socio-cultural and political dimensions, and the experience of illness by patients.

As another patient said to me:

There are not many thalassaemics in Cyprus right now that are over forty-five or fifty years old. But their number is increasing. In the past you didn’t used to have any, but now you get more and more of them because of better treatment. What does it mean for these people to reach such an age? What are the results of cumulative treatment? The fact that they’ve been transfused all these years, that they’ve been taking medication all these years…new problems and considerations arise: the liver, the heart, the kidneys, hormones, bones, all organs are affected by a chronic disease. The last year or so, the message we’ve been trying to pass to ministry officials is that thalassaemia does not have to do with mortality anymore. The challenge is not to tackle mortality like it used to be, but to improve treatment and, having to do with this, our quality of life. Thalassaemia is more than just the need for blood. Thalassaemia is also about life, friends, family, obligations and responsibilities.

In many ways, the efforts of patients to reconfigure thalassaemia in the governmental agenda is a continuous attempt at reframing perceptions of illness as overflowing pathological considerations: as not merely being a matter of life or death, but living. Unlike its static depiction in the biomedical and governmental imagination, thalassaemia as a form of pathology has, ever since the inception of the treatment programme, become entangled with social and political dimensions which have affected and changed its everyday enactment. Such changes mainly include the integration of thalassaemia in Cypriot society, the introduction of patients in the workplace, as well the wider formation of a Cypriot civil society following the 1974 Turkish invasion. The democratisation of the island, the formation of a state republic and the formation of a patients’ association in 1973 meant
that a politics of illness and therapeutic citizenship were developed, according to which patient demands of better access to healthcare and medical provisions could be politically articulated. On the whole, these are factors which increased the life span and quality of life of Cypriot thalassaemia patients but which, at the same time, opened up new spaces of pathological enactment.

One must also be aware of the particularity of a chronic illness like thalassaemia, which is much more prone to change in terms of symptomatology and, related to this, therapy. The processual nature of a chronic illness such as thalassaemia implies that it requires a robust healthcare system able to account for the unpredictable emergence of new symptoms, as well as the implication of these with social and political factors. The changing nature of thalassaemia, as well as the urgency to attend to this, is made evident by the below snippet of my conversation with W, another patient:

We are the first and the last of our kind. Before us, thalassaemia patients didn’t have a problem because there was no cure. They just died back then. We are the first and last generation of thalassaemics that have been unlucky enough to be born with thalassaemia but lucky enough to have access to some sort of therapy regime which allows us to lead a pretty much normal life. After us, there won’t be anyone else, because the generation of patients born after us will have access to more effective technologies, if not a final cure. So, to make it clearer to you: the therapy did not exist before us. And, as said, neither did the problem. The therapy of thalassaemia evolves, it develops alongside us. It’s not like other diseases, like heart disease or diabetes, where patients are born and find a ready-made system of therapy. Thalassaemia is not like that. New technologies keep coming out, new medicines. The state must provide us with access to these things. It must keep an eye on them and integrate new forms of therapy into its healthcare system.
“So, if the therapy of thalassaemia develops with you, does the problem too? Are you the problem?” I asked him.

Yes, we are the problem. A perpetual problem of sorts you could say. Nobody else before us lived as long. The longer we live the more problems appear that doctors hadn’t encountered before: heart arrhythmia, endocrinological problems, osteoporosis, diabetes - these are problems which slowly came up as we grew older. That’s why new technologies and new therapies keep being developed, because problems arise in patients that didn’t exist before. Both problem and therapy develop as we grow older.

I was provoked by his evaluation because it exactly attended to the processual character of his ailment. W’s conceptualisation of thalassaemia and patients as a problem inverts the mannerism by which we often think of illness and those affected by it. “The problem”, as D explains, is not the idealised version of illness as constructed in medical imagination. Rather, the problem to be addressed by medical practitioners and governmental officials are the patients themselves – that is to say the actualisation of an illness in real life, its embedded enactment in Cypriot society, and the problems such experiences create for patients. In this respect, the problem of illness does not reside in illness per-se, but emerges out of the interaction of illness and the wider extra-pathological milieu which develops along time (the workplace, the home, the laboratory). D’s statement “we are the last ones of our kind” makes this explicit. This statement does not mean there will not be any more thalassaemia patients in Cyprus, but that there won’t be any more patients who find themselves in such political, pathological, social, and technological entanglements as they do. Here, an inversion of how pathology is understood by Cypriot state officials is required: patients should not be understood through the illness they carry. Rather, the illness should be understood through the collectivity and lives of the patients it affects.
An important dimension of change in the past few years regarding thalassaemia is that of a lack of blood. Thalassaemia patients need to have regular blood transfusions to replenish their haemoglobin levels. This usually amounts to each patient having a transfusion once a week. Transfusions take place in clinics set throughout the island, and blood kept in the central blood bank in Nicosia is distributed to these thalassaemia therapy centres on a regular basis. Lack of blood is a relatively new problem facing the Cypriot thalassaemia programme. Whereas before the amount of blood secured from voluntary blood donation and state procured blood was enough to cover the needs of patients, this is increasingly no longer the case.

This lack is not to be thought in relation to an increase of thalassaemia in its quantitative register but qualitative one. In other words, it is not a matter of more patients needing blood, but of the same number of patients needing blood differently. More blood is needed nowadays than before, due to the longer life spans of thalassaemia patients. Improved medicines and technologies received at an early age mean that current thalassaemia patients have a much higher life expectancy than before. But this does not come without cost: as patients grow older they need more blood for their transfusions. Thus, as I was often told by patients, the amounts of blood collected through voluntary donation in the past can no longer account for the rising demands of thalassaemic bodies.

The same can be said about the issue of an inadequate number of beds and space that some of the thalassaemia clinics in Cyprus face. Like the lack in blood supply, this lack of beds and space does not have to do with an island-wide increase in the number of thalassaemic patients, as this has been marginal. Rather, it once again has to do with the changing nature of thalassaemia in relation to the existing population of patients and also in relation to the extra-pathological space where thalassaemia is enacted. In the past, young-
er thalassaemia patients were able to receive transfusions at faster rates because of their stronger bodies, however, this is no longer the case.

As patients grow older, not only do they need more blood, but also their hearts becomes less and less able to process the copious amounts of blood required by the transfusion process. Being transfused frequently can prove taxing. Your body has to do a lot of work in a very short period of time, so sleep is often the best resort to spend the period of the transfusion. A sudden influx of a large amount of blood causes side effects like heart palpitations, dizziness and nausea. For this reason some patients told me that they prefer to have one bottle of blood transfused weekly, rather than two biweekly, as this division proves less tiring for their bodies. As a result of these two increases – in the amount of time and blood required – transfusions take longer than they used to, so beds are occupied are for a longer duration of time – thus resulting in instances where the number of beds in a clinic cannot cater to the number of patients requiring transfusions.

In addition, the lack of beds must also be attributed to the introduction of thalassaemia in the workplace. Ever since being socially integrated, many thalassaemics have had nine-to-five jobs, and thus opt to have their transfusions after work, resulting in a “rush hour” of sorts where clinics are unable to accommodate all of them. Finally, another factor to consider is that thalassaemia patients need to “compete” for blood with other, non-chronic, patient groups. As another patient said to in relation to this point,

If there’s not enough blood then thalassaemics are the first ones cut from scheduling. This is because we don’t carry as much risk as other cases. An accident or a surgery is much more urgent than a routine transfusion. Although, thinking about it, they could also reschedule heart surgeries if there’s not enough blood around.

But they don’t do that, we’re always the first ones cut.11
More specifically, in relation to its total population, Cyprus has a proportionally high percentage of motor accidents and heart surgeries, meaning that blood from the central blood bank must cater to these circumstances. Evidently, the transfusions of motor accident victims and surgery patients are considered by the blood bank officials as more urgent than those of thalassaemia patients, and are thus prioritised. A typical heart surgery requires thirty litres of blood, an immense amount which could treat a thalassaemia patient for a month. Overall, one could say that the lack in blood supply faced by thalassaemia patients in Cyprus is a primary example of how pathology is not merely pathological in its constitution; rather, the relational regimes according to which pathology makes itself perceptible often evade human suspicion and intentionality, but nevertheless serve in the configuration of pathology as such.

The negative effects of delayed transfusions extend beyond the need to reschedule transfusions and reorganise one’s daily routine. It also has physiological effects which drastically affect the bodily capacities and at the same time cognitive functions of patients. Patients would often tell me how they felt drained when reaching the end of a transfusion cycle. Of how, because of their lack of energy, they would not go out with friends or would be unable to sexually please their partners. As another patient told me:

If I arrange to have a transfusion on Tuesday, by then my haemoglobin level is going to be at its lowest, around 8mg. If I go to the clinic and the doctors tell me there’s no blood, come back Thursday, I’m done for. I’ll spend those two days feeling weak as hell. I’ll have headaches, dizziness, nausea, joint pains. Doctors know this but they act as if they don’t, they act as if two days is nothing. The truth is I can barely drag my feet to the kitchen for that time.

You try to cope, but it’s simply impossible.

Likewise, as another patient told me:
If you keep rescheduling our transfusions you intrude into our life. In order for me to get transfused I need to take the day off work, I need to arrange for someone to pick up my kid from school – but if I show up at the clinic and there’s no blood then all that was for nothing, I have to do it all over again. This messes up my work and the time I spend with my family. We have to live with this illness for life. We go to the clinic almost every week, either to get transfused or to have our routine check-up. But with the lack in blood supply, you’re not sure if you are actually getting transfused. You might go to the clinic on the day of your appointment and they’ll tell you, “Oh sorry, we’re out of blood, come back in two days,” or something along those lines. It’s easy for them to say, but things like that mess up your life. You can’t organise your daily routine. You can’t do these things to a chronic patient; treatment for us doesn’t just have to exist, it also has to cater to our daily needs and responsibilities.

Once again, narratives such as these do not present pathological symptomatology as something isolated from the social world, but as entangled and imbricated in it (a truism for medical anthropologists by now, but one which as these narratives show often does not register in medical and governmental imaginations). Moreover, such narratives convey perceptions patients have of life and also of illness, not as solely having to do with a certain biological prerogative of being alive and ill, but as a social process in which life and illness are always in relation to one another, thus giving way to a multiplicity of practices.

These narratives thus make explicit the problematic relation and disconnect which exists between the Cypriot state and the life of thalassaemia patients. Much like the case of transfusion scheduling and hospital space, the case of the de-ironing pumps which thalassaemic patients regularly use is a prime example of this disconnect. The pumps are a daily medical technology thalassaemia patients use to cleanse the excess iron which accumu-
lates in their body because of the weekly blood transfusions they undergo. Patients connect the pump to a central vein of the body - usually the one situated on the joint of their elbow and bicep - and leave it there for ten to twelve hours every day in order for the therapy to be complete. In the initial steps of the treatment system pumps were bulky and expensive, and as a result the process of de-ironing the body took place inside the clinic. This arrangement caused many thalassaemics at that time to not treat themselves properly because they were either unwilling to spend ten hours a day in the clinic, or because they were situated in villages far away from the main urban areas and could not make the trip to the clinic daily.

The invention and popularisation of portable pumps by pharmaceutical companies in the 1980s reconfigured the way by which pathology was enacted in the daily lives of patients, by allowing for more flexibility and portability (Biehl and Moran-Thomas, 2009). Nowadays thalassaemics use one pump per day, which they can have on them while on the move. Pumps have been free in state healthcare since 1978, and patients acquire their supply every month in designated lockers from their local clinic. Nevertheless, the Cypriot state’s decision regarding which type of pumps to buy in bulk is increasingly being affected by economic and monetary considerations, especially with respect to the climate of financial degradations Cyprus is undergoing. According to Cypriot healthcare officials, the cheapest, rather than the more ergonomic pumps are the most appropriate ones to buy in bulk. This entails that, while patients do have access to a constant supply of pumps, the model of the pump given to them is often clunky and difficult to carry around, which consequently interferes with their daily needs and activities.

It’s not as good as the last ones we had. It’s not as comfortable: it’s large and has a hard shell. It’s hard for me to have it on me the whole day while moving around, it’s not convenient. And then you have women – it’s even more incon-
venient for them because sometimes they wear a dress or a skirt to work or for going out. The previous model we had did not have a hard shell; in its place was this bubble or balloon of sorts that got smaller and smaller as it infused medicine into the body. It was much more flexible and easy to conceal and have on you—you’d put it on you before you went to bed at night and by the time you woke up it’d be half the size. Now with the financial crisis and everything they got these ones instead. They might save money, but it makes our lives harder. But they don’t recognise that. We’re chronic patients— they should look after us more.

Our treatment isn’t a one-off, it's for life.

Once again, as conveyed by the above passage, the inefficiency of the Cypriot healthcare system in responding to the needs of thalassaemia patients has more to do with the changing nature of thalassaemia in existing patients than a rising number of thalassaemia patients. Once again, infrastructural deficiency emerges out of changes in relation to other changes; lack and deficiency is not intrinsic to an infrastructure, but rather temporally emerges out of the connections the given infrastructure has to its surrounding socio-cultural milieu. This is important to understand, because it points to the fact that thalassaemia in Cyprus is not changing in quantity as much as it is changing in quality. A healthcare system that operates under the assumption of a quantitative increase in the number of patients in relation to a static form of pathology is unable to cope with a qualitative increase of existing patients as they pertain to a changing form of pathology.

_Thalassaemia as excess: “Sometimes I have other stuff to do”_

We sat and spoke on the far side of the wall in the common room of the clinic.

“There were a lot of things I wasn’t allowed to eat when I was growing up.”
“Because excess iron is bad for you…”

“Yes. But all of this was precautionary. They later found out that iron absorption from food is miniscule, and that it posed no danger to us.”

“What kind of things didn’t you eat?”

“Bananas, strawberries, liver, red meat, lentils…that kind of stuff.”

“Spinach…”

“Yes, I definitely wasn’t allowed spinach. But I then again I didn’t really like spinach growing up. I always craved more strawberries. My mother would give some from time to time, but I always wanted more. Nowadays I eat loads of strawberries so I can make up for those I didn’t have as a child…”

We were in the Nicosia Thalassaemia Centre, the clinic where thalassaemia patients living in Nicosia go to get treated. Treatment involves getting your weekly or bi-weekly blood transfusion, as well as receiving your provision of Desferal tablets and dialysis pumps. The clinic is attached to the central city hospital, but accounts for only a small part of it. You enter by way of the common room, where I and H previously sat. A corridor on the far end left hand side leads you to another corridor, where the doctors’ offices were contiguously stretched out. If you don’t take a left from the common room and go straight instead, you will encounter the entrance to the treatment room. Albeit boxed by four walls, the upper half of these is glass, and you can see even from the outside what goes on in the treatment room. Keep going straight and you will find the beds. There are two adjoining rooms. Patients come to lie down once they get blood stand set up. Contrary to the vitality and vigour which it eventually provides, being transfused blood is initially a very tiring process for thalassaemics.
We were both slouched over plastic chairs with our legs spread out in front of us. It was a hot March day. There were more empty chairs against the wall to our left and right, stretching around the perimeter of the room. In the middle of the rectangle created by the plastic chairs a mauve carpet sat over the linoleum floor. Scattered on the carpet were toys; plastic cubes, plastic soldiers and colouring books that a kid, maybe five or six, was playing with. His mother was watching, seated on one of the chairs across us. In her arm, in that cavity where the inner forearm connects to the rest of the arm, a tube ran up, filled with maroon, connected to a stand where a packet of blood hung off a hook. She was dressed in a black pencil skirt and a white shirt, with tights, a silver bracelet and her nails in some sort of metallic blue. Her hair was arranged in an immaculate bun, caught with a golden pin. It was around two in the afternoon, and my impression was that she must have got off work, picked up her son from school or nursery and then come straight here for her transfusion.

We were waiting for H to be called in by the nurses to also have his transfusion set up.

A few moments of silence passed between us, made livelier by the background noise of a television mounted on the wall in front of us. It was 20 March 2014, a few days after the Cypriot economy had gone bust. A bailout agreement had been in the process of being agreed upon for a week, but everything was pretty much up in the air. Somebody in a suit and sunglasses was talking to microphones on the TV, holding a bunch of papers under one arm and gesticulating wildly with the other.

“Man, these guys sure messed up,” H says, to no one in particular. “I hope they don’t end up cutting our free meds with all these austerity measures they’re talking about.”

I say nothing to this. Given the air of facticity by which he uttered such plausibility, he seemed more at comfort with it happening than me (see next chapter).
I probe, once again. “What about Dr. C.?” I ask. “Is she any good?”

A sudden burst of energy. He sits upright. “…Dr. C. is great. She’s like our mother. She’s been treating us all these years - Dr. C. has a really good relationship with all of us. Sometimes I’ll be late to get my blood checked or get transfused and she’ll start screaming at me for being late as soon as she sees me coming through the door.”

Dr. C is the head doctor of the clinic. She’s been in charge of treating patients ever since the early 1990s.

“Why would you be late in getting your blood checked or transfused, isn’t that dangerous?”

“Ah you know how it is. Treatment takes time, getting transfused takes me three hours every time I come here! Sometimes I have other stuff I need to do. I almost always take care of myself but sometimes work stacks up. It’s not like I’m neglecting my body or putting myself in danger though, I know my limits, I’ve got to know them after all these years. If I feel that I can miss a transfusion by a couple of days then I’m ok doing so, but only as long as I have to.”

A nurse, short, slender, in scrubs and white gloves, peeps her head out from the treatment room. “Come in, we’re ready.”

He slowly pushes off the chair handles. He looks at me while he is getting up. “Why don’t you have a stroll around the clinic while I get my transfusion set up? You might want to steer away from the corridor where the doctor’s offices are. Some of them don’t like strangers messing about, but I’m sure it’s no problem for you to check out the rest of the rooms.”
As I was getting up I noticed that on my left was a box screwed on the wall filled with sterilisation liquid. “Hey…” He was on his way to the treatment room but stops short to turn around.

“Should I sterilise my hands?”

“What for? Everything in here is clean. Everyone too.”

“I know. I’m talking about me.”

He stood still a bit longer, contemplating, after which he once again looked at me and casually responded, “It’s ok, you look clean too,” before walking into the treatment room.

*Everyday play and perseverance*

This was a motif which repeated itself whenever I talked to patients in the clinic. The pathological always seemed to overflow its boundaries. Something always came from the outside or, at least, something always alluded to it: “Sometimes I have other stuff I need to do.” Similarly, conversation would not focus on thalassaemia as a form of pathology “as such”. Whenever they started talking about their condition, patients’ descriptions of thalassaemia would overspill and supersede clinical settings and biological symptoms. They might start from there, but would soon extend into facets of work, going out, music, eating, hobbies and school. They would relate to past experiences of childhood as well as future professional ambitions, financial anxieties, and marriage and travel desires, and also of national politics and economic predicaments.
For a thalassaemic patient in Cyprus the mundane aspects of treatment nowadays often remain veiled. It involves puncturing the same vein with your de-ironing pump every morning, which has to remain attached to your body for twelve hours in order to clean out excess iron from your system. Tablets might seem like the easiest route, but they can give rise to side effects with intense and disturbing dimensions. A patient once poetically and fluidly recited these side effects in sequence, a sort of pathological litany, for me to hear:

Well let’s see: Drowsiness, opening up of the appetite, constipation, bloating, stomach pains, joint pains, nausea and headache. It can also damage your kidneys and drop your count of white blood cells in the long run. This means that every week you also need to have extra tests to see if your white blood cells have reached a low count.

As I was also told, another negative point of this method was the number of pills one had to take daily. The number of pills required is determined according to body weight; a patient weighing around 90 kilograms has to take approximately 17 pills a day.

Many thalassaemics express the relationship they have with their condition in anthropomorphic terms. They would often tell me how they personify thalassaemia, and perceive it as a lifelong opponent against whom they constantly do battle. As one thalassaemic said to me, “It’s a fight, a constant struggle. We must always stay in control. You must not let it gain the upper hand.” To embrace struggle as an intrinsic aspect of life itself is often the distinguishing mark of a thalassaemic patient. To externalise an illness is at the same time to internalise struggle and perseverance, but also to adopt therapeutic play as a form of orientating in the world. In other cases, such an antagonistic ethos would be replaced by a diplomatic demeanour, a sort of symbiotic agreement with one’s own body. Some patients would thus similarly personify thalassaemia, but they would perceive, treat
and talk about it as a partner, rather than an opponent, with whom they must learn how
to deal with. They would tell me how you have to learn how “to live with it.”

Thalassaemia thus comes in different guises for different people. Although unavoidably
intertwined with one’s biology, the ways in which thalassaemics intellectually and socially
orientate and come to grips with their disorder varies. Thalassaemia can be similarly con-
ceptualised as a demon, a parasite, a lifelong partner (Van Gorp and Vecruysse, 2012), or
even an accomplice who encourages conversation, sociality and the fostering of new
connections. “Patient” and “thalassaemia” are thus unavoidably intertwined in a co-
constituting dialectic of reciprocal affectivity. The patient is an agent, insofar as the illness
is a patient and an agent itself (Gell, 1998). The patient affects the illness, one’s own body
in reality, through his or her implication with medical technologies.

In addition, illness, understood as a socio-technical assemblage, is affected by the rela-
tions, interactions, encounters and activities a patient enters into. According to the extra-
pathological terrains where therapy takes place, the consumption of these medical tech-
nologies is not only incorporated, it is also differentiated. Conversations with patients
attested to these modalities of medicinal and technological incorporation and differentia-
tion. Patients, through their descriptions of their daily treatment rituals, revealed their
attempts at delimiting their illness by experimenting with the medical technologies of-
fered to them. Experimentation in terms of treatment entails that one, through a process
of “tinkering” (Mol et al., 2010) finds the correct therapeutic routine in relation to one’s
daily activities; no one patient has the same everyday routine as another. Patients have the
choice to solely use the pump or the pill, but they are also offered the option of combing
the two. I was thus presented with various modalities of treatment, tailored according
to the daily practices and habits of patients, as well as the bodily sensitivity they displayed
to each of these methods.
For example, one patient told me she preferred to only use the traditional pump:

I don’t take the pills so the good thing is I get to skip the tests. I tried taking it and I didn’t have many side effects. The only thing was that I felt sleepy whenever I took any. It wasn’t a big deal but it prevented me from functioning at work, so I stopped. I use the pump instead. It’s not ideal, I have to puncture myself seven days a week, but I’ve learned to live with it.

In another case, the patient preferred a combinatory approach: “I use both pumps and pills. I am too bored to puncture myself every single day, so I combine the two. I mostly take pills and the pump a bit less.” Another patient also cited boredom, but also mobility, as the reason for preferring one method over another, but in his case he opted for solely using pills over the pump:

I don’t like the pump. I don’t like carrying it around and I don’t like puncturing my body every day, so I only take tablets. It’s hard at first because your body has to get used to it. You get really nauseous at first and throw up a lot. Some people can bear with it and adjust others give up and only use the pump or a combination of the two. My body was able to adjust to the pill so I only take that now. It works for me. The clinic started getting 1000mg pills the last couple of years. They contain double the Desferal as before so that means I can take half the pills, so it’s even more convenient for me.

Pills and pumps are thus medical technologies and forms of treatment which are readily available to thalassaemia patients in Cyprus but which, unlike transfusions, do not take place in clinical settings under medical supervision. In the case of thalassaemia, mobile therapeutic technologies such as pumps and pills invert the hierarchy of traditional clinical-patient relations, and de-territorialise treatment. The capacity and flexibility for movement these technologies bear relocate treatment practices into spaces and practices
of the everyday. In return, the mobility offered by such therapeutic methods entail that thalassaemia is increasingly enacted beyond the clinical encounter, thus further intensifying knots of pathology, society and politics.

*Discrimination in personal and professional relationships*

The hindrances and obstacles patients face extend into what can be demarcated as the social domain. For all their social integration over the past decades, people with thalassaemia in Cyprus still occasionally face discrimination. Such discrimination is most evident in cases of personal and professional relationships. For example, many employers in Cyprus often discriminate against thalassaemia patients because they don’t want to want to hire what they perceive as a less than capable person. One example given to me by a thalassaemic person is particularly striking:

I once went to a job interview. I had the best CV and I was the most appropriate and competent in terms of experience out of every one there. But during the interview I made the mistake of telling them that I had thalassaemia. They gave the job to someone else, citing him as the most suitable. I managed to get a job elsewhere so no harm done. A couple of months after that I met one of the people who interviewed me in a business gala, and there he confessed to me that the only reason they didn’t give me the job was because I am a thalassaemia patient. I don’t mind. It’s his loss he didn’t hire the best person.

Indeed, contrary to what certain employers in Cyprus might believe, a patient who treats him or herself properly can be as competent in work as anyone else. As a woman who works as a nurse once told me:
Employers sometimes won’t hire you because they think you won’t pull through. They don’t want to hire someone who will have to leave work once a week to go and get transfused, or who might be feeling weak during work hours. They will instead prefer to give the job to someone “normal”. Whatever, it doesn’t matter. You might be “normal” and I might be “abnormal”, but the fact is that many normal people can’t handle thirteen hour shifts. I can, and I can even do more. My boss knows I am a thalassaemic and he doesn’t mind as long as I get my hours in.

The same goes for personal relationships. Certain people are hesitant to become intimately involved with a person with thalassaemia because they fear that they will have to cope and deal with a difficult relationship. In my fieldwork I never encountered a married couple comprised of two thalassaemia patients. This because of the recessive pattern by which thalassaemia transmits; if two people with thalassaemia conceive it means that the baby will also be born with some degree of thalassaemia. The gradual acceptance and social integration of thalassaemia as a form of pathology in Cyprus over the past few decades has meant that most thalassaemia patients in Cyprus are now married, and many of them with children. Even so, I was told of cases where one half of a relationship walked away when they found out their match was a thalassaemia patient.

More or less we’ve all lost a relationship because the other was afraid to commit. They are scared of becoming involved with a thalassaemic because they don’t know what to expect and they run away. Often it’s not the person him or herself who chooses whether to marry or form a relationship with a thalassaemic. Sometimes their parents or friends put them off. They convince them that it’s not going to work, and that they’re going to be miserable living with a thalassaemic.

Although the intimate space of a sexual relationship provides little space for manoeuvring and delimiting such obstacles, patients were nevertheless able to cope in cases of organisational and even familial settings. For example, I was told of a thalassaemic woman who
has been married for several years, and has had two children. However, apart from her immediate family – her husband and her children - she keeps thalassaemia a secret, to the extent that not even her parents-in-law are aware of her condition. In cases such as this, secrecy and silence are not indicative of subversion but of relational creativity and dexterity (Throop, 2010; Lin, 2013).

Also, particularly evident were the tactics and methods thalassaemia patients employed in order to reconcile their transfusion cycles with their employment. In one case a patient told me about how he would strategically arrange the time of his blood transfusions in order to save time from his daily routine:

In the last couple of years I integrated my transfusion into my daily work routine. So I get my blood checked on either a Monday or Tuesday, and I arrange my transfusion usually for Thursday or Friday, which are the less busy days at work. I’ll have my lunch break and instead of the office I will go to the clinic to eat. I’ll have my transfusion for a couple of hours and go back to work. I might be a bit late but no harm done, someone will cover for me or I’ll just put the hours in later. Doing this saves me the trouble and time to get my transfusion done after work.

After he was done describing his transfusion regime, he went on, with a certain panache: “Man, you mustn’t let it get to you. You mustn’t get tired of this whole transfusion thing. You must play with life, you have to work things through, make them work for you. You have to take care of your body…”

These narratives thus make evident the extra-pathological space according to which illness is negotiated in everyday life, as well as the potential of such spaces for creative connection. Such extra-pathological factors are productive of, not only illness, but also life. That is to say, for chronic patients illness is not that which hinders life but rather is life; illness, as a modality of being and also a mannerism of acting and thinking in the world, is
in return productive of practices, habits and events which shape everyday experience.

Conceptualising illness as productive, rather than restrictive of life, entails looking at the trajectories of sociotechnical “self-poetics” (Ishii, 2013) and the “overwhelming practicality” (Kleinman, 1999: 360) by which pathological subjectivities navigate, orientate and ultimately make their worlds.

The need for constant politicisation

Ethnographic encounters, such as the ones previously described above, convey the patient play at work outside clinical settings and how, although being (partly) part of these, such play is capable of superseding the meanings and practices of regimes of medical control, care and risk (Edwards et al., 2010; Stephenson and Papadopoulos, 2011; Brekke and Sirnes, 2011). The patient as a sort of relational and temporal bricoleur (Lévi-Strauss, 1962: 16-36; Broom, 2009; Biehl and Locke: 333) is not a far-fetched claim. Unlike the engineer who is gifted the unrestricted space and unlimited expanse of the blueprint to carry out his or her work, the bricoleur is the one who is grounded, and who works with what resources and abilities he or she has. Akin to a bricoleur, patient agency thrives in scarcity, uncertainty and adversity because it is exactly such conditions which demand and presuppose its existence. The space of possibility of care as it pertains to a clinical setting cannot fully account for the creative potential of the patient subject. In addition to clinical care, self-care or “care of the self” (Foucault, 1987) as uncertain, improvisatory practice demands a certain relational dexterity and acuteness, of strategically bringing one’s body into interactions of positive potential.

Yet, narratives of play and improvisation such as these, more than attesting to patient agency and dexterity, also make evident the constant need for communication with the
Cypriot state. In the case of Cypriot thalassaemia patients, everyday play and improvisation as a form of patient agency relates to this problem. It fills the gaps caused by disconnects between the Cypriot healthcare system and the needs of patients. Although ethnographic perspectives of liminal agency attest to the perseverance of patients, they do so by exactly locating agency in such a liminal rather than political realm, thus segregating patients from the dimension and prospect of politics as a means for collective change.

Existential perspectives of patient agency might present a version of illness that is political in its manifestation, but not one that reveals how patients can participate in carving out these political forces. To put it differently, and to return to the distinction made in the introduction of the thesis, existential perspectives on illness deal with the political, but not with politics.

As stated in the introduction of this chapter, narrative should not only be thought of in its descriptive and communicative capacities, but also as vessels of emotional and affective forces. While patient narratives made evident the inefficiencies of the Cypriot state, as well as the tactics of patients to deal with them, they also unveiled the perpetual urgency, anxiety and desire to face these problems on a collective and political scale. This can be seen from narratives denoting the lack of blood supply, the erratic scheduling of transfusions, as well as the effects these conditions have in the everyday experiences of patients. Consider this following snippet from my conversation with a patient, which explicitly emphasises the need for patient politicisation:

Every single time a new medicine or a new form of therapy comes out we have to go and plea with the ministry. It’s getting tiring. There should be some sort of system ensuring that whenever something new comes out it immediately becomes available to patients. It’s been years now, it’s getting tiring, it’s wrong for us to go plea with the ministry to provide us with the medicines that will make
our lives and therapies better. There should be some sort of infrastructure for
new medicine and technologies to get integrated into once they go through the
testing phase and become available for general use.

Such demands kept recurring during conversations I had with patients. The need for po-
litical deployment and a further need of the Cypriot state to acknowledge the voices of
patients are also made evident by the following patient narrative which returns to the
problem of bulky pumps:

Ask anyone and they’ll tell you they prefer the old pumps but the ministry
doesn’t care. In other countries patients have some say when it comes to mat-
ters of treatment but here it’s entirely up to the ministry. But they don’t ask us
our opinion; the ministry is just people anyway, they come and go.

A certain change is noticeable when thalassaemia patients such as H, D and W switch
between these two modalities – that of the patient and the activist. The language and de-
meanour of a long time patient is, for lack of a better word, light hearted; it proceeds
through a certain intimacy, friendly gestures, timid smiles and relaxed explanations – a
certain ease that chronic thalassaemia patients have, which acknowledges and amicably
recruits pathology as an intrinsic part of the mundane and the everyday. A shift in atti-
tude, however, took place when D assumed the second modality, that of the politicised
patient. This second modality introduces new words into the conversation, such as “the
state”, “the association” and “ministry”. This is a vocabulary, a verbal panoply of sorts,
by which D bears the capacity to speak in the name of a “we”, as opposed to the private
nature of the previous modality, that of the patient. This political modality of expression
is not a matter of one patient speaking in the name of many. To clarify, it is not a matter
of representation. Rather, it is a mode of subjective and at the same time collective enun-
ciation which results from the pragmatic and affective dimensions of the relations of one’s embroilment in a political struggle.

The case for the primacy of politics

I would like to conclude this chapter with regards to a classic text of medical anthropology, *The Mindful Body* (1987). There, Margaret Lock and Nancy Scheper-Hughes propose that at the centre of medical anthropology should be placed the conceptualisation of the body in what they perceive to be its three basic manifestations: the experiential body, the social body and the body politic. Following this proposition, in this chapter through narratives I have explored how personal experiences of thalassaemia patients in Cyprus are at all times connected to elements of national politics and to a wider context of Cypriot society. Such narratives indeed show how the experiential aspect of illness is at all times connected to a wider milieu of social and political activity. I have decided to call this wider milieu the space of extra-pathology insofar as it denotes that illness is not merely experienced in terms of individual symptomatology and experience but always in relation to something extra. In this regard, in its excess, illness is not that which negates life but rather that which produces it. As seen through descriptions of personal treatment, illness as that which resides in the biological, singular body is that which always connects, adds and multiplies relations courtesy of the interaction of bodily experience and pathology with these other social and political realms of forces.

Taking this three-fold recurring process of co-constitution in mind, the present insufficiencies of the Cypriot thalassaemia treatment system do not stem from changes in the experiential, social or political enactment of thalassaemia per-se, but rather from changes in each of these realms in relation to changes in the rest. For example, the lack of blood
and its consequences for the biological body can be understood through changes which took place in the wider socio-cultural context – such as an increasing need for blood by ageing thalassaemia patients and also other “secondary” groups such as surgery patients. Likewise, the lack in beds and hospital space can be understood through the introduction of patients in the work place and longer transfusion periods. With this in mind, words such as “deterioration,” “degradation” and “failure”, used consistently throughout the chapter to describe the Cypriot thalassaemia treatment system, can be traced to changes which took place outside of it, rather than the system itself. Undoubtedly, the Cypriot thalassaemia treatment programme is, if juxtaposed to its counterpart in the 70s and 80s, far superior in technological, diagnostic and pharmaceutical provisions. What is deemed to be lacking, then, is not the form of the treatment system itself, but rather this given form in relation to changes which took place in other, non-clinical, spaces of pathological enactment.

The work of Lock and Scheper-Hughes attends to these three unfolding and co-constituting trajectories which, in their interactive totality, perpetually de- and reconstruct a terrain of pathological enactment. As they conclude, “Sickness is not just an isolated event…it is a form of communication - the language of the organs - through which nature, society and culture speak simultaneously” (1987: 31). And yet, a question which remains, whose answer differs according to the context in which it is asked, is, “Which dimension of illness speaks the loudest?” As argued, the insufficiencies the Cypriot healthcare system developed can be attributed to its ignorance of thalassaemia with this extra-pathological space. Instead, it perceived illness in its archetypical biomedical form and symptomatology. The resulting gap which developed between governmental understandings and patient experiences of illness has led to a treatment system which is largely ignorant of the daily need of patients.
Conceptualising the production of illness as enacted according to an extra-pathological space serves in blurring or even deeming defunct the epistemological boundaries which separate all three of the given terms of experience, society and politics. Yet, as I want to argue in this final part of the chapter, these three fields of demarcation – of illness, society and politics – must be kept since they provide the contours of meaning and action by which one can navigate and manage an otherwise insoluble extra-pathological space. On an ethnographic level, the distinction between thalassaemia as a form of pathology, social condition and political project was evident in patient narratives. In their descriptions of everyday illness, their narratives tended to focus on one of these versions of thalassaemia at a time: They did so, not by completely disregarding the rest of the versions and favouring one, but rather by making particular factors the locus around which the others revolved. For example, if thalassaemia was talked about as an experience of pathology then the symptoms experienced by patients would be used as a perspective to talk about social and political facets of their illness. On the other hand, if patients described thalassaemia as in social terms, as is the case with narratives of social discrimination, then it would be this social dimension of thalassaemia which would lead as a gateway into talking about forms of treatment.

Narrative thus proves to be a versatile tool in locating problematic knots of illness, society and politics, as well as in treating these in their particularity and specificity. This is because narrative does not merely denote illness in its entangled experiential, social and political dimensions, but also makes evident which of these dimensions holds affective superiority over the rest. Narrative thus acts as a form of “cutting” (Strathern, 1996) and navigating the otherwise insoluble mesh of biological, social and political relations by which illness is ontologically enacted. Acting as a proliferation of perspectives, patient narratives did not only indicate the multiple guises of Cypriot thalassaemia, but also
served in establishing an affective hierarchy by which one can discern which perspective and element of illness holds primacy over the rest and when. Although the three fields of politics, society and experience similarly partake in the enactment of illness, they are not equal in their inter-affective capacity.

A rebuttal to this proposition, and one which I tackle further in the rest of the thesis, is raised by the question of what exactly constitutes the political, social and experiential? My answer to this is that the affective interconnectedness and yet distinction between the three realms indicates that what is regarded and referred to as “experiential,” “social” or “political” is not the result of differently, yet relatedly, enacted regimes of practices, and thus of power. Simply put, the schism between experience, society and politics does not only exist in human perception, but is rather materially grounded through different regimes of practice. If the experiential body of illness is distinguished by a patient’s intimate and private relationship with his or her pathology through experimental and playful practices of therapy, then the social body is distinguished by relations and practices which aid or restrict patients to reconcile illness with their everyday lives and responsibilities. Finally, the political is enacted and attains power according to practices of alliance, public visibility and rhetoric. The difference which exists between the three bodies of illness in terms of practices and locales implies that connections and relations between them are not to be regarded as readymade but as a task which requires effort to be completed.

What becomes apparent in the narrative of patients is that, in the context of Cyprus, the political realm and its practices maintain a grasp and exert an influence which demands more urgency than the experiential and social realms. The narratives considered in this chapter presented the entanglement of the three realms, yet the political dimension of patient-state relations was often placed in the centre of conversation as something very important for Cypriot thalassaemia patients, but which was also lacking. Although patient
narratives displayed the interconnectedness of the three registers, they most convincingly displayed the need for further political connection. Ironically, if though these narratives the political body of illness spoke out the loudest, it did so by its absence. And yet this is an absence which I purposefully manufactured in this chapter. In the narratives provided I deliberately gave the impression that none of these patients are actively implicated in the political scene of thalassaemia. This is not the case, as most of them are implicated with the main channel of politicisation for thalassaemia patients in Cyprus - the PanCyp- rian Thalassaemia Association. If I deliberately obfuscated their political activity, it was only to denote and accentuate its importance.

This last claim, that the political body of illness holds an affective superiority over its social and experiential modalities, leaves us with one last obstacle to overcome: It is exactly the interconnected nature of the political and affective, through its particular practices and mechanisms, superiority to the social and experiential which deems it to be the agent of change par-excellence. Yet, how does one partake in the political configuration of illness if the links between the three bodies are ontologically insoluble? My answer to this question is that, once again, a distinction must be made between the political dimension of illness and its politics. Simply put, if “the political” is an ontological dimension of illness through which illness comes to be enacted and experienced by patients, politics are the practices through which one can isolate, contest and reconfigure such political dimension. In other words, in order to reconfigure the political dimension of their illness, patients must achieve a connection between the ontology and politics of their illness. Using the PTA’s activities, I further explore this proposition in the next chapter.
Chapter 3: Doing politics: Matters of concern as raison d’être for patient groups

This chapter focuses on the involvement of the PanCyprian Thalassaemia Association (from now on PTA) with a medical rationing scheme implemented by the Cypriot state. I describe a case study where, when faced with the governmental implementation of this potentially disastrous for patients’ treatment rationing scheme the PTA, by contesting the Cypriot state’s decision in public media, managed to accrue political leverage and overturn the decision. On a conceptual level the chapter addresses the PTA’s involvement through Bruno Latour’s concept of “matters of concern” (Latour, 2004a, 2004b, 2008). By putting the case study of the rationing scheme in conversation with the given concept, I make the case that “doing politics” for patient associations entails, through processes of public deliberation and contestation, making explicit and achieving a continuum between the ontology and politics of their illness. Through my analysis of the case study I provide five tactics through which the PTA was able to achieve this link.

In addition, I suggest that this theoretical perspective, of illness as a matter of concern and of doing politics as establishing an onto-political continuum, can attend to addressing the developing nature of illness as explored in the previous chapter, and also to the changes in social and political context in which illness is enacted. By providing a tool to explore the changing nature of illness, the notion of matters of concern also aids in showcasing how patient organisations likewise develop through time. As Koay and Sharp point out regarding patient associations, “Attention to historical origins and contextualisation aids our understanding of their shifting identities, missions, strategies, organisational structures, and cultures” (2013: 581). Some have already started conducting work in such a vein. Moreira (2007) has written about how ethnographers can document changing “temporalities of health”, while more recently O’Donovan et al. (2013) discuss
how patient associations go through constantly changing “cause regimes” which determine their objectives and identity. As I argue in this chapter, the processual character of the concept of matters of concern can likewise provide an analytic springboard for ethnographers working with patient associations, and aid in identifying the developing dimensions of illness as well as its politics.

Before describing the case study, I situate it in the longer historical trajectory of the PTA. Although the historical trajectory of thalassaemia is provided in greater detail in Chapter 1, the historical background on the PTA provided here is useful since it demonstrates how thalassaemia as a matter of concern in Cyprus has changed through time, as well as how the objectives of the association have been reconfigured in accordance with political, social, organisational and technological change. This juxtaposition between the long duration of a matter of concern and the particularity of a single event will help clarify what in the conclusion I deem to be the relation between the perpetual and particular dimensions of a matter of concern.

**A brief history of the PanCyprian Thalassaemia Association**

The PanCyprian Thalassaemia Association emerged out of the conditions of discrimination and superstition which surrounded thalassaemia in the 1960s and 1970s (once again, see Chapter 1). At the time, it wasn’t only young patients with thalassaemia who were suffering, but also their immediate and even extended families. The association was unofficially established sometime in the mid-1960s by a group of parents whose children suffered from thalassaemia. Steven Epstein notices that this is the case for many patient organisations around the world; that they are founded by what he refers to as “proxies” to patients – namely, not the patients themselves, but members of their immediate or even
extended families (Epstein, 2007: 504). This can be attributed to the common phenomenon that at the point in time when chronic illnesses become established as pathological objects of medical knowledge and practice, patients are often too young to express their demands and be politically active.

The stakes back when the PTA was put together by parents were different from the present time. Medical knowledge about thalassaemia was at a very basic level, and thalassaemia patients were treated with superstition and prejudice. Parents were also stigmatised by, at the time, rural communities in Cyprus. Another factor in the founding of the organisation was the necessity to gain political leverage and demand better medical provision from a newly founded Cypriot state, whose medical infrastructure at the time was practically non-existent. As a founding member of the association described during our interview

The idea of the association happened in the old Nicosia clinic, where parents took their children to be transfused. Treatment at the time was really basic, nothing was offered to us except transfusions. There was no schedule, no access to deferoxamine and no blood quality checks. The children were also treated by paediatricians so there wasn’t any specialised treatment. We felt the need to create an association in order to resist the climate of discrimination which surrounded thalassaemia at the time. We first needed 23 families to join in order for the association to be ratified by the government, but after that pretty much all of the families joined.

Initially named “Association for parents with children with Mediterranean anaemia”, the association was later renamed “PanCyprian Thalassaemia Association”. By 1973, when the association came to be registered as an official body, several studies had been conducted which had conclusively determined the high prevalence of thalassaemia in Cyprus. As detailed in the first chapter such conclusions acted as the impetus for the putting to-
gathered together of a prevention system in order to counter the spread of the disease. In addition, the accelerating construction of thalassaemia as an object of medical knowledge aided in decreasing prejudice and discrimination against patients from the rest of their community. Nevertheless, even after thalassaemia being established as an object of scientific study and practice, medical facilities and treatment methods in Cyprus were still at a basic level. Matters of concern thus started shifting; it was a point where the crux of the matter was not to gain social acceptance as human beings, but to gain access to better treatment methods. Priorities thus changed for the association; politicisation did not aim for social integration, but therapeutic and medical provision.

Fig. 6: The logo of the PTA. This is a reference to thalassaemia treatment:

once transfused, the yellow skin of anaemic patients

acquires a healthy red colour.

Having established these new objectives, through continuous effort the PTA came to stake a claim in governmental decisions regarding thalassaemia. This was no easy feat, and on several occasions drastic measures had to be taken in order for the thalassaemic population to be heard. Up until that point deferoxamine had to be individually purchased, and due to the medicine’s high price and scarce supply at the time only a few patients were sufficiently treated. This short supply of medicine was obviously a mortal danger to all those who could not afford it. Currently, every thalassaemia patient requires
four bottles of Desferal per day, which are freely provided by the Cypriot government. If one considers that back in 1977, when demonstrations took place, patients could on average afford two bottles of Desferal per week, the discrepancy and progress made becomes evident. After a series of demonstrations the association succeeded in including deferoxamine in the state’s healthcare system. The association also played a decisive part in founding the blood donation coordinating committee – a quasi-governmental body which, even today, accounts for collecting the majority of the blood required for the weekly transfusions of thalassaemic patients. As the founding member went on to say:

We achieved a lot of things. We managed to introduce a transfusion programme, we managed to introduce blood quality checks and we also managed to improve blood supply by organising voluntary blood donations. We also managed to get one doctor devoted specifically to treating thalassaemia patients. But we were still housed in the old hospital. We needed more space and better facilities. We pulled a lot of strings and put constant pressure on the Cypriot state, until finally in 1981 we managed to move to the new hospital. When we moved here we managed to also get two more doctors in the clinic. There were about 450 of us at the time, and it was clear that the one existing doctor needed more help.

The PTA was also catalytic in exercising pressure on the state to implement a premarital certificate, an objective which was achieved in 1983 (see Chapter one). According to this, in order for two individuals to get married they had to be tested regarding whether they were carriers of the thalassaemia trait, an arrangement between the Cypriot Church and state which stands even today. The introduction of the certificate coincided with the main objective of PTA at the time, which was the prevention of the future births of thalassaemic children in order to provide better care for existing patients. In 1986 certain key members of the PTA were also instrumental in the founding of the Thalassaemia Inter-
national Federation (TIF). TIF houses its headquarters in the capital of Cyprus, Nicosia, and has grown into an umbrella organisation consisting of over 80 thalassaemia patient associations from around the world (see Chapter 4).

Fig. 7: Newspaper clipping from 1977 detailing the PTA’s picketing for a free deferoxamine supply. The headline reads “No more unhappy couples because of anaemia”. The picket in the photograph reads “We want to live, Desferal is our life.”

Since 1983 the PTA has been constantly involved with state politics. Patients who were too young to act as members of the association when it was first founded started taking over from their parents. Nowadays the entire board of the association is patient-led. The association has achieved public visibility through a number of mediums; the chief members of the association often make appearances in media such as newspapers, television and radio. The annual thalassaemia week, established in 1976, is now a regular fixture.
The educational week has a three-fold purpose. It aims to increase public awareness and knowledge of thalassaemia, gather funds required for the operation of the association, and to also run educational workshops for patients and medical practitioners regarding emerging therapeutic technologies. These workshops are tailored to the demands and needs of doctors and patients.

The PTA has also established and maintained relevance on a techno-scientific level. As another member said to me, the association has been implicated with technological advancements on the thalassaemia front ever since its early days:

After we became ratified as an association we tried to always keep an eye on international medical conferences on thalassaemia and keep track of what progress was made in terms of technology and therapy. Every year we would bring doctors and inform doctors and patients of these advancements and would also offer advice as to what we could do in the future for better treatment.

Throughout its history the association has consistently provided funding for research on technologies of genetic diagnosis in Cyprus. As mentioned, the success of preventing new thalassaemia births through antenatal and prenatal testing led to better medical provision for existing patients. Nowadays, the relation between PTA and technological advancement is maintained through workshops run in the Cyprus Institute of Neurology and Genetics (CING). CING, a largely state-funded institute, was established in 1990, and has ever since developed a close working relationship with the association. A research branch devoted to thalassaemia has been formed in the institute; geneticists there are working at improving the diagnostic and therapeutic methods of thalassaemia, and are also working with other labs around the world on developing a gene therapy which could prove to be the final cure to thalassaemia.
In sum, these are activities and alliances which perpetuate thalassaemia as a matter of concern in the eyes of patients, the state and the public alike. By attaining a certain rhythmic quality to their activities, the association has managed to gain a foothold in public perception and scientific research agendas, and they have also staked a claim in governmental decision making. These, then, are tactics by which a perpetual matter of concern is maintained; they set up “motifs” and “refrains”, (Deleuze and Guattari, 1987: 300) by which a political entity persists but is also renewed in light of developments and changes. One can see how the structure, operation, and political involvement of the PTA went, and continue to go through several transformations, according to predicaments it was facing as well as according to changes in the extra-pathological space it was operating in. Take this remark from a board member of the PTA, which denotes a renewed interest by the PTA for blood donors:

I think one of the biggest successes of the PTA was managing to bring voluntary blood donation up to 100%. Before we started getting involved with this, the blood acquired by the state only amounted to 3%. It was truly a remarkable achievement and even other organisations from other countries come to research the specifics of what we did to see if they can do something similar. But now we’re facing a new problem. The original blood donors are getting older, and that means they cannot donate any more blood. You aren’t allowed to do so after 65. So we need to keep communicating to the public in order to sustain this blood supply, in order to bring new donors in.

This statement neatly encapsulates the shifting space according to which thalassaemia is enacted in Cyprus, as well as the need to maintain a sense of urgency. As made evident by the history of the PTA, politics of illness are always enacted in relation to problematic entanglements of illness, society and politics. Rather than a linear trajectory, the history of
patient associations can be better perceived as a chain of erratic events of political activity. These were events which not only made explicit the relation between illness, society and politics, but also urged the PTA to deploy and unfold its political prowess in order to reconfigure these. In the next section I attend to a single incident, where the PTA managed to overturn a governmental decision which, if affirmed, would have had disastrous consequences for thalassaemia patients in Cyprus.

**The PTA and its recent involvement in the Cypriot politics of healthcare rationing**

About halfway through my fieldwork, in March 2013, the Cypriot IMF bailout took place. Talking to some of my informants shortly after, they expressed worry about how the austerity measures imposed by the IMF on the Cypriot economy would affect their free, up until then, treatment. A couple of months after I returned to Manchester to start writing my thesis, in September of 2013, a patient with whom I had been in touch throughout my fieldwork started sending me PDFs of newspaper clippings from Cyprus. The clippings had to do with a rationing scheme the Cypriot state was thinking about implementing. The drug to be rationed was called Exjade, which is a deferoxamine agent used to treat iron overloads resulting from blood transfusions. Exjade is one of three therapies available for treating thalassaemia. The other two are a pill called Desferal and the pump method described in Chapter 2. What differentiates Exjade from Desferal is that it is easier to use, since patients only have to take one Exjade pill daily as opposed to the twelve pills required for Desferal. Exjade is also more efficient in excreting excess iron from the human body and presents fewer side-effects. Likewise, Exjade is more efficient and convenient in comparison with the pump method.
Exjade, however, is much more expensive than the two other therapies. Several patients narrated how hard it was to get the Cypriot government to provide the medicine. As one of them recalled:

   It’s quite expensive. We’ve been fighting for many years to make Exjade available to all thalassaemia patients in Cyprus. Since Exjade became available in 2005 we’ve managed to get the state to provide 28 patients with it. We had to go all the way to the parliament to get the government to do so. Unfortunately the financial crisis thwarted our plans to get all patients treated with it.

Even after conceding to patient demands, the Cypriot state introduced Exjade with certain conditions and restrictions. Whereas patients in Cyprus receive their monthly dosage of Desferal and pumps for free from the Cypriot state, Exjade is reserved only for thalassaemia patients whose bodies display intolerance and do not respond to the two other forms of therapy. According to the protocols and procedures set by the Cypriot state, before a doctor prescribes Exjade to a thalassaemia patient, the patient first has to be evaluated and approved by a governmental committee and then by a medical committee. The purpose of this dual audit is so that Exjade is only prescribed to those who really need it. The result of these bureaucratic arrangements is that a waiting list has been created for patients who require the drug. On the one hand, the number of people granted a supply by the state healthcare system is kept low due to its high cost. On the other hand the long time required for someone to be approved by both committees has resulted in prolonged period of time during which the patients who indeed need the drug are not supplied with it.

Besides newspaper clippings, I also started receiving emails about the Exjade situation in Cyprus in November of 2013. These weren’t sent from my informant; after I left Cyprus
I set up a Google alert that emails should be sent to me whenever newspaper articles containing the words “thalassaemia” and “Cyprus” were published. The first email I received said that the Health Ministry of Cyprus “ordered an investigation into the supply of Exjade, a drug used to treat thalassaemia, after alleged irregularities were found in its supply dating back to 2011” (Stevenson, 2013). As a later newspaper article revealed, the Cypriot Ministry of Health made an offer towards the end of 2011 to buy a three year supply of Exjade required for 118 patients who had been approved to use the drug by the governmental and pharmaceutical committees (Panayi, 2014). The deal in question was locked in January of 2012.

In February of 2012 the offer was scrapped after the Republic of Cyprus Auditing Board objected to the deal, deeming it too expensive. The Ministry of Health renegotiated the deal, which concluded in buying a two-year supply of Exjade for 64 patients. At that time 104 patients were prescribed the drug, but only 40 were supplied with it. In November of 2013 the Auditing Board once again reacted to the supply deals, and ordered an investigation regarding the February 2012 deal. The investigation was concluded when the two government employees in charge of finalising the deal were put under suspension for these irregularities in the supply of the drug (Panayi 2014).

After January 15th 2014, several Greek and English newspaper articles started being published saying that eleven thalassaemia patients had died since 2007, when Exjade was first introduced and regulated in Cypriot healthcare (Dyspirou, 2014; Kallinikou, 2014; Koumasta, 2014; Molyvaa, 2014; Panayi, 2014a; Stevenson, 2014). The claim was made by the president of the PTA, a patient herself, although one not requiring Exjade. According to her, the eleven deaths resulted because four patients had to wait too long to be inducted in the list of those supplied Exjade by the Cypriot government, while the other seven deaths happened while patients were on the waiting list.
The impetus for the PTA to mobilise and make these claims came after the Ministry of Health began considering cutting down the list of patients being supplied with Exjade in Cyprus from 76 to 64. The patient I was in contact with through email at the time also sent me some wires published by the Cypriot News Agency, a governmental media organisation. The wires were also dated 15 of January; in them three MPs – one from the ruling party, one from a conservative party and another from the opposing party – similarly expressed their concern with the Exjade situation. The newspapers publishing these articles also varied in political orientation, encompassing left, conservative and right wing perspectives. It is thus worth pointing out how the rationing scheme as a matter of concern cut through, and was not enacted according to the classic template of partisan politics, but rather according to a collective climate of urgency.

On the 16th of January, another article was published in an English-speaking newspaper. The first sentence of it reads, “The Health Ministry is doing its best to get medication to patients with thalassaemia and multiple sclerosis despite having its hands tied after it had its budget slashed by parliament, Minister Petros Petrides said yesterday” (Stevenson, 2014). Another Greek article, this time directly quoting the Minister said, “We shouldn’t face the dilemma of choosing between human lives and economic matters, but these are the facts laid in front of us” (Panayi, 2014b, my translation from Greek). This reduction in governmental spending, much like the cut back in the Exjade supply, can be traced back to March of 2013, when the Cypriot economy had to succumb to austerity measures imposed by the IMF in order to repay a ten billion euro loan.

This same article also said that the PTA opposed the statement made by the Minister of Health regarding the deaths of the eleven patients. More specifically, the Minister declared that the eleven thalassaemics did not die because they weren’t taking Exjade. According to him, after consulting the official records of the Thalassaemia Centre based in
Nicosia, none of the eleven died because of iron overload but due to heart failure. Since Exjade is a drug specifically made to counter iron overload, and since none of them had this cause of death, to him this meant that the lack in the Exjade supply was not the crux of the matter. The next day the PTA swiftly rebutted that heart and organ failure in general is derivative of iron overload, and that the death of the eleven patients must thus be considered as connected and related to the lack of Exjade supply, and not coincidental (Panayi, 2014b).

These skirmishes between the PTA and the Ministry of Health were taking place in relation to wider contexts regarding the politics of thalassaemia and health in Cyprus. The attention that thalassaemia politics received after the death of the eleven patients overflowed to other matters of concern for thalassaemia patients in Cyprus, past and present. Elsewhere, in another Greek article, besides calling attention to the lack of Exjade supply, the PTA was lamenting the overall constant deterioration of the thalassaemia treatment system. As the article says, “The PTA reports that, while Cyprus was once considered a model and pioneer in treatment, recent developments in treatment are not implemented, while there has been a backward development in other dimensions of treatment” (Constantinou, 2014, my translation from Greek). Another article on the same day said that thalassaemia patients in Cyprus were caught in the middle of “clan wars” between the Ministry of Health and the state Auditing Board (Panayi, 2014b).

Other articles mention the firm grip unions of pharmaceutical companies have on the Cypriot economy; according to them, Cyprus is one of the countries with the most expensive drug prices in the world, thus further limiting the already inadequate governmental budget (Landou, 2014; Stylianou, 2014). Comparisons were made with other countries with a high prevalence of thalassaemia, according to which Cyprus had the lowest supply of Exjade in relation to the number of patients. Other articles focused on the lack of
quality controls used in transfusions, and the need for a centralised blood centre in Cyprus, where quality checks can be conducted before blood is sent to the clinics and hospitals around the island. These articles also touched on the Cypriot central blood bank lacking the standardised European blood check protocols, the disruptions thalassaemia patients face in the scheduling of their weekly transfusions, as well as the lack of blood (Molyva, 2014b; Koumasta, 2014b; Kasinidou, 2014).

On the 23rd of January reports circulated that the Ministry of Health was to release 1.8 million euro in funds in order to attend to the immediate needs of thalassaemia and multiple sclerosis patients (Paisanou, 2014; Daniel, 2014). The reports also said that the Cypriot parliament would meet again in two weeks in order to confer on a deal to increase the supply of Exjade, and also that an investigative committee would be put together in order to verify the exact causes of death for the aforementioned eleven thalassaemia patients.

The spree of newspaper publications ended on the 29th of January 2014, when the Minister visited the hospital in Limassol, the second biggest city in Cyprus. The state-led hospital is where thalassaemia treatment for patients living in Limassol takes place. The Minister visited the hospital after thalassaemia patients being treated there started complaining when chemotherapy also started taking place in their section. This was because, as several of the patients who I talked to during fieldwork also told me, their bodies and immune systems are weakest at the stage of transfusion, meaning that an unsanitary surrounding could prove fatal. The Minister had already visited the hospital once the week before in order to evaluate potential solutions to the predicament of the lack of space. According to several newspaper articles, when the Minister visited the thalassaemia section of the clinic for the second time then week after, the patients undergoing treatment at the time
clustered around him and even started shouting at him and pushing him (Sigmalive, 2014).

Shortly following the incident the Minister announced that he would attend to the demands of the patients by relocating the thalassaemia section to a new site. The PTA president, based in Nicosia, reported that pushing and shoving was not the right approach to solving the matter, and that “The Minister of Health has consistently been attentive and supportive to the demands of thalassaemia patients” (Simerini, 2014, my translation from Greek).

**Tactics as means of reconciling the ontology and politics of a matter of concern**

How does one fruitfully conceptualise these series of events, as well as the historical narrative provided in the section before? In this part of the chapter I make the case that Bruno Latour’s notion of “matters of concern” can be deployed in order to trace the socio-political and techno-material dynamics at work, which provide the space of possibility for the genesis and operations of patient associations such as the PTA. Latour uses the notion of “matters of concern” to replace that of “matters of fact.” As Latour (2004, 2008) points out, whereas a matter of fact is taken for granted and is thus closed to the potential of modification, a matter of concern is an open ended relational arrangement in a constant process of remaking and revision through political processes of deliberation and contestation. As Latour explains, matters of concern “have no clear boundaries, no well-defined essences, no sharp separation between their own hard kernel and their environment. It is because of this feature that they take on the aspect of tangled beings, forming rhizomes and networks” (Latour, 2004a: 24). Likewise, as Puig de la Bellacasa makes clear, “The notion of matters of concern extends the early insight that technological and
scientific assemblages are not just objects but knots of political and social interests” (2011: 87). Conceptualising illness as a matter of concern thus aids in conveying that illness, thalassaemia or any other, is not a closed field of symptoms and effects to be simply diagnosed and treated according to standardised protocols, but an ongoing political process, enacted and contested by actors of diverging yet related interests.

Going through its history, it is evident that the PTA emerged as a reaction to an issue which collectively affected thalassaemia patients in Cyprus and which was not merely biological in nature – namely social discrimination and prejudice against patients of thalassaemia. Through its historical trajectory the PTA managed to affect the extra-pathological space according to which thalassaemia is enacted; through public sensitisation they have managed to socially integrate thalassaemia as an acceptable condition, and thalassaemia patients as rightful citizens with claims to healthcare access and medical provision. Along time, a shift in the composition of the association, from parents to patients, entailed that objectives were to be revised and rearranged in light of such changing membership and organisational structure. As often put by patients I was talking to, the objective for thalassaemia patients in Cyprus nowadays is not social acceptance, but an improvement in their quality of life. In addition to these changes in its internal composition and political objectives, the association went through changes in its external relational milieu: technological changes, national politics, economic turmoil and war – all of these were elements the PTA had to acknowledge and adjust to.

As made evident by the PTA’s historical trajectory, political landscapes, those of illness included, are cut and carved by worldly forces which often evade human intentionality. If such unpredictable forces have the capacity to affect, they also have the capacity to activate. The problematic and unpredictable conditions out of which a matter of concern emerges also have the capacity to bring forth the formation of collectives, events and
practices aimed at rethinking and reconfiguring the problematic conditions out of which they emerged. As Ingunn Moser writes, matters of concern “come into being in a process that brings together and aligns actors and elements in particular ways, and so enacts and shapes both matter of concern and collectives” (2008: 99). Courtesy of this formation of collectives which it facilitates, we can pinpoint a dual and related – political and ontological - signification to the notion of matters of concern. On an ontological level, a matter of concern gestures to the material conditions of its emergence: the relational arrangements and everyday practices out of which a matter of concern arises and affects a certain population. On a political level, thinking with the given concept can shed light on the conditions of political deficit out of which a matter of concern emerged for a patient association, as well as the reactive deliberative practices and alliances by which a patient association succeeded in attaining political leverage and addressed the particular matter.

Matters of concern as a processual assemblage of onto-political dimensions overlaps with the differentiation of a chronic extra-pathological space along time: with the changing symptoms of an illness as showcased in Chapter 2, as well as with changes of economic, technological political and social dimensions. The two axes of politics and ontology are thus always in dialogue: If illness in its ontological guise is a process of shifting forces, practices and affects, then so is politics. This because, what comes to pass and be understood as a matter of concern in the eyes of the wider public is a political endeavour and a matter of concern in itself. As Michel Callon writes, “matters of concern exist only if the concerned groups create them as such by making them visible and perceptible in the public sphere” (Callon, 2005: 312). In this sense, matters of concern can be considered the very lifeblood of a patient group since its operation is, at all times, tied and related to this material, ontological and political circumstance from which it is negatively affected. As Isabelle Stengers writes, “Materialism loses its meaning when it is separated from its rela-
tions with struggle” (Stengers, 2011: 369). The materiality of a matter of concern in its ontological guise is always related to the conditions of political struggle which it gives way to. The essence of “doing politics” for a patient collective is indeed this: *achieving a connection between a matter of concern in its ontology and politics* – in other words, to discover means, channels, practices by which the ontological, material arrangements of a matter of concern, are able to inform its politics.

The connection of the ontology and politics of a matter of concern must be maintained as long as patients remain “concerned” or, in other words, affected by the given matter. Yet, the connections between the ontology and politics of a matter of concern are not to be taken for granted. Elsewhere Latour (2007) writes that the adjective “political” has descended into meaninglessness (Latour, 2007; 812). Latour’s concern is that, in deeming everything as potentially political, one loses sight of what politics. Or, as Matei Candea puts it, “the political has become such a pervasive explanatory form, that some anthropologists have forgotten to ask what politics is” (2011: 310). Following Latour and Candea, we can do away with the Aristotelian motto that “everything is political”, not because it is false to say this, but because as a statement it presents no consequent challenge. Instead, one must embrace another qualification presented to us by Pignarre and Stengers: “One doesn’t do politics without knowing it” (Pignarre and Stengers, 2011: 122). Once one becomes aware of the political implications of his or her actions, then the divisions between politics and subjective experience are bridged. Only then is the gap between the ontology and politics of a matter of concern reconciled. As Puig de la Bellacasa writes, “personal ethico-political practices [are]…situations when people are changing their ways of doing at the level of personal everyday life, not individually, but in connection to a collective (2010: 157). At this point, once the connection between individual experience and collective politicisation is achieved, one can additionally claim the motto
“the personal is the political” (Pignarre and Stengers, 2011: 132), because, once again, the connection between the two is not to be taken as ready-made, but as a feat to be achieved.

In return, once such a connection and continuum has been achieved, the result is a productive feedback loop between the ontological dimensions of an illness and its politics: once the ontological dimensions of illness give way to the formation of collectives, then these collectives, through their politics, are able of influencing the ontological conditions which initially gave way to their emergence. The activation of illness operates and oscillates between these two movements of non-intentional affect and intentional strategy: While the first movement gathers the elements through which a problematic circumstance non-intentionally arises in its materiality and affects a patient collective, the second movement is an intentional process of apprehension which serves in serialising and making sense of the predicament a collective finds itself in. These are the two poles of a matter of concern: the non-intentionality of “what happened?” (Deleuze and Guattari, 1987: 192) but also the declaration, urgency and intentionality of “what are we trying to do?” (Stengers, 2000: 90). In order to further clarify the suggestion of doing politics as achieving an onto-political continuum, in what follows would like to identify five tactics the PTA utilised in order to achieve a connection between thalassaemia as a matter of concern in its ontological constitution and its political demarcation as such. Although each of these tactics is presented separately for the purpose of analytical clarity, one can also see how they intertwine and complement each other.
1. Comparison

In the statements by the PTA president given to the press, comparison was often made between the arrangements regarding Exjade supply in Cyprus and elsewhere in Europe. In one newspaper article the PTA president was quoted as saying that problems for Cypriot thalassaemia patients “Started ever since 2007 when, because of the high cost of Exjade, the state set restrictions [on its supply]. According to these restrictions, and in contrast to the rest of the countries where prescription by a doctor is adequate to receive it, in Cyprus the drug is administered only to those who provide proof that they prove resistant to other means of therapy” (Phileleftheros, 2014, my translation from Greek). In the same article, an emphatic heading reads, “Cyprus is Last.” After the heading, statistic evidence is provided to demonstrate the lack in Exjade access and supply thalassaemia patients in Cyprus face in relation to other countries in EU and elsewhere. According to the statistics, Cyprus is the country with the lowest percentage of patients being administered Exjade; in the US 52% receive the drug, in the UK 33.3%, in France 65%, in Israel 48%, in Greece 25%, in Bulgaria 15%, and in Cyprus 6%. As the article proceeds to emphasise once more, in these other countries patients do not have to go through ad-hoc committees and bureaucratic delays in order to receive the medicine. Relatedly, in the newspaper clippings released one can also pinpoint the demands of the PTA for the Cypriot government to implement the EU standards of blood quality control - standards which are largely adhered to by other countries in the European Union.

What does it mean to compare? What is the purpose of comparison and what are the effects of comparing, but also, and perhaps more importantly, how is comparison facilitated? In the case of patient associations, acts of comparison can prove as formidable tool of pragmatic and political capacity. Comparison as the act of contrasting otherwise non-related healthcare arrangements serves in multiplying and producing perspectives of the
possible (Toren, 2002), and thus further enhancing and enriching the very space out of which comparison tactics are deployed. A patient organisation deploys comparison as an agent of reform, and a survey of possibility, of an inefficient extra-pathological arrangement. By comparing themselves to patients in other countries who have better access to Exjade, and to countries where blood checks are adhered to, Cypriot thalassaemia patients convey the gap which exists in healthcare arrangements in Cyprus and elsewhere. Comparison as means of addressing a particular matter of concern points out that a certain extra-pathological space can be, and is, elsewhere, enacted otherwise. Comparison is emergent of and at the same time productive of a possibility that “another world is possible” (Stengers and Pignarre, 2011; Osterweil, 2013; Lindisfarne, 2004).

Comparison must be constantly encouraged and deployed. Processes of comparison are not abstract, ghostly juxtapositions independent of time and space, but rather enacted practices, which often require effort and an organisational infrastructure. As Isabelle Stengers points out, comparison itself is in this regard a matter of concern: “The problem begins with the imperative ‘comparison must be possible’…the ethical and political challenge associated with comparativism makes itself felt here” (Stengers, 2011: 58). Accordingly, mechanisms which facilitate comparison must also be protected and promoted. In the case study provided, newspapers and media articles were the means by which comparison entered the public domain and inform Cypriots of thalassaemia as a matter of concern. If I analyse this incident primarily using these newspaper clippings, it is because they were not merely representative, but rather productive of the given event. That is to say, circulation of such media is itself a technology and tactic capable of forging a connection between the ontology of thalassaemia and its politics. In addition, in further tracing the articulations out of which comparison is made possible, one must also recognise the statistical procedures and technologies which produced the numerical data by which
comparison manifests. Such statistical technologies form a numerical nexus and facilitate the becoming-visible of relational healthcare insufficiencies which manifest in the in-between of otherwise unrelated extra-pathological spaces - that is to say, *insufficiencies which are exactly relational in nature and which would not have become visible if not for the act of comparison itself.*

The political potency of PAs which accrues from these acts are a reminder that the notion of relationality, and also that of comparison, are not to be thought of as restricted to the anthropological toolkit, but are intentionally and purposefully enacted in the world. Relationality and comparison are emergent of practices and they, themselves, are also practices which can have concrete and discernible effects in a political field. Towards this, the act of conducting ethnography must not be thought of as distinct from the milieu it engages, but part of it. To put it another way, ethnography can also act as a mechanism and political technology of connection. Separated milieus where patient activism takes place can benefit from the anthropological project par excellence, namely comparison. Epstein, for example, writes how patient associations study the “strategies, or action repertoires of previous movements or organizations” (Epstein, 2007: 507) before them. By fostering connectivity between separate extra-pathological spaces, ethnographers implicated with patient associations can collate a repertoire of the strategies used by patient associations in their struggles for political relevance. Already, some are engaged in this task. For example, Panofsky (2010) shows how certain modalities of “sociability” can help PAs become implicated with scientific research, while Moreira (2012) shows how the deployment of “small news” through media outlets can help PAs enter the political field of perception.
2. Experience as counter-knowledge

Certain ethnographers have noted how the very experience of patients as sufferers of an illness can be mobilised as political gravitas. Rabeharisoa et al. (2014) utilise the term “evidence-based activism” to describe the manner by which patients, through their everyday experience of their illness, construct regimes of knowledge which run counter to faulty healthcare policy and misinformed perceptions of experts and politicians, and aim to adjust and reconfigure these. Using their claims as “experts of experience” (Rabeharisoa, 2008) patients deploy such “experiential knowledge” (Borkman, 1976; Carol-Flinterman, 2011) as chronic carriers of an illness in order to legitimise their political demands. By achieving a continuum between everyday life and political representation, a connection is also achieved between a matter of concern in its ontological and political registers. By making their status as carriers of an illness explicit, patients promote the somatic dimensions of the mundane – in other words the body and its discontents, life itself - as the locus around which policy and governmental decision making should centre, as opposed to financial and economic considerations. More than turning their knowledge “into science” (Pols, 2013), patients should also turn it “into politics” and into a pragmatic tool used for attending to a matter of concern.

In the newspaper excerpts provided above, the Minister of Health claimed that the deaths of the eleven thalassaemia patients did not happen because of iron overload in the organism, but because of heart and organ failure. This standoff denotes the often disparate regimes of knowledge and practice at work, as well as the divergence and disconnect between them. As Moreira puts it, the Minister was “right, about the wrong kind of knowledge” (Moreira, 2012: 314). Evaluated by way of its means of production, knowledge is indicative and emergent of a certain milieu of activity and, in this case, attests to a gap but also the connective potential between the production of state-
knowledge and patient-knowledge. By granting their everyday status as sufferers with political potency, and by translating their bodily experience into a regime and language of knowledge, patients are able to foster a connection between the private realm of subjective experience and pathological constitution, and the political realm of representation. The deployment of somatic counter-knowledge by patient associations demands that what previously evaded the political field becomes discernible and respectable. Patient-knowledge as a self-referential mechanism of somatic experience entails that it, itself, in its activity and perpetual recreation, acts as its own register and technology of “inscription” (Latour and Woolgar, 1979) and hence empirical facticity. The PTA’s response to the Minister of Health was that heart and organ failure in general are caused by iron over-load in the organism, and therefore the deaths of the eleven patients were caused by insufficiencies in the Exjade supply.

In addition to mobilising experiential knowledge, associations use the objectivity granted to the numerical and statistical as a form of counter-knowledge in order to oppose and readjust faulty policy making (Rabeharisoa, 2008: 23). Although not implemented in the Exjade case study provided (the percentages provided came ready-made from elsewhere), this tactic was used by the PTA to address the Cypriot state on another occasion. More specifically, as a patient who was also a PTA board member informed me, the association conducted an analysis of the number of times transfusions had to be rescheduled in a given amount of time, and presented this data to the Ministry of Health in the forms of statistics and charts. The study revealed the structural insufficiency at work, as well the negative impact it had in the daily lives of patients. As the PTA board member exclaimed:

Numbers don’t lie. The state doesn’t keep records on this kind of stuff - they don’t know what’s going on. By giving state official statistics they are able to see what’s
wrong in present healthcare arrangements, and how these insufficiencies affect our daily life. Our research provides irrefutable proof which the state cannot ignore.

Another example where numerical objectivity was mobilised was in the case of a pay-per-visit scheme the Cypriot government was thinking of implementing in light of economic austerity and the need to raise money in order to repay national debt. According to the scheme, each time thalassaemia patients visited their local treatment centres they would have to pay a certain amount for each visit, as well as for each tablet of deferoxamine they received from their local treatment centre. The PTA opposed the scheme even in its preliminary stages of consideration. They knew that paying for each of their visits and tablets would impose a heavy economic burden on them, which would make receiving adequate treatment even harder than it already was. In order to counter the scheme they conducted their own studies and presented estimates to the state of how much a patient would have to pay monthly. The estimates displayed the severity of financial hardship a typical thalassaemia patient would go through and, at the same time, showed that the scheme would ultimately be unable to respond to the urgent need of the Cypriot state to repay the ten billion euro bailout. The association managed to reduce the amount a patient has to pay for each tablet to fifty cents, which is the standard compensation implemented for the entirety of the state-led healthcare system.

3. Autonomy (to a certain extent)

Activism, in the widest sense of the term, is often conceptualised as a practice opposing a dominant existing political order, this often being the state. Nevertheless, the activities of patient associations are not simply antithetic to the state apparatuses but rather adopt a more ambivalent stance which, much like a matter of concern, changes through time. Po-
liticisation, for Cypriot thalassaemia patients, is mainly enacted through their relation to the Cypriot state, since thalassaemia treatment in Cyprus is state-led. Nevertheless, I believe that patient organisations should attempt to maintain a certain distance from the state, so as to achieve organisational and thus ontological autonomy: these are activities which are not opposite and opposing to the state but rather contiguous to and independent of it: beside and besides the state. Thus, although patient associations undeniably proceed and operate through a certain symbiotic agreement with the state apparatus, this symbiotic arrangement does not exhaust their spectrum of activity and reservoir of potency.

The need for partial autonomy is made all the more urgent considering the weakening power of the state apparatuses to respond to the demands of patients amid a global climate of economic degradation. Even in 1920s, prior to state apparatuses being subsumed by capitalism, Dewey goes as far as to hint that the state as a modality of governance is outdated. As he writes, “Emerging publics cannot use existing institutions because they are insufficient to address developing needs. Rather, existing institutions may be inimical to those new needs” (Dewey, 2012 [1927]: 28). The proposition that a rigid and imprisoned state apparatus cannot attend to developing needs rings especially true in the case of patient associations, if one considers the changing dimensions of chronic illnesses, as well as the shifting extra-pathological space where these are enacted. Noortje Marres, taking her cue from Dewey and also another pragmatist philosopher, and Dewey’s adversary, Walter Lippmann, points out that the need for public participation and involvement precisely emerges from “issues that existing institutions cannot settle” (Marres, 2007: 770).

Cyprus is a country which has been struck especially hard by regulation and economic austerity from European and international organisations. The intrinsic relation state apparatuses have to the capitalist nexus not only weakens them due to economic turmoil, but
it also gives them a way out of addressing the demands and expressions of therapeutic citizenship, especially if the given healthcare system is state-led. For example, as Berg et al. argue regarding the Dutch state, “An important feature of the Dutch health-care policy-making system is the government’s powerlessness. It does not directly control the main financial flows driving the health-care system; nor are there clearly legitimated and fully equipped governing institutions for implementing decisions on the arrangements for health care” (Berg et al., 2004: 35). Amid such financial uncertainty, “lack of funds” - to recall the excuse given by the Cypriot Minister of Health - seems to have become a skeleton key for the state in addressing demands from all kinds of activist groups. In addition, the participation of nation states in committees and organisations of European and international scope gives them a way to point the finger at these upper echelons as the source of their failure, for example the IMF. The facticity and straight-forwardness by which these words are uttered serve in fixing and deeming a matter of concern as redundant; if there are no funds, there is nothing we can do.

Take, for example, another statement by the Cypriot Minister of Health circulated in the media, “These are the facts laid out for us.” In such ways a matter of concern is fossilised; no space is left for political negotiation, deliberation and contestation – matters of concern risk being reduced to matters of fact. This entails that alternative tactics and means to perpetuate a given matter of fact must be devised – means which situate such an endeavour away from the incapacity of the state to participate. As Marteen Hajer aptly terms it, the relegation of state power amid socio-economic turmoil has resulted in an “institutional void” (Hajer, 2003). In such contexts, one can see how patient activism is not enacted according to a patriarchal relationship between state and patient organisations, but rather according a climate of instability where both state and PA are immersed in chronic conditions of precarity and unpredictability.
In the case of the PTA, staying partial and external to the state entails tactics of constant communication to the public and searching for alternative funding sources. As mentioned in the overview of the PTA’s history, the association has, ever since 1977, organised an annual awareness week. This activity serves the two-part purpose of perpetuating thalassaemia as a matter of concern in the eyes of the public and also raising funds for the needs of the association. With the funds raised from such events the association proceeds to, for example, organise workshops for patients but also for medical practitioners across the island. To give another example of fundraising, the association has applied for and received a grant of a hundred thousand euro from the European Economic Area Grant Scheme. Amongst other activities, the money went to organising five workshops for medical practitioners across the island in order to educate doctors on aspects of thalassaemia therapy, the production of educational material, and the creation of an electronic database used for recording the medical history of each thalassaemia patient on the island, which replaced the more traditional method of keeping hard copy medical records. Such tactics of contiguity serve is situating the PTA outside of the complete control, and also inefficiency, of the state apparatus, while at the same time perpetuate thalassaemia as a matter of concern. By fleshing out such tactics of autonomy, ethnographic description can produce an image of patient associations as more than a mere antithesis to the state, but as entities with solid organisational foundations in their own right.

This is not to say the state should be completely excluded from politics of illness or that complete autonomy is something PAs should aspire to. On the contrary, my impression is that patient activism cannot completely exclude the state, especially if it is in charge of the healthcare system as is the case in Cyprus. Although tactics of contiguity can be deployed in order for a patient association to avoid being completely swallowed by it, the state is ultimately a useful ally in order for a matter of concern to emerge and persist in its
second, political articulation. By conceptualising patient associations as partially external to the state apparatus, one understands that the relation between the two is not static but, much like a matter of concern, is also shifting and enacted according to changes in the extra-pathological space where an illness takes place. As Biehl puts it, taking his cue from James Scott (Scott, 1998), often it is not a matter of opposing the state but being “seen” by it (Biehl, 2007: 11). Yet, as it becomes evident, the relation of the PTA to the Cypriot state is not merely one of opposition, as is often conceptualised in activist accounts. As mentioned in the previous chapter, if the main matter of concern for patients is that of a political deficit, then this demands a further connection to the state apparatus. Indeed, to return to the case of thalassaemia members in Cyprus, shoving, pushing and yelling were mechanisms of redistributing the politically ocular and sensible in a time of need. Relations between states and PAs are not be thought of as ready-made, but as a knot of circumstance to be masterfully and elegantly managed (consider the diplomatic statement given by the president of the PTA at the end of the case study), and embroiled in a common project of maintaining a matter of concern.

4. Spokespersons

We must attend to spokespersons as another tool that the PTA used in applying political leverage and perpetuating a matter of concern. The statements made by the president of the PTA at various stages of the standoff between the association and the Cypriot Ministry of Health were catalytic in unveiling, but also salvaging a particular matter of concern. Politics as it pertains to a matter of concern demands that what comes to pass as political requires “good speakers” (Akrich et al., 2002: 218). Borrowing from Bruno Latour, we can pose the question, what is at play when someone adopts the political “regime of
enunciation?” (Latour, 2003: 144) What potency do such acts of enunciation carry, and how do they relate to protecting a matter of concern?

The constant implication of a spokesperson in a matter of concern serves as a revisionary practice of navigating the discussion and framing of the given matter in light of ongoing developments and deliberation by the parties involved. As Latour writes, by “speaking politically” (Latour 2003, see also Latour, 2013: 339), spokespersons “transform the several into one” through a process of constant “regrouping”. Through a certain process of representation, the spokesperson amasses the members of the association into her persona, thus attaining a political potency of collective dimensions: these are the metaphysics and pragmatics of speaking politically. The spokesperson serves in providing coherence and direction to an otherwise muddy, messy and inconceivable, in the eyes of the state and public, matter of concern. Spokespersons provide framings which provide foundations for what is at stake and what is of concern; their acts of political enunciation constitute the very contours and “field of perception” (Rancière, 2013) of a space of political possibility and representation amid which a matter of concern comes to be enacted and deliberated over.

In addition, we can attend to the event of representation and political enunciation as of particular importance. As Latour writes elsewhere, “‘Representation’ here does not mean either election nor epistemological accuracy, but the reflexive production of a plausible and revisable version of what risks we take by experimenting collectively” (Latour, 2004: 13). As he explains, these two traditional notions of representation, that of electoral representation and epistemological representation, “have now merged into one around the key notion of spokespersons offering clearly staged demonstrations for proving the existence of some new entity that becomes the object of collective concern” (Latour, 2004: 4). Thus, according to a matter of concern, what previously was the task of perpetuating
a certain political ideology is now replaced by a collective sense that something much more important is at stake. The spokesperson, on the occasion of speaking, does not only speak in the name of the members of the association, but in the name of the given matter itself. As Latour writes elsewhere, “to speak well of something to someone is first of all to respect the precise ontological tenor of the value that matters to him and for which he lives” (Latour, 2013: 144, emphasis in original). Enunciatory acts of representation by a spokesperson allude and point to a matter of concern which would otherwise be inconceivable to the political field of perception; they represent the matter of concern not in the form of epistemological accuracy, but of verbal and declarative urgency.

The pragmatic capacities of speech must be emphasised here. Borrowing from Marilyn Strathern, one can say that the taking place of such events of political enunciation “summon the tracery of heterogeneous elements that constitute [it]” (Strathern, 1996: 521). Speaking politically is the art of presenting yourself as a matter of concern and tying oneself to a matter of concern, making it clear that the event of enunciation would be inconceivable if not for the problematic conditions which force its coming. Tying oneself to a matter of concern entails that the distributed, interactive and otherwise sensorially elusive dimensions of the matter manifest in the unity of your person.

In such way, speaking is not merely communicative, but first and foremost palpable and capable. Acts of enunciation emerge and derive from certain relational conditions, but also carry the potential to fall back and alter the conditions out of which they originally emerged. The feedback loop of ontological relationality and political representation makes itself most felt at this juncture of enunciation, and the means required to articulate this to a wider public. At this juncture, at this oscillating continuum between bodily health and political deployment, words are not merely vehicles of meaning, but mediators of the ontological and the political. The spokesperson of a patient association manifests
as the harbinger of the extra-pathological space; he or she speaks in the name of this space as much this space speaks through him or her. This event of political enunciation emerges from the matter of concern from which it addresses and which can also affect.

5. Alliances

Finally, we can attend to alliances as perpetual means by which a patient group maintains and also navigates a given matter of concern. Going through the historical trajectory of the PTA one can see how the extra-pathological space of thalassaemia in Cyprus has been altered according to alliances forged between the PTA and other organisations. The forging of alliances constitutes a space of possibility of the extra pathological space where a matter of concern comes to be enacted. More than dictating political alignment, or being on the same side, patient alliances dictate the realm of the possible: they constitute how a given matter is articulated in both of its versions - ontological and political - as well as it how it can be enacted in the future.

In the case study provided, the alliances and connections forged and maintained by PTA with MPs and media outlets were crucial in deeming the lack of Exjade as a matter of concern, as well as promoting the matter to the political and public field of perception. The fact that Cypriot MPs representing several, even opposing, political orientations aligned themselves with the PTA conveys that politics as it pertains to matter of concern supersedes traditional politics of representation, instead making the possible the creation of new ephemeral congregations and collectives (Gomart and Hajer, 2003; Latour, 2011). It is also worth noting that, even though the state as a collective entity is largely not responsive to the demands of the PTA, certain key individuals belonging to the state apparatus are. The importance of this point is that by forging alliances with such key individu-
als, PAs are able to cut through the seemingly monolithic facade of the state. Caroline Gatt, in a theoretically and strategically impressive examination of relationality, shows how smaller in scale organisations can influence larger organisational entities by breaking down the latter in smaller vectors, some of which they can recruit, and the rest of which they can oppose. As she writes, this tactic allows smaller organisations to partake in policy making processes by populating the “interstices of decision-making” (Gatt, 2013: 360) of larger organisational personas. Thus, even though the PTA could not enroll the entirety of the Cypriot Ministry of Health, by forging and maintaining alliances with specific MPs they manage to grant their struggle with political relevance and incorporate it into state procedures.

Alliances of patient associations extend into the techno-scientific domain. The PTA maintains a tight relationship with the Cypriot Institute of Neurology and Genetics (CING), where research is conducted on a potential gene therapy for thalassaemia as well as on other therapeutic and predictive technologies for thalassaemia. The relationship between the PTA and the CING is enacted according to common workshops held on CING premises where thalassaemia patients are invited to learn, as well as to interact with medical practitioners regarding the implications of developing biotechnologies. Through forging alliances with such organisations, PAs can influence the course of technological trajectories. By bringing together a “techno-collective” (see Chapter 5), such events acknowledge the ontological status of patients as sufferers of a chronic illness and allow this to partake in processes of technological advancement. Another research initiative to which the PTA is connected by way of the CING is ENERCA (for more details see Chapter 3), an international cluster of laboratories conducting research on rare forms of anaemia, with the task of setting up a network of expert centres in order to combat such conditions. In addition, the PTA maintains a strong relationship with the Thalas-
saemia International Federation (TIF), founded in Nicosia in 1986. The TIF acts as an umbrella organisation for national thalassaemia associations around the world, and now is comprised of over 80 of them.

Hence, as Epstein notes, although first operating on a national or even local level, the proliferation and increasing interconnections forged between patient associations battling the same disorder in different countries have set up a network of “transnational alliances” (Epstein, 2007: 501). Such collective mobilisation situates these connective endeavours as important participators in what Rabeharisoa and O’Donovan deem to be the “Europeanisation of healthcare policies” from below (Rabeharisoa and Donovan, 2014). The common standards and procedures set by such healthcare policies, or at least the struggle to implement them as is often the case with the PTA, provide a terrain of conversation according to which associations in otherwise disparate settings can exchange knowledge, and also according to which comparison can be facilitated.

**Protecting a matter of concern (the relation between the perpetual and the particular)**

Throughout this chapter I have been using Bruno Latour’s matters of concern as an open-ended, temporally unfolding relational arrangement, and as a raison d’être essential to the genesis and activity of patient organisations. I will conclude this chapter by making what I believe to be a fruitful separation between the perpetual and the particular dimensions of a matter of concern. In the case study provided, the extra-pathological space according to which thalassaemia was enacted at a given point in time came to be influenced by political and economic events which were unpredictable in their gathering. In return the PTA had to mobilise its political reservoir, such maintaining alliances with MPs and
journalists, as well as accumulated, up to that point, political leverage. One must thus not restrict an inquiry to non-intentional episodic events; one must also attend to intentional motifs and refrains by which associations maintain given political enterprises - incessant tactical practices which largely provide the foundations and relational reservoir by which tactics are deployed when needed.

As Latour emphasises, matters of concern must be “cared for, accompanied, restored, duplicated, saved” (Latour, 2008: 49). Such tasks are delegated first and foremost to patients since they are the protectors of a matter of concern. The difficulty in this task is that a matter of concern is not an intentional process of construction, but a non-intentional process of assembly by which a problem gathers together. As mentioned earlier, one doesn’t choose one’s concerns but, more importantly, one doesn’t choose whether his or her concern is also a concern to others. One knows the political gravity of his or her actions only when others do so too. It is not farfetched to claim that the pushing and yelling of the thalassaemia patients against the Minister of Health was a political act par excellence. It was not a negative gesture of dismissal but, on the contrary, one of trying to achieve a connection - an urgent attempt at activating illness and achieving an ontological-political continuum. Perhaps we should follow philosopher of science Paul Feyerabend’s well-known observation that “anything goes” (Feyerabend, 1993: 14), even pushing and shoving, in order to salvage a matter of concern.

A matter of concern, as a constantly ongoing development of making and unmaking, as well as in deriving from particular events and happenings of significant importance, seems to oscillate between fluidity and fixity, and movement and stasis – in two senses. In the first sense, a matter of concern is enacted between those who want to deem it as “done”, who want to fix it, render it still and transform it into a closed matter of fact. On the other pole are those who want to salvage it, to keep it as such: as a matter of concern.
While the purpose of those who wish to fix a matter of concern is to deem the milieu out of which the given matter emerges as monolithic and unchanging, those who wish to protect it pinpoint, in this same milieu, nodal points prone to modification and change. The fixers seek to reduce, while the protectors seek to connect, enhance and pluralise. In the second sense, the oscillation between fixity and fluidity takes place on the side of the protectors of the matter of concern; this is because, yes, they want to keep the matter of concern alive but, at the same time, they want to say what is of concern: to freeze, fix and “frame” the political gaze to what exactly is of concern at a particular moment and event in time, as well as how this particularity can be addressed.

These, then, are the two motors of a matter of concern: fluidity and positive fixity. Means must then be devised by the protectors of matters of concern; on the one hand, they must develop the capacity to maintain the matter of concern. They must keep stirring the pot, to keep the conversation going. On the other hand they must develop the capacity to attend to what is important, to point the finger and prove that something is of concern; to talk about, mobilise and prove – a matter of concern oscillates between these two poles; it is enacted according to a constant rhetoric but also episodic ruptures; the politics of matters of concern fluctuate between persistence and validation, intentionality but also contingency. This is the relation between perpetual concern and particular concern. The relation of the two is that the perpetual concern must remain as such, perpetual, for the sake of carrying the potency, preserving the ability of accommodating and attending to future particular concerns, creating it anew, again and again. In addition, such perpetual matters of concern must also, at times, be framed in terms and dimensions particular to an episodic event: the breakthrough of a new medical technology, a lack of therapeutic care or medical provision or an incidence of discrimination in the workplace. The maintenance of a matter of concern oscillates between these two modalities, or perhaps
we should say is synthesised in the demand of perpetual particularity. The fourfold of a matter of concern thus unfolds along the axes of ontology-politics and the perpetual-particular.

Fig. 8: The fourfold of a matter of concern

Perpetuating a matter of concern is thus no easy task. Adopting an “affirmative style” (Stengers and Pignarre, 2011; 9), in this chapter perhaps I have given primacy to the potency of certain tactics over the possibility of their failure to deliver anticipated results. Even so, I would maintain that such a form of failure has its benefits. Sometimes the strategies of patient associations might not achieve the anticipated results but they nevertheless succeed in maintaining illness as a matter of concern. A matter of concern should, ideally, never be resolved until all parties involved reach an agreement which satisfies their terms. The resolution of a matter of concern could mean two things. It could mean
that all parties involved in the matter at hand have reached an agreement that satisfies both. But it could very well mean the opposite: it could mean that a so-called “consensus” has been reached by way of one party overpowering the other. It could very well be that consensus acts as a silencing mechanism of oppression (Pignarre and Stengers, 2011: 129). Protecting a matter of concern demands that as long as a collectivity of patients is negatively affected in their everyday lives, and as a long as a matter of concern perseveres in its non-intentional, ontological articulation, then work has to be put in to attain political continuity and leverage, and to maintain the given matter of concern.

Maintaining a matter of concern entails that new issues are constantly being put on the table, that new alliances are being forged, and that new means of collectivisation are being devised, but also revised. Because, as Latour writes elsewhere, “power” is not the starting point but ending point of doing politics (1986). Power is not to be presumed but achieved, and thereafter preserved. In the case of patient associations, achieving and maintaining power entails forging and preserving networks which can be activated in times of need. I find this imperative of devising and revising strategy to be especially important for associations influenced by socio-economic turmoil but also the promise of therapeutic finality by way of technological advancement (see Chapter 5). Perhaps one would not be mistaken in assuming that the extra-pathological space where many chronic illnesses are currently enacted is more activated and uncertain than ever: the imperative to deem this space of pathological enactment as one of perpetual concern, but also to frame what in this space is of concern at particular periods of time, makes itself more urgent than ever before.

Some wider methodological and practical implications are at stake in such a proposition. Although patient associations do not operate in similar socio-cultural and political contexts, it is possible that life-lessons and strategies derived from how illness was politically
activated by certain patient organisations can be used effectively by other ones. Although the context of the PTA certainly differs from the contexts of other PAs around the world, these tactics, as implemented by the PTA, cut through socio-cultural difference and can be implemented elsewhere, as well as otherwise (according to different socio-political actors and circumstance). This is because, such tactics, although enacted according to dimensions specific to the Cypriot context, are also predicated on an element universal to the human condition, namely relationality, and the power and leverage one can derive from correctly managing, organising and deploying one’s relations. Although certain rigid socio-cultural contexts might prevent these relational processes - i.e. tactics - from taking place, I also maintain that the rigidity of the former does not entirely erase the possibility of the latter. Such political and infrastructural rigidity, to a large extent, exactly depends on such tactics not taking place. As Stengers and Pignarre put it, this is not a question of “generality” but, rather, one of “complementarity” (Pignarre and Stengers, 2011: 84). It is not a matter of saying all patient associations are the same and can utilise the same tactics, but rather of identifying, as well as devising, the means by which PAs across differing contexts can inspire, connect to and empower one another. Engaging with specific events of patient activism unveils the tactics which patient associations used to accrue political leverage. Anthropological theorisation of such events and practices provides conceptual foundations which can in return be fed back into the activities of patient organisations and aid them in achieving political relevance. To engage with such matters of concern hence provides an anthropology of relational dexterity and political strategy both on an ethnographic and also conceptual front: an anthropology of tactics but also a tactical anthropology.
Chapter 4: Conferences as events of organisational revision

Conferences are of particular importance to modern biomedicine, yet not enough attention has been given to them in anthropological literature. As Dimond et al. point out, “the conference is an under researched and under theorised space in social studies of biomedicine, particularly when compared to the hospital and laboratory” (2014: 2). This chapter tackles medical conferences as events of integral political gravity for the enactment of illness. More specifically, this chapter goes into further detail of examining the event of the conference as a means of reconciling and fruitfully managing individual difference and collective organisation for patient associations. On an ontological level, difference is a mode of being, and becomes evident through the different relations according to which patients enact and experience illness. Ethnographically, this ontological difference becomes evident through the ways patients talk about, understand, and experience their illness. Those attending medical conferences are embroiled in illness in different yet related ways. Some of them might be patients, others doctors, others politicians and others anthropologists. But even if two or more of these delegates belong in the same “category”, they retain spectres of ontological heterogeneity insofar they “do” illness in different ways (Mol, 2002). Thalassaemia for one patient might be different than for another because it is emergent of different practices and relations which take place in different locales. At the same time, these individuals are part of the same event. In many cases they are part of the same patients’ associations and medical organisations, and fall under the same mechanisms of representation. The conference is thus a site which is preoccupied with the tension between the collective and specific facets of illness.

The main point I make in this chapter is that conferences are deemed positive by specifically recruiting and deploying this tension of individual circumstance and collective association. An event is deemed positive insofar as it manages to activate and navigate rela-
tional oscillations between singular difference and collective essence. While the term *difference* denotes the unique circumstance each patient finds him or herself in, the term *essence* denotes the ideologies, structures and mechanisms of representation according to which large organisational entities operate. The chapter is structured as such: following my ethnographic description of a conference I attended, I begin by making the case that ontological difference is essential and a prerequisite to the event of the conference taking place. I proceed to show how during the event of the conference the oscillation between organisational essence and individual difference is enacted according to a two-step of exclusion and inclusion: On the one hand, individual difference manifests and makes itself apparent so it can disrupt the collective essence of an event - difference thus excludes itself from essence. On the other hand, organisational essence responds to this act of exclusion by acknowledging and including individual difference in its political organisation and collective mechanisms of representation. The rest of the chapter is concerned with the social, relational and material dimensions which must be in place in order for this two-step of exclusion and inclusion to take place. On a social register, the two-step of exclusion and inclusion is facilitated through what, borrowing from French philosophers Gilles Deleuze and Félix Guattari (1987), I call a sociality and organisation of discernibility. On a relational and material register, the oscillation and relation between individual difference and collective essence, inclusion and exclusion, is aided and accompanied by another oscillation which I explore in the final section of the chapter – that between what Edwin Ardener (1989) calls the “free” and “determinist” aspects of space and time.

**The setting**

The 3rd International Conference on Haemoglobinopathies took place in a seaside resort in Limassol. The conference was being organised by the Thalassaemia International Fed-
eration (from now on TIF). Since its inception TIF in 1987 has grown to be an umbrella organisation comprised of over 90 national thalassaemia associations, whose locations stretch from Asia to Europe and the Americas. A cross-fertilisation of knowledge, policy and opinion takes place between these patient associations. The result has been a global in scale organisation which, through events such as this and also through various research initiatives, strives to attend to the needs of thalassaemia patients around the world.

The information pack sent to my email said that the conference was going to take place in the “The Hawaii Grand Resort”, a beachside hotel located in the tourist area of the city. The pack, however, did not say that there was another resort in town simply named “The Grand Resort.” By way of Google maps I made my way to the latter, only to be redirected by the receptionist to the former. Judging by her facial expression some others must have followed the same course that morning. Courtesy of my navigational mishap I arrived at the conference half an hour before the registration table closed for the day.

When I entered the lobby of the resort I saw that the floor was filled with a number of individuals engaged in conversation. This initial commotion took me by surprise, perhaps because of its magnitude, or perhaps because of the contrast between the calm exterior of the building and the deafening echo of the myriad conversations simultaneously taking place inside the large space. The architectural arrangement of the lobby also presented a spectacle; a wide expanse of red, smooth, marble tiles reflected the numerous crystal chandeliers hanging low from the high ceiling. In the middle of the room was a large bed of thick cacti.

I didn’t have much time to observe or explore the setting at the time because I still had to pick up my identification card. Upon reaching the stairwell I noticed a large banner directing me downwards, to the registration area. The banner was adorned with a faded backdrop logo which would recur throughout the duration of my stay at the conference;
it was the logo made specifically for the conference - an orange coloured dove in flight, carrying a bright green olive branch. The parallels with the Cypriot flag were apparent. Next to this was the typical logo of the Thalassaemia International Federation (TIF) - a matte, conical drop of blood containing a white world map with the TIF acronym embedded over it. The two logos were connected by a slogan underneath them: “Knowledge is our Power, Unity is our Strength”. I made my way to the registration table and joined one of the three available queues. When I reached one of the desks the woman in charge seated there greeted me in English:

“Hi, what is your name?”

I provided my name in Greek, which prompted mild surprise from her. “Sorry, I thought you were foreign.”

“That’s alright - it means I blend in. Are most of the attendees from outside?”

“Yes, it is mostly foreigners, but there are quite a lot of locals too.”

Fig. 9: Conference badge of the author.
I picked up my ID card for the duration of the conference. Printed on the card was my name, along with the attendance category to which I registered: “Theodoros Kyriakides, Student”. Student, evidently, did not say much about my purpose, but I hoped that people would take a liking to the causes of an inquiring and aspiring “Student”, whatever those may be. Along with the card I was also provided with a pack containing several other documents pertaining to the conference: a programme of the panels, events and their locations; a booklet outlining the activities, objectives and board members of the TIF; and a CD containing abstracts of the papers that would be given during the conference. There was also some promotional material for the TIF World Congress which would take place the following October in the United Arab Emirates. Finally, amongst other things, the pack included two coconut stuffed dates and a tourist guide to Abu-Dhabi (“Abu-Dhabi is blessed to have two golf courses…”).

I had had the chance to study the programme beforehand, because it was emailed to me after I registered for the conference. The panels were distributed across two days of the conference (there were no talks on the first day), and each would be taking place in one of the three halls provided. When I skimmed the programme for the first time I found it interesting that the panels for each day were sorted into two programmes: a “scientific programme” and a “patients’ programme”. So, for example, on the second day of the conference the scientific programme would include talks on topics such as “the metabolic effects of excess iron and its assessment”, and “optimising treatment and managing complications in pediatric patients”. The patients’ programme would simultaneously unfold, and would address topics such as “Doctor/patient relationships in chronic conditions” and “pain management”. In certain cases, although this proved to be limited, there would be panels that would extend to both programmes (see Figure 10 for a scan of the programme).
According to the programme the opening ceremony for the conference was about to begin. I made my way to what the programme referred to as the “Grand Hall”, the biggest of the three halls of the conference, where the opening ceremony would take place. Making my way to the hall I walked by another image: the two logos - that of the TIF and of the conference - were now resting against a blue background, but the aforementioned slogan was replaced with another one, this time reading “Patients as Equal Partners”. There were three of these posters, each about two metres tall, set on the wall next to the entrance of the Grand Hall. The doors were open and the room was nearly full by the time I got there. The hall was a contrast to the scene I witnessed in the lobby. While it was also crowded, it was neatly arranged in rows of chairs, around fifty of them in length and a dozen in width, while at the front stood an elevated stage where the opening speeches would take place. The backdrop to the stage was a large screen where the two aforementioned logos and a slogan were vividly projected.

I found a spot in one of the back rows, next to two patients. They were locals, conversing in a Cypriot dialect. From the back where I was seated I could see many heads adorned with a headscarf or veil. I could make out all sorts of colours and patterns: Single coloured like black, gold or blue, but also intricate patterns of sage, lily and leopard. Six consecutive speeches took place in the duration of the opening ceremony, made by TIF officials and local politicians. Following the ceremony a welcoming cocktail party was to take place in the courtyard of the resort. I made my way there while talking to the two patients who sat next to me in the ceremony. The two said that they were attending the conference to meet friends and learn what’s new in terms of treatment. I was anticipating that they would ask why I was attending, but before they did we reached the courtyard, which was densely populated, and we got separated. I picked up a glass of red wine and leaned against a nearby column, collecting my thoughts of the day. A scene
25 October – THURSDAY

Scientific programme – Plenary Session
Grand Hall – Hall A

09.00 – 11.00 Session 1: Scientific Overviews

Chairpersons: C. Kattamis & H. Heimpel

Changing the Natural History of Thalassaemia from fatal to chronic – D. Loukopoulos

The metabolic effects of excess iron & its assessment – I. Z. Cabantchik

Genetic/metabolic defects of iron metabolism & rare anaemias – C. Camaschella

Iron Load – A. Maggio

Iron Monitoring & treatment – R. Galanello

11.00 – 11.30 COFFEE BREAK

11.30 – 12.30 Session 2: Cardiology

Opening Statement by Commissioner A. Vassiliou

Chairpersons: R. Galanello & J. Porter

Pathophysiology of cardiovascular disease in rare anaemias – A. Aesopos

Cardiac arrhythmia: the emerging cardiovascular complication – M. Walker

Patients' programme – Plenary Session
Grand Hall – Hall B & Hall C

09.00 – 11.00 Session 1

Chairpersons: P. Englezos & I. Ivanov

Premature ageing of patients with Thalassaemia/Haemoglobin disorders – M. Angustinotto/N. Michaelidou

Bone disease, osteoarthritis and pain – R. Chatterjee/L. Brunetta

Pain management – P. Telfer/S. Beacher

Patient-centred services – F. Shah/C. Radescu

11.30 – 13.00 Session 2

Chairpersons: R. Ellard & A. Apple Michael

Challenges in personal relationships – P. Ellidios

Are rare anaemias a disability? – A. Skafli

Doctor/Patient Relationship in Chronic Conditions – S. Chrestou

12.30 – 14.00 Satellite Symposium

Improving mortality in thalassaemia – What’s behind the progress?
similar to the one I first witnessed in the lobby, when I arrived at the conference, was unfolding before me. It was late September and Cypriot nights were still warm and humid. I went to say hi to Dr. Angastiniotis. As detailed in the first chapter Dr. Angastiniotis is an important figure in the Cypriot thalassaemia scene. He played an important role in setting up the thalassaemia treatment and prevention system back in the late 70s, and nowadays he acts as an advisor for several TIF initiatives and projects. We had met twice before, and had another interview arranged for shortly after the conference. In our previous discussions we briefly touched on the objectives of the TIF and also of events such as these. A snippet from our conversations struck me as especially pertinent at the time. As he had said to me a few weeks before:

The TIF has a historical trajectory which kind of parallels the transformation of patient-doctor relationships from being paternalistic to being a partnership. In the past doctors adopted a godly stance when it came to patients; I say, you obey. We wanted that to change, especially because we are dealing with a chronic illness like thalassaemia. Patients should feel like they have a say in their lifelong treatment, that it is not simply dictated to them. It’s not easy to change this attitude of doctors, especially if they come from countries like Greece, France and England where patient-doctor relations are deeply rooted in paternalism. So that was one of the objectives of the TIF – to bring patients and doctors together to establish a partnership.

Dr. Angastiniotis’s evaluation of patient-doctor relations within the TIF organisational structure resonates with the slogan I saw on the banner: Patients as equal partners.

I went to the wine table to have another glass and brushed shoulders with a woman waiting for the waiter to open a new bottle. I introduced myself and asked where she was
from. She keenly shook my hand and said her name was Anna. We talked a bit, I told her about my research, and she told me she was Albanian, but that she lived and worked elsewhere in Europe. She said that she was one of two thalassaemia patients where she lived (which is why I won’t disclose the actual country). I asked if the other one was around, to which she laughed and replied that she wasn’t, but that she was hanging out with some other people. “We’re all patients”, she informed me. We each got a glass of red and, still conversing, I followed her back to her group which proved to be entirely comprised of patients - a woman and two men, seemingly in their early twenties. I introduced myself. The other woman was also Albanian. One of the men was Bulgarian and the other one Cypriot.

I continued talking to Anna. I asked why she was attending the conference. She said that it was mainly to learn about new treatment methods. She elaborated: due to the low prevalence of thalassaemia in her country of residence, treatment facilities are non-existent. She told me that when there she is treated by an oncologist, apparently the most appropriate of the specialisations at her disposal. “He always tells me I am doing fine”, she tells me. “He is very content with me. I don’t think he really knows much. That’s why I come to these conferences, to learn about new treatment methods because I don’t hear anything back home. But it’s always nice to meet old friends too. It’s nice this time around, the last conference was in Berlin and it was too cold to go out.” When I inquired as to what these new treatment methods might be she told me that the hottest thing around were the new Desferal tablets: “You swallow them and then just excrete the excess iron when you pee, you don’t need to have an injection to take it out of your body.” Thalassaemics have to excrete excess iron from their bodies or else they will suffer from liver failure. This was previously done through some sort of dialysis, but according to Anna these new tablets offer a much more comfortable alternative.
Difference as the essence of the event

Ruth Benedict famously once declared that the goal anthropology should aspire to is “a world made safe for differences” (1967: 15). Benedict’s advice is inspiring in its proposed scope, but also somewhat ambiguous in its articulation. What is this “difference” Benedict speaks of? How, and in what ways are humans different from each other? Moreover, how does such difference influence human interaction and sociality? Perhaps Benedict relates the term difference to the principle of cultural relativism, but my impression is that the given term can also prove anthropologically useful if deployed in an ontological and political register.

While I cannot attend to the entirety of the TIF assemblage, the event of the conference gave me an opportunity to witness in what ways Cypriots (thalassaemia patients, but also medical professionals) are implicated in such organisational settings. The diversity of the topics covered and people attending, put in relation with the specificity of conditions of patients, implies that the conference can be conceptualised as a space where the local meets the global – an important intersection of the particular and the general. The questions at the heart of the chapter are as follows: How does such a large organisational entity like TIF regulate the heterogeneity of its members? How can the diversity of people I encountered in the lobby be justly represented by the banner I saw going down the staircase? How can the event of the conference prove as an occasion of making visible the national and cultural diversity of associations and individuals comprising the TIF, and what is the importance of achieving this visibility?

Coming out of the conference, “difference” was a term I was thinking about as I was trying to deal with the cornucopia of characters I had witnessed and interacted with. Each one of them was, indeed, different: they had their own story to tell, their own way of thinking about things, and their own place in the construction of an ever ongoing assem-
blage that has come to be known as “thalassaemia”. My conversation with Anna kept repeating itself in my head, over and over. She was a “patient” of thalassaemia at the conference much like many others but, at the same time, she was implicated in a unique and one-of-a-kind relational arrangement of her own which, by and large, overflowed the settings of the conference. This was a conference on thalassaemia that we were all similarly attending. However, each one of us was immersed in our own particular circumstances, whether they were an implied lack of treatment and medical advice, a professional obligation or an ethnographic prerogative. We all had our own trajectory, and the plurality of these is what brought us together.

In an important article and sympathetic critique of Actor Network-Theory, Mike Michael and Vicky Singleton direct us to actants which, although partly belonging to a network, also maintain relations outside of it (Singleton and Michael, 1993). Relevantly, Leigh-Star (1993) reminds us that some things remain excluded from a given network, or have to fight for their inclusion. As such theoretical perspectives on sociality remind us, for all their participation in a network, the individuals who comprise such an arrangement largely remain external to it, courtesy of the alliances and relations they maintain outside of it. Such external relations are not to be disregarded as insignificant, since they also serve in granting the network with consistency. Much like a mathematical Venn diagram, the insight offered by Singleton and Michael serves in shifting focus from the overlapping parts of the diagram to the parts which remain distinct and external. To pose this in terms of social inquiry, once we begin to attend to individuals comprising a collective in their own relational terms, including what is external to a given network, the façade of functional coherence and similarity characterising such social congregations begins to give way to a swarm of individual differences.
As Bruno Latour writes, borrowing from Gabriel Tarde’s monadology,14 “When a society is seen from far away it seems to have structural features … but when a society is seen from the inside, it’s made up of differences and of events and all its structural features are provisional amplifications and simplifications of those linkages” (Latour, 2008: 19). How does one, then, look at a society, or any other relational arrangement for that matter - a conference in my case - from the inside? The position of individual, rather than cultural, difference holds a dubious position in anthropological analytics. A common assumption, more so for the non-anthropologist, is that social analysis consists in finding “links” amongst social settings - common points of reference between individuals such as traditions, rituals, beliefs and practices. Such links, in their plurality, constitute what came to be known in anthropology and sociology as a social structure.

Benedict’s advice, however, even in its ambiguity, presents us with an alternate and, in my opinion, even nobler anthropological enterprise: to explicate and promote the mannerisms of a mode of sociality powered by difference, rather than commonality and resemblance. An anthropological project focusing on individual differences would strive to determine how people in a given event, for all their diverging circumstances, relate and interact with each other. More importantly, an inquiry into the plurality of individual circumstances will show whether such circumstantial heterogeneity is attended to by a collective and political arrangement, or whether it is muted through macro-mechanisms of representation. It is unavoidable that whenever we speak our mind we speak in terms of our circumstance. Gianni Vattimo refers to such circumstantial enunciations as individual “dialects” (Vattimo, 1992: 9). According to Vattimo, each one of us has his or her own dialect, courtesy of the unique and inimitable relational arrangement we find ourselves in. As Vattimo writes, our dialect is the result of a “local rationality” (Vattimo, 1992: 9). It is a way of thinking and acting deemed “local” because it is derivative of the territory one
occupies in the world, and the relational multiplicities one entertains amid this territorial milieu - one’s own circumstances. With this in mind, perhaps we should join Byron Good in quoting Ortega and Gasset: “Reality cannot be observed except from the point of view to which each of us has been inescapably assigned in the universe. That reality and this point of view are correlative, and just as reality cannot be invented, so the point of view cannot be feigned either” (Good, 1994: 177).

Lest we succumb to methodological individualism, it is important to acknowledge that individual circumstances are informed from the outside: they are affected, carved and largely sculpted by social norms and cultural values and beliefs. The relation between the individual and the collective directs us to an irreducible tension between the two, whereby neither can fully appropriate the other. As Marshall Sahlins writes, regarding this tension:

> The event (any event) unfolds simultaneously on two levels: as individual action and as collective representation; or better, as the relation between certain life histories and a history that is, over and above this, the existence of societies […] Every reproduction of culture is an alternation, insofar as in action, the categories by which a present world is orchestrated pick some novel empirical content […] every implementation of cultural concepts in an actual world submits the concepts to some determination by the situation. (Sahlins, 1985: 108, 144, 149)

To attend to what Sahlins refers to as “determination by the situation” is to attend to the specificity and particularity of circumstances, and the relation of such circumstances to collective socio-cultural categories and political alliances individuals belong to. It is also important to remember that “a situation” is not merely enacted according to the spatial milieu where the given situation “takes place”. Although situated in a certain location, an individual might entertain relations which, albeit not discernible at a given moment and
place, nevertheless affect his or her standing in the world. Events such as conferences are knots tied by lives led elsewhere; it is the convergence of these “elsewheres” which gives way to the event of the conference. More than being spaces and events of political alignment, conferences are spaces of circumstantial heterogeneity and relational divergence.

Whenever we talk to others, we always talk to them in our own distinct dialect, courtesy of our unique relational arrangement. Moreover our individual dialects do not speak on behalf of, but of our circumstance. That is to say, we are not in complete control of it: insofar as the term circumstance designates a subjective state emergent of a plurality of interacting entities - affective processes of the active but also passive kind - a subject is not only one of many, but also one amongst many. Anna was entangled, even as we spoke in the courtyard of a beach resort in Cyprus, in her own circumstance which was like no other. She might have been a thalassaemic, like many others around her, but such a widespread similarity did not attend to her own personal situation. What differentiated Anna from all the other thalassaemia patients was the multiplicity of relations she entertained: her home back in her country, her lack of treatment and medical advice, her friends, and so on. As Marilyn Strathern writes, “Insofar as relationships are the condition of persons in communications with one another, we could say that relationships create persons in not-quite similar states to one another” (Strathern, 2006: xiii).

This “not quite similar state” of Anna’s was not entirely laid out for me to grasp and, in fact, it evaded not only my spatial settings and sensorial experience but also hers. Her home back in her country was not present at the time of our conversation, but Anna was undeniably related to it. We were both situated in the very same courtyard but, at the same time, our circumstances were very different. When I spoke to her, Anna responded to me about her circumstances in her own dialect, some sort of “Anna-ese”: she was one of the two thalassaemics in her country, she wasn’t happy with the treatment and advice
she received from her doctor, and she was seeking new technologies and methods to attend to her condition. In other words, Anna’s relation to me, and to the site of the conference, was “partial” (Strathern, 1991). I could somewhat comprehend what Anna was saying to me, and what her problems and predicaments were, but I could neither fully understand nor entirely relate to her condition. I cannot speak for her. I cannot fill her shoes. To not be able to speak for them and to not be able to fill their shoes; to showcase, instead, the specificity but also social implication of their circumstances: One could say that such an ethnographic disposition is one which takes our informants seriously (Edwards, 2002; Candea, 2012).

Nevertheless, unlike Vattimo’s post-modernist school of thought, and the anthropological strand inspired by it (e.g. Clifford and Marcus, 1986; Abu-Lughod, 1991; Gupta and Ferguson, 1992), my purpose here is not to deconstruct and dissolve the event’s political essence into an undifferentiated magma of individual difference, and neither was this the objective of the people attending the conference. Rather, as Papadopoulos puts it, “it is an attempt to preserve the specificity of scientific knowledge production while also opening it up to contributors who had not been acknowledged previously” (Papadopoulos, 2010: 181). Thus it is this political and organisational essence that I, and also those participating in events such as conferences, want to further affirm. As shown in chapter 3, such organisational essence allows thalassaeamia patients to amass and deploy political momentum at times of need. Although in this chapter I emphasise the inner workings of the thalassaeamia political scene, the previous chapters make apparent the large network of institutions which thalassaeamia patient associations must deal with on a regular basis. It is crucial for thalassaeamia patients to maintain such organisational essence since it grants them political leverage when dealing with these other institutions such as national states and scientific bodies.
Paradoxically, in order to affirm such an essence, one must first disrupt it, not in order to destroy it, but to redraft it anew. In order for this organisational essence to maintain its political potency, it must keep being revised from the inside out and stay attuned to technological, social and political changes. In the next section I make the case that, in conferences, this task of maintaining, revising and updating an organisational essence is achieved through occasions of dissensus. Such occasions of conflict facilitate a two-step of exclusion and inclusion of individual circumstances, through which patients inadequately represented by collective organisational parameters disrupt these in order to revise and update them. In this respect, conferences are events of essential difference, since they stem from it, and also of differentiated essence; conferences are technologies of inciting and articulating the multiplicity of difference from which an organisation emerged and persists, which largely remain external to the conference. Furthermore, conferences recruit such multiplicity in processes of collective recombination and representation, thus recreating both, illness and politics, anew.

An occasion of dissensus

On the second day of the conference I attended a panel presenting the findings of ENERCA (European Network for Rare and Congenital Anaemias). ENERCA, a cluster research centre of TIF, is a ten-year research programme aimed at setting up and evaluating what are called “expert centres” around Europe in order to treat local cases of rare forms of anaemia. The goal of the programme was not only to set up such centres, but also to compile a list of parameters and requirements which, if attended to, would delineate the status of such centres as “expert”. Following the conference, the research results would be penned down in what was constantly referred to in the conference as the “White Book” – a guide detailing the operation such expert centres would have, the technologies
that they would offer to the public and the staff that they would be comprised. The book would provide a guideline for the operation of these centres across Europe, as well as a checklist for evaluation and inspection.

The last speaker in the ENERCA panel was the aforementioned Dr. Angastiniotis. In his twenty-minute speech he presented, along with many slides, the goals and results of the ten-year ENERCA initiative thus far. Perhaps anticipating the end of the long project, Dr. Angastiniotis’ speech conveyed a certain disposition of finality and closure. A telos seemed to be looming ahead. When all speakers were finished fifteen minutes was allocated for discussion and questions. As soon as the moderator opened the floor to questions, several spectators, including a woman sitting in my row, exuberantly threw up their hands. When her turn came to talk, she stood up and dived into what appeared to be a well prepared and formulated rhetoric. She, Hannah, was a lawyer residing in the Netherlands. In her speech Hannah conveyed the need for a better definition of the term “expertise”. According to Hannah, the so called ENERCA “expert centres” in her home country of the Netherlands not only lacked the appropriate technology to counter the rare forms of anaemia the ENERCA initiative is aimed at, but it also lacked appropriate staff. In other words, in her opinion, expert centres in the Netherlands lacked both expert technology and expert staff.

Hannah’s points raised certain issues, at least to my mind. Firstly, are the parameters set by ENERCA in terms of staffing and equipment adequate to qualify a clinic as an expert centre? In other words, are expert centres, courtesy of their ideal array of staff and technology, justified to be called as such, even if they upkeep the criteria set? And, secondly, even if on paper the parameters set by ENERCA were adequate, was there some sort of audit procedure to determine that the clinics that on paper qualified as expert centres did indeed attend to these parameters? Dr. Angastiniotis attentively listened to her the whole
time. When his turn came to reply, he started by saying, “Yes, I hear what you are saying, and I know that you are a fighter.” This characterisation, of a fighter, caused widespread laughter in the audience, and from this I gathered that the woman in question was actively involved in the ENERCA initiative, and that she must have previously stirred up controversy. “I assure you,” Dr. Angastiniotis finished, “that all your considerations will be included in the writing up of the White Book.” The woman seemed pleased with this treatment and, before she sat down, offered an olive branch to Dr. Angastiniotis by replying that she was very much looking forward to the publication of the report.¹⁵

When I met up with Dr. Angastiniotis, about a week after the conference, he confirmed that the woman in question was indeed very actively involved in the ENERCA initiative. “She is a fighter,” Dr. Angastiniotis reiterated. Dr. Angastiniotis also informed me that the given person is an “expert patient”. The expert patient scheme was initiated in order to better inform patients in medical but also administrative aspects of the TIF network. The premise was that a handful of selected patients were to be recruited by TIF and educated in important matters pertaining to treatment and prevention of forms of anaemia, as well as how the TIF network was organised and operated, what facilities and services it offered in terms of treatment and prevention of forms of anaemia, and how patients could better make use of such facilities and services. The plan, Dr. Angastiniotis concurred, was that expert patients would act as mediators - a kind of ambassador of sorts - between medical practitioners, administrative staff and patients.¹⁶

What are we to make of this aforementioned event of dissensus within the ranks of ENERCA and the TIF? An outsider to TIF’s organisational structure might interpret the event in two ways. On the one hand, the given event attests to the organisational dynamics of the TIF conference which allow for moments such as these to arise. On the other hand, events such as these are also indicative of the spatial, temporal and semiotic hierar-
chies permeating the given conference. In short, one can perceive the given occasion as attesting to the circumstantial heterogeneity which permeates conferences, as well as how this heterogeneity often conflicts with collective, organisational parameters of representation and operation. To me, this given event of dissensus was indicative of the importance of the conference as an event: namely, that since an event is emergent of circumstantial heterogeneity, it must provide the opportunities for such heterogeneity to rise to the surface and provoke though moments of dissensus – insofar as dissensus does not entail the destruction of an organisational essence but its revision. In the next two sections of the chapter I further pursue this theoretical trail of thought. If the task and importance of the conference as an event is to justly attend to the circumstantial heterogeneity of its composition, then the question is, what arrangements – of sociality, relationality and materiality – must be in place in order for such a task to be achieved?

Exclusion and inclusion of difference as a sociality of discernibility

What Isabelle Stengers refers to as a cosmopolitical mode of sociality demands that individual circumstances are not overlooked, and that mediums and channels are provided for individuals to render their unique circumstances visible to their peers. Such channels are of integral importance when several individuals have a stake in a mutual cause and project. As Stengers writes:

"The stakeholders, those who have an interest in a new enterprise binding them together, should not be limited by anything external. The common world must be free to emerge from the multiplicity of their disparate links, and the only reason for that emergence is the spokes that they constitute in one another’s wheels. (Stengers, 2005: 999)"
For Stengers, the term “cosmos”, in “cosmopolitics” implies that such a modality of politics is not enacted according to rigid ideological devices of representation, but according to the heterogeneity and urgency of cosmic circumstance. A cosmopolitical setting thus involves accommodating the plurality of relational circumstances from which it is emergent of, and not by separating such circumstances from each other, but by putting them at work together on a common cause. Cosmopolitical settings do not require a connecting link to operate, but instead thrive on the juxtaposition and intensification of the diverging circumstances of the parts out which they emerge. They do not flatten the specificity of the myriad conditions of which they are comprised but strive, through some sort of paradoxical manner, to accommodate and nurture these in their particularity and, at the same time, mutuality.

I suggest that such a form of doing politics is driven by what Deleuze and Guattari would call a sociality and an ethic of discernibility. As the two write, “A fuzzy aggregate, a synthesis of disparate elements, is defined only by a degree of consistency that makes it possible to distinguish the disparate elements constituting that aggregate (discernibility)” (Deleuze and Guattari, 1987: 344, emphasis in original). A sociality of discernibility seeks to define, clarify and render visible the circumstantial heterogeneity by which a collective is composed and enacted, as well as acknowledge the mutual attachments and projects amid such heterogeneity. An ethical and practical mannerism of orientating one’s self in the world is implied here: Deleuze and Guattari demand that the term “discernibility” remains an ethical, rather than ontological, concept. Circumstances might remain ontologically distinct from each other, but whether one discerns, addresses and attends to these distinctions is an entirely different, ethical, social and political question and challenge. A congregation of individuals will always present ontological heterogeneity, but a sociality of discernibility demands that such circumstantial heterogeneity is translated to organisational, ethical and political terms.
Thus, as Deleuze and Guattari write, “To attain the multiple, one must a have a method which effectively constructs it” (1987: 22). Or, as Bergson would have it, “It’s not enough to shout ‘Vive the multiple!’; the multiple has to be done” (Puig de la Bellacasa, 2012: 199). Similarly, as Annemarie Mol writes, “Attending to the multiplicity of reality is also an act. It is something that may be done — or left undone. It is an intervention” (2002: 6). More than an ontological reality, a sociality of discernibility is a practice, intentionally and consciously enacted. Such practice demands that one not only attends to (discerns) the circumstances of others, but also that one makes one’s own - usually problematic - circumstances discernible to others. One must adopt an intentional stance in enacting this sociality of discernibility. A certain fighting spirit and vigilance, akin to that of Hannah, is sometimes required for one’s self to become discernible.

In order to become discernible to others, one has to exclude one’s self from a certain organisational arrangement in order to denote how he or she currently bears a problematic relation to it. Becoming discernible in the eyes of others demands standing out, and standing out demands standing up - literally - much like Hannah who stood up and challenged the definition of expert centres provided by the ENERCA initiative. In no other cases is the irreducibility of personal circumstance more apparent to the ethnographer than in such examples of deliberative dissensus. Standing up and voicing your opinion is a process by which you intensify the particularity and specificity of your circumstance in the eyes of others by disrupting and excluding yourself from a certain superficial facade of similarity and resemblance. For Bruno Latour, every narrative - every “script” - provides the field of possibility by which an organisation operates: its objectives, structures, and future trajectories. Yet, as Latour goes on to say, every single part of an organisation, however small its position in an organisational hierarchy, must be provided the opportunity to have a say in how a script is written and also re-written through time. As he
writes, the feeling of “smallness” one has in an organisation “depends crucially on the number of opportunities one has to revise the script” (Latour, 2013: 420). Or, as Strathern puts it, “If one can ask ‘big’ questions on ‘small’ data, then the difference between big and small disappears” (Strathern, 1991: xx).

In the case of Hannah, revising the script - becoming discernible, asking big questions - demanded that she present the specificity of her circumstance to the collectivity of individuals making up the ENERCA initiative. As she said, in her home country of the Netherlands, the expert centres provided by ENERCA did not provide adequate treatment in terms of professional and technological expertise. Even though most individuals in that conference room were similarly implicated in the ENERCA initiative, such similarity does not attest to the particularity of their condition. As with Hannah’s case, standing up and making one’s circumstance discernible in the eyes of others is an act by which you affirm your very own relational standing in the world, as well as the the partial understanding and relation others have to this – an occasion whereby “persons grow and establish themselves through separating themselves from others” (Strathern, 2011: 125). It is an act which serves in distancing you from others by affirming your circumstantial specificity, but, at the same time, it is an act by which one attempts to further connect to others courtesy of such specificity.

Yet, as Stengers writes, “Affirming closeness, in this sense, is not the same as affirming similarity” (Stengers, 2011: 58). To become discernible is a “paradox”: it is “an attempt to render oneself visible in social or political processes according to someone else's framework which simultaneously ‘excludes’ and ‘includes’ one from a socio-cultural framework” (Dixon and Peachey, 2012: 2). It is here, according to the opportunity to inform collective processes of politicisation and deliberation from one’s own unique relational standpoint and perspective, that organisational essence is revised. By challenging the pre-
sent definition of expertise, Hannah excluded herself from the collective, organisational essence of the event of ENERCA and the TIF. The two-step was complete when Dr. Angastiniotis accepted Hannah’s input and included it in the publication of the White Book. Here, the importance of both individual circumstances and macro-mechanisms of representation becomes evident: an event and organisational setting has to encourage and provide the means for individual circumstances to become discernible, and it must also bear the political technologies and common projects to collectively receive these through occasions of dissensus. Events operating under such parameters could be understood as working in the middle. As Casper Bruun Jensen writes, under such circumstances “productivity would be created at the middle ground, where no position would be able to silences any other, rather than made to disappear either by force or by consensus” (Jensen, 2005b: 231).

It could be confused that a sociality of discernibility advocates in favour of circumstantial equality - that is to say, that all individual circumstances should be treated in an equal manner. One could refer to the array of posters I saw while making my way around the conference: “Patients as Equal Partners”. This, however, is a misunderstanding of equality; a sociality of discernibility does not operate according to a principle of circumstantial equality. Rather, it operates according to a principle of what Stengers refers to as “immanent discrimination” (Stengers, 2008: 58). If an ethic of equality permeates a sociality of discernibility it is one which dictates that all circumstances should be equally discernible in their heterogeneity, or that they are equally allowed to become so should they wish to. Insofar as “discrimination” implies treating someone or something differently, it constitutes the very essence of a sociality of discernibility. Stengers’ immanent treatment of discrimination, however, inverts its colloquial definition, which proceeds by transcendent imperatives such as race, gender and religion, and instead attends to the particularity and
worldly conditions of individual circumstances. According to a sociality of discernibility, discrimination does not proceed through a comparison of what one is or is not in relation to others, but instead affirms the difference of a given circumstance and addresses it in itself: “Identity is established in relation to differences that have become socially recognised” (Gottweis, 1995: 127).

It is important not to confuse discernibility with equality. In this case, not only are the two not the same, they are also mutually exclusive. Amid a cosmopolitical setting, you cannot have discernibility if you proceed by way of equality (equality flattens the specificity of individual circumstance and deems the plurality of these circumstances as non-discernible) and, vice versa, you cannot have equality if you proceed by way of discernibility (insofar as discernibility demands addressing circumstances in their heterogeneous and thus non-equal relational states). Hence, insofar as a sociality of discernibility positively discriminates in favour of individual circumstances by treating them in their own terms, it positions a principle of equality as unobtainable and even not desirable. Through my implication in the conference, my interpretation of the phrase “equal partners” which I saw on the banner is not that patients and doctors alike are treated equally, but that all have an equal say in deliberative processes of policy and knowledge making. That is to say, they are all equally provided with the opportunity and technologies to make their circumstance discernible in favour of informing a mutual project.

Such are the dynamics of the event as a field of inclusion and dissensus: the positive event does not simply include what was previously excluded. Unconditional inclusion as equality erases and flattens individual circumstances. Rather, through a sociality and a politics of discernibility, an organisational field expands by that which previously evaded it and through that which contested it – it grows through what Deleuze and Guattari would call its lines of flight (Deleuze and Guattari: 1987). Cosmopolitics thrive on multi-
plicity and feed on complexity; their purpose is to proliferate the space of possibility of encounter and action of a given event, rather than restrain them to a predetermined trajectory. As aforementioned, the ability of space to incite multiplicity does not come readymade. If conferences and, more broadly, organisational structures such as TIF’s, can intentionally provoke multiplicity and render the diverging circumstances of those attending discernible, then of concern is through which mechanisms can this task be achieved?

In the next and final section of the chapter, I further conceptualise the technologies and relational arrangements by which an event can be pre-emptively designed with a positive purpose in mind – that is to say, with the purpose of seeking to provoke dissensus and revise organisational essence.

**Relational architecture as amalgamations of free and determinist dimensions of the event**

In anthropological literature little has been written on the dynamics of space by which an event is deemed politically meaningful. While some have done well in documenting and deploying the creative potency of the event, the dimensions and arrangement of space - material and immaterial, human and non-human - by which such outcomes are procured is a topic which demands further inquiry (relevantly see Welsh et al., 2007; Schillmeier, 2011; Kerr et al., 2007; Davies, 2011). This lack of literature pertaining to the creative potential of the setting of the event, rather than the event itself, can perhaps be attributed to a widespread philosophical conceptualisation of the event as a moment of rupture and contingency. Insofar as it is perceived as such, one fails to account for the creative potential of the event in its arguably more useful programmatic, arranged modality. Following Roy Wagner we will say: “The reflexivity between the apparent randomness of ‘event or ‘happening’ and the choice that is made in noticing it or expecting it runs like a crack through the mirror of mind and all it might disclose” (Wagner, 2001: 248). Thus, rather
than perceiving it as a moment of exceptional rupture, I argue that the conference as a political technology can be creative, but also frequent, programmatic, and traditionally political in its orientation and purpose.

In this final section of the chapter I examine the setting of the event through the analytical lens of perhaps the only anthropologically conceptual strand which preoccupies itself with the relational architecture of space and event, that of Edwin Ardener and his theory of world-structures. Ardener calls the compounds of time, space and language “world structures”. As he writes, “World-structures are located in physical space, and in real aggregates of human beings. It should not be surprising that the extension of physical space, and of the experience of those beings, produces a genuine extension of the structure, with all its co-ordinates in language and thought” (1989: 145). World structures are thus not simply contained by physical space. Rather, they are the result of the amalgamation and interaction of a physical site with other intellectual, relational and symbolic aspects of human sociality. For Ardener, the relations between individual persons and world-structures are always in a state of ambiguous equivocation and always maintain transformative potential.

What concerns Ardener is how such world-structures can be altered through the actions of certain individuals. Ardener acknowledges the ability of individuals to alter world-structures through their will and strategic disposition. As he makes clear, “The world is a construct which is dependent upon the coherent and coordinated defining powers of individuals” (1989: 154). The capacity of individuals to adopt a strategic disposition and vigilance, and to become aware of the world-structure’s nodal points which are prone to change and alteration, rather than simply re-enacting them, is what leads to alteration and transformation. Like this chapter, Ardener also conceptualises such transformative occasions as ones of initial exclusion or “stepping out”, to use his term. As he writes, “Indi-
iduals experience, and can generally only express what their world-structure registers, yet individuals can, as it were, ‘step out’ of the structure under certain conditions [and achieve] a partial separation from the structure as expressed in dominant ideas, praxis and language” (1989: 148). Events of “stepping out”, of excluding yourself, as it were, is what Ardener calls “prophetic moments” (1989: 152).

Yet, we must be careful to note that Ardener does not adopt a naive stance of idealism and social constructionism. To clarify, the event of stepping out does not constitute an event of creative freedom, but rather of struggle and possibility. As he acknowledges in the aforementioned passage, individuals can only change world structures under certain “conditions”. The problem is that the prophetic act can sometimes go unnoticed by the structure. It might be the case that even if one manages to partially separate – to exclude him or herself from the structure – one is not granted the necessary tools to facilitate an inclusion into the structure. In such cases, rather than becoming a prophet, one becomes an outcast. Thus, as Ardener writes, “There remains for such individuals the problem of the expression of their own experience in a suitable language.” He goes on to pose a problem: “If the space defines, it also redefines. What kind of space is required to generate the kind of transformation symptoms we have discussed?” (1989: 149).

How can a space promote and provoke “prophetic moments”? As Gilles Deleuze relevantly writes, “space enjoys potentiality as long as it makes the realisation of events possible” (1995: 10). If, as I have discussed above, individual difference is the essence of the event, and if dissensus is the essence of transformation, what kind of space can allow individuals to partially step out – to exclude themselves from structures and collective associations to which they belong - not in order to abandon them, but to update them through their own experience? A space must provide both the tools for individuals to step out, and also the tools to inform collective parameters (or, as Ardener would have it,
the ability to express themselves in a language understood by all in the structure). I understand the occasion of dissensus as one Ardener would describe as prophetic. Dissensus is accomplished through correct management and deployment by individuals of what Ardener elsewhere calls the “free” and “determinist” aspects of an event (Ardener, 1989: 134). Although Ardener does not elaborate these two terms, I have recruited them for my own analytical purpose: if free aspects of a world-structure allow individuals to move and act more freely, then determinist aspects serve in regulating individual actions according to predetermined structural, linguistic, symbolic and socio-cultural dimensions. Rather than assuming that free dimensions of space allow for unconstrained sociality, whereas determinist ones constrain sociality, it is best to think of the two as enabling and restraining in different yet related ways. Because, on the one hand, free space presents the aforementioned problem of expression, while determined space presents the problem of meaning. It is exactly the relations and oscillations between these two modalities of space and time which allow for both problems to be resolved.

Thus, on the one hand, fluid, free dimensions of space allow one to step out of one’s structural inheritance and transform it through updating it with a perspective which was previously unaccounted for. On the other hand, determinist aspects of the event recruit and include such individual circumstances in collective arrangements by tying them to slots of meaning, hierarchy and terminology. One can assert that here the term “deterministic” does not imply a hegemonic act of subverting one’s agency. Rather, to determine in this case is an act of acknowledgement and granting of meaning, where one’s individual circumstance is granted collective meaning and purpose. Should an event be altogether comprised of free, individualistic dimensions, it would dissipate amid particularity and difference. On the other hand, determinist aspects, akin to “floating signifiers” (Lévi-Strauss, 1987: 63), circulate in an event and, gather, and attach collective meaning
to otherwise alien acts of enunciation. Compounds between such free and determinist aspects provide the contours of possibility - an architecture of relationality, symbolism and temporality - capable of opening up pathways by which positive interactions of dissensus can manifest.

The conference I attended was enacted according to such frequent oscillations of free and determinist dimensions: The lobby and wine reception, but also the opening ceremonies and the panels. While the first two settings provided a free-flowing, unconstrained sociality of mingling, the latter two settings proceeded through a rigid structuration of temporal and spatial dimensions - the arranged rows of chairs, but also the specificity of the time allocated to the speeches and presenters. Yet, these two types of enactment are not to be thought of as antithetic, but complementary and supplementary to each other. It is exactly the to and fro movements between free and determinist dimensions of events which allow for a connection between individual difference and collective association to be established. To return to the occasion of dissensus provoked by Hannah, the rigid temporal segregation of the panels, in relation to the time allocated to discussion, opened up a space of possibility of fluid dimensions where anything could be said. The consistency and structuration of programmatic time (the panel) permeated by the unpredictable potential of deliberation is what allowed Hannah to engage in a two-step of exclusion and inclusion - of excluding herself from collective arrangements in order to disrupt, update and rejoin them. The amalgamation of such free and determinist dimensions of space and time provided the contours of possibility for this two-step to be facilitated.

I would like to also return to the programme of the conference, which was divided into two halves of patients and doctors. Although this could be initially perceived as a form of segregating medical knowledge from patient knowledge - and thus reinforcing a gap of
inequality and knowledge production between the two - another interpretation would be that the two programmatic strands acted as a form of immanent discrimination, to once again refer to Stengers’ term. The two strands were more attentive to the specificity of individual circumstance. If a common programme had been provided, under the guise of equality, the specificity of individual circumstance would have been flattened. Hence, the organisation of the conference did not involve dissolving the patient/doctor distinction - of making the two equal - but instead it rather intensified the distinction because the circumstances of doctors and patients, although co-implicated, greatly differ. In such a case of patients and medical practitioners, the intensification of a distinction does not entail putting the two terms in opposition. Rather, the intensification of a distinction (doctors/patients in this case) leads to a productive juxtaposition. A distinction by way of juxtaposition serves to render the terms distinct but co-existent, and places them in relations of a symbiotic agreement whereby “a contradiction (either/or) has been turned into a contrast (and, and)” (Stengers, 2005b: 193). A “partnership”, to once again allude to one of the slogans of the conference, does not demand that the individuals comprising such an agreement are synthesised into a singular, functional whole. On the contrary, a partnership demands the intensification of differences, but also the co-existence of its comprising participants. A partnership - a proper partnership - does not result in a synthesis or a whole, but a mosaic of related, distinct and discernible parts.

Finally, one must also mention the array of imagery present at the conference: symbols like the logo of the droplet of blood, categories such as “patient” and “student” included on name cards, slogans such as “patients as equal partners” and “unity is our strength” - these elements provided an architecture of symbolism, a common language if you will, by which individual circumstance could grasp on and be included in collective arrangements. We can conceptualise such symbolic totems as “boundary objects” (Leigh-Star and
Griesemer, 1989) which unite and hold together otherwise individual and disparate circumstances and political objectives. By deploying such a collective language, the delegates participating in a conference can communicate their personal circumstances in terms understood by all. Relevant to such collectively understood enunciations are also common endeavours and projects, such as that of the White Book. More than just a name, the White Book as a common process and project brings together a collectivity of individual circumstances under an umbrella of organisational agendas and political objectives. The importance of such organisational language to events and also transnational associations such as the TIF cannot be understated. To return to Ardener’s theory, the individuals comprising an organisation must be provided with the appropriate means - with a “suitable language” (Ardener, 1989: 148) - of politically communicating with the collective which they belong to (we can even go so far as to say the formation of the collective requires such collectively understood acts of enunciation.) The danger, should such language not be provided, is that all those whose lives are permeated by suffering and political negligence are “shut up within the unspeakable” (Favret-Saada, 1980: 89) - that is, that they are not provided with a common set of tools by which they can become discernible and understood by all those whom they wish to rejoin.

The conference as experiment

This chapter has several yet related objectives. On an ethnographic register, I attempted to convey the conference as an event of importance political activity for patient associations. Conferences, as a site of organisational evaluation and revision for patient collectives, have the potential of making discernible the plurality of circumstances which patients face in disparate locations, as well as the capacity to reconcile such multiple circumstances under common parameters of representation and practice. In such sense, confer-
ences, more than events of mutuality and similarity, are events driven by difference. They are events which stem from a multiplicity of circumstances and worldly arrangements, as well as the need by all those involved to meet and deliberate over these diverging conditions. Secondly, I argued that examination and re-articulation of existing organisational parameters is the purpose of the conference, and that such tasks take place according to a two-step of exclusion and inclusion, whereby individual difference excludes itself from collective essence, only for the latter to further differentiate itself by including the former. Since such events of exclusion and inclusion are events of dissensus, I finally argued that a relational architecture of symbolism, spatiality and time must be in place in order to facilitate such events to take place. In this respect, the event provides the language to both upset collective essence, but also to inform it.

The proposition and conceptualisation of the event as artificial and constructed and as potentially tactical in its purpose is an important claim in the chapter, one which I believe fruitfully supplements previous philosophical and political perceptions of the event as contingent to the locale of its enactment (Badiou, 2006; Humphrey, 2008; Lynteris, 2014). This is why I perceive the event of the conference as more of an experiment than a rupture, since, unlike the latter, the former can be constructed and set up (one can make the case that a rupture can be provoked and anticipated, but I maintain that intentionality is much more evident in the case of an experiment). Nevertheless, the notion of the experiment here goes against the perception which sees its purpose as confined to verifying anticipated results. Rather, the conference as experiment deems itself useful insofar as it produces and evokes unanticipated results. To put it another way, the event should be arranged and enacted in anticipation of dissensus, rather than the validation and affirmation of already existing dominant perceptions and practices within an organisational field.
The suggestion that an experiment should produce unexpected results is one which has been advocated by several philosophers of science for a long time now. Thus, as Feyerabend writes, “A research programme is said to progress if the sequence of theories leads to novel predictions” (2006: 363). Hajer and Gomart relevantly write, “The good experimental setting, and perhaps, by extrapolation, the political form, is not one which is neutral but one which deforms, constrains and enables in interesting ways … Good experiments are those where surprise occurs” (2003: 39). The notion of the arranged event as experiment is anchored on such meditations: “What does a setting (practice, form) do to those who are engaged in it?” (2003: 41). Such trails of thought can be transposed onto the fabric of the politics of illness and the taking place of events such as conferences. Insofar as scientific knowledge is the result of experimentation, the set up of the given experimental apparatus is of integral importance. Likewise, if conferences are places where illness and the dimensions of its enactment come to be contested and negotiated, then of integral importance is the relational architecture by which such events take place. Much like how a good experimental set up is one which aims to generate surprise, conferences should similarly proceed through such objectives; they must be designed with the purpose of encouraging individual difference to rise to the surface and to disrupt collective essence, not in order to deem such essences defunct, but in order to reconsider them and construct them anew. Conferences should be “events in which uncertainty locally emerges as a shared concern for partners in an interaction” (Bérthome et al., 2011).

The task of justly designing events becomes more urgent if we consider that the temporal and spatial dimensions of events such as conferences are constructed by a select few. With this in mind, those who participate in events must maintain a certain stance of awareness as to the potentially insidious nature of such settings. Not all events are meant to incite multiplicity. Some are meant and designed to restrain it. For example, Luigi
Pelizzoni (2003) writes of spaces and events organised according to a “top-down” mannerism by an elite who, through managing the space of possibility and action, set up a sterile space which silences and prevents attempts at dissensus. Similarly, Mike Michael writes of organisational events which, though “formalised mechanisms of voicing” (Michael, 2012: 530), seek a consensus at the expense of that which such mechanisms cannot articulate, and those not included in the given consensual agreement. As Schillmeier relevantly warns, “Cosmopolitical events become problematic and dangerous matters of facts if their effects 1) do not multiply but restrict, exclude or endanger relevant actors and 2) constrain or erase the possibility of alternative politics of imagination” (2011: 520).

If the chapter manages to provide a refreshed understanding and perspective of the notion of the event, I hope that it manages to do the same with the notion of difference - a notion which has long be secluded in the annals of metaphysical discourse. Difference, as I show here, is ethnographically accessible and does not simply operate in an abstract metaphysical register, but rather makes itself evident through concrete events and happenings. Thus, as Steve Epstein writes, “The inclusion-and-difference paradigm is no abstract idea; it is undergirded by an infrastructure of procedural standards, encoded in regulations, and enforced and overseen by new bureaucratic offices” (Epstein, 2010: 14).

This is an important point to consider because, although difference might be an ontological and metaphysical given, whether such difference is politically recognised is up to the organisational, infrastructural and material dimensions of a social field. Insofar as events such as conferences are programmatic in their manifestation, they can be intentionally constructed, rather than unintentionally received. Such a proposition entails that one examines the ways in which events such as conferences as constructed, as well as the objectives of such acts of construction – because, if event such as these can serve in revising
the organisational essence of PAs, they can also fossilise it, thus deeming such essence insensitive to the processual character of the illness which it is meant to address.
Chapter 5: Imagination, hope and uncertainty as techno-collective ethics

When I first contacted him, Dr. V replied by saying that he was too busy to talk at that moment and that I should call back later. He seemed to have got the impression that I wanted to talk over the phone. I tried explaining that this was not a phone interview, and that I was just looking to arrange a time and day when I could pop down and talk, but he would have none of it. “Call me tomorrow, I’m in the middle of something right now.” It was a Friday so he’d be gone for the weekend.

When I called him Monday V. picked up the phone and shouted “Yes!” into the phone, more of an exclamation than a question.

I tried triggering his memory. “I am writing about thalassaemia in Cyprus, I’m an anthropologist, I called you Friday to-“

“I’m in the middle of an experiment, call back later!” He hung up.

I called V. again, after about two minutes had passed.

I still do not know how he figured out it was me calling him again – my guess is he doesn’t get many calls on that number, or maybe it was the case the he was talking to no one in particular and everyone at the same time - but before I could say anything he picked up, and carefully, word by word, articulated “What part of ‘I’m in the middle of an experiment’ don’t you understand?” and hung up again.

There is something to be said about the vigour by which natural scientists approach their work. Unlike social scientists, conceptual labour and knowledge production takes place with respect to an interactive other – the particle, the neutron, the gene - the experi-
mental apparatus, whatever that might be. On the other hand, anthropology entails doing fieldwork, but ultimately demands a sort of conceptual labour which takes place in the researcher’s mind. This is a much more solitary and intimate kind of labour and knowledge production. You do fieldwork, and you talk to people. But ultimately, if the concept or idea you are working on does not acquire consistency, if it does not stand on its own two legs, it’s your fault. Ironically, for the social scientist, work is an undeserving-ly ascetic task. On the other hand, for the natural scientist, the laboratory - a space which has acquired dimensions of an esoteric, cult-like status - carries immense interaction.

He was conducting an experiment. What about my experiment? I reaffirmed his urgency, and also mine.

I finished the coffee and called again.

Imagination and anthropology

Marx famously stated that what separates humans from animals is the capacity to imagine: to “raise structures in imagination before erecting them in reality” (Marx 1978: 174). Despite Marx’s sweeping proclamation, imagination is a relatively new topic of anthropological inquiry. I agree with Vincent Crapanzano that until recently the concept of imagination had been largely left unexplored in the field of anthropology, or at least, as he makes clear, “Anthropologists have been less concerned with imaginative processes than with the product of imagination” (Crapanzano, 2004: 1). Anthropology has a certain preoccupation with the historical, rather than the potential – the historical not only as a heuristic device, but also as an ethnographic object to be documented. One can gather this much from Sahlin’s statement in his Islands of History: “Culture is precisely the organisation of the current situation in terms of a past” (Sahlins, 1985: 155).
Crapanzano does an eloquent job of producing concepts of imagination, hope and desire, which are connected yet ultimately different from each other. I do not have the objective to do so, nor the luxury of time and space, so in this chapter I will be using these terms as interchangeable: imagination, hope, expectation and desire. At the same time, I use each of these terms because, like Crapanzano, I recognise the connotative differences they contain. I justify my decision to group all of these concepts together because they all have the common capacity to activate. To put it another way, whether it is desire, imagination, expectation or hope (or even pessimism or disappointment), these are affective and emotive processes which similarly trigger, or diminish, one’s will to act in the world.

In his introduction Crapanzano writes that he intentionally focuses inquiry on an individual level. As he states it:

I find that the singular has often been sacrificed to the general in the human sciences and that, more often than not, this has resulted in a distorting simplification of the human condition; in a failure to fully appreciate its ambiguous nature and the ambivalence it generates; in an implicit if not explicit emphasis on determinism; in an indifference to human creativity, transgressive possibility, and imaginative play; in a failure to address the question of human freedom, however delusional that freedom may be. (Crapanzano, 2004: 6)

His point is well taken; in attempting to generalise our findings, we risk flattening the multi-plural spectrum of individual disposition and circumstance, and presenting it under umbrella terms of the collective, the social or the political. Nevertheless, beyond situating it in an individual register, it is important to also explore how imagination becomes implicated in everyday sociality and politics through specific events and practices. Anthropological engagement with imagination must treat it not only as an essential mechanism of
human cognition, but also as a versatile tool of political action and an agent of change. An ethnographic ethos of engaging imagination does not only occupy itself with what the effects of imagination are, but also how these are produced - in what settings, by whom, and through what channels and happenings? In order to attend to the social and political dimensions of imagination, expectation and hope, it is not only important to explore how these emerge in the mind of one person, but also how they are multiplied in the minds of many.

Under a political register, it is not only the capacity to imagine that matters, but also the capacity to incite imagination in the minds of others. David Graeber has explored the relevance of imagination and its potential for radical political change in his *Revolutions in Reverse* (Graeber, 2011). There, Graeber distinguishes between Cartesian contemplative imagination and Marxist immanent imagination. While the former understands imagination as merely faculty of human cognition, the latter grasps imagination as a force and a flow, able of participating in social and political issues. As he makes clear, “[Imagination] is in no sense static and free-floating but entirely caught up in projects of action that aim to have real effects on the material world, and as such, always changing and adapting” (Graeber 2011: 53). Like Graeber, Latour also situates imagination in its political register. For Latour, imagination or, as he calls them, “beings of fiction”, are essential to any attempt of politicisation. As he writes, “Fiction is not fictional in opposition to ‘reality’… no chain of reference can be established without a narrative populated by beings which comes only from fiction” (Latour, 2013: 249-250).

Such theoretical perspectives attest to the political nature of imagination and expectation, as well as the imperative to ethnographically document and conceptualise these as such. To me, this is what Crapanzano’s treatment of imagination is largely lacking: a deployment in its political and collective registers. The danger is that if we restrain imagination
to an individual key, it might end up as primarily melancholic and contemplative: a yearning which ultimately remains socially and politically sterile. An inquiry into the politics and socio-poetics of imagination need not necessarily erase the multiplicity of imagination and individual circumstance, as Crapanzano warns. Rather, it directs us to what Isabelle Stengers would call an “Ecology of Practices” (2005). Ecologies of practices maintain the specificity of individual circumstance and disposition but, at the same time, discern how multiplicities of such circumstances form cartographies of socio-political interaction and imaginative action working together on a mutual cause.

Why do imagination and expectation constitute important parts of this chapter? As we will see, in the case of thalassaemia patients, future-worlds of techno-therapeutic finality are not abstract, ideal and utopian contemplations. Rather, expectations and imaginations of better future-worlds can, under the right circumstances, acquire practical potency of political capacity and relevance. In many ways, such imagined worlds are already as real and as material as the chair you are sitting on.

**Gene therapy and thalassaemia in Cyprus**

The first time I heard about gene therapy as a potential cure for thalassaemia was when I spoke to M after she got off work, in a cafe in downtown Nicosia. She didn’t know much about it. In fact, she almost knew nothing except that “it was coming”. M was one of the most self-assertive people with thalassaemia I met during fieldwork. She was one of the first who accepted to sit down and talk to me, and during our first chat she told me that there were two kinds of thalassaemia patients: those “who keep it a secret” and those who “shout if from the rooftops”. She belonged to the second category. She was working in an accounting firm, and was pretty open about her condition as a thalassaemic. To an
extent she was proud of it because, despite thalassaemia being a hindrance, it hadn’t stopped her from having a successful career thus far.

M casually mentioned gene therapy in the midst of conversation. We were talking about her daily therapy routine of pumps and pills (see Chapter 2), and she went off into a slight tangent: “And then you have all that talk about gene therapy and what not.” She stopped talking and took a sip from her coffee, and I asked what that was, somewhat annoyed at myself for not already being aware of it. She told me this and that, that “they put good genes into your body to replace the bad genes,” and after that “your body starts producing haemoglobin again.” M was quite laconic and she exhausted her knowledge of gene therapy with a Cypriot gesture of dismissal and futility, where the palm swirls in mid-air, as if patting someone on the back. When I asked for more details - “Is this thing happening in Cyprus? Who’s in charge?” - she responded that she didn’t know any of these answers. I asked her why she didn’t seem that interested, and why she didn’t pursue finding out more about it. From what I had understood from her few sentences, this could be a potential cure to the ailment she has been experiencing all her life. She blew smoke, stubbed out her cigarette in the ashtray and shrugged her shoulders. “I don’t see the point in finding out more about it. If it comes, it comes. If they manage to do it then I’ll find out about it.”

M was also one of the few patients I talked to who was not part of the PTA. She maintained the same apathetic stance regarding the PTA as she did with the potential of gene therapy being actualised: “Why should I get involved with them? I don’t think they get much done. As long as I am doing fine with my treatment I don’t see why I should spend more of my time on other things having to do with thalassaemia.” She said this with certainty, and then leaned on the table to light another cigarette.
M directed me to a friend of hers, also a woman with thalassaemia. She said she knew her from the thalassaemia centre – the clinic in Nicosia where they as patients go to have their transfusions and get their blood checked from time to time. The two would sometimes arrange to meet at the clinic, if their schedules allowed, to chat away the three or so hours the transfusions would last. I called M’s acquaintance and tried setting up a meeting. When I first talked to her over the phone she seemed hesitant to meet. When I gave her the pitch of my research (“I am interested in the political dimensions of thalassaemia in Cyprus” etc.), she replied that she wasn’t sure she would be useful to me. I replied that I was not looking for any “use” in particular and that I wouldn’t take much of her time. She thought about it for a couple of seconds and eventually agreed. I suggested that we could meet in the clinic, but she replied that she didn’t feel comfortable doing so, and that she preferred to meet somewhere outside. I did not know the exact reasons for this, but I agreed to her proposition.

A week later I found myself in the same café where I met up with M the last time we talked. I rang her on the phone because I didn’t know what she looked like. She was sitting in the outside area with another woman. “I thought it’d just be two of us?” I inquired.

“It’s ok, she’s a patient too. I thought she’d be able to help.”

The other woman replied to me, somewhat annoyed, “She didn’t tell me you’d be coming. I thought it was just the two of us going for coffee, like we do every Tuesday afternoon.”

Contrary to her initial reaction the second woman eased up once we all started talking and seemed at ease with my presence, so I went ahead with the interview as normal. Conversation followed the trajectory it often did when I talked to someone for the first
time, a trajectory which in certain ways parallels the structure of this thesis. We first talked about the history of thalassaemia in Cyprus (Chapter 1) and the current merits but also insufficiencies of the health care system (Chapter 2), and also the activity of the patients’ association (Chapter 3). Like M, these two women were not involved with the PTA. Both of them were married and had children. Similarly to M, the two women cited lack of time as their reason for not becoming implicated with the association. Their sentiment was clear. As one of them said to me, “I have to deal with this disease every day, I don’t want to also do it in my free time.”

At some point I asked them what they knew about the potential coming of gene therapy in Cyprus. Also like M, they did not seem to be that knowledgeable on the subject, nor particularly interested.

“I don’t know much about it,” one of them replied. “I know that some scientists in CING are working on it [CING stands for the Cypriot Institute of Neurology and Genetics] but that nothing is really for sure. These kinds of things, only doctors know what they really are about.”

The other woman concurred, “Yes, they don’t tell us much about it - we only keep hearing that they are working on it.”

There wasn’t much else to be said on gene therapy at that point, but I was interested and wanted to learn more. So I posed a question of speculative nature: “If it became available on a widespread basis at some point would you go for it?”

The two remained silent and pondered the question for a second or two.
Eventually one of them replied: “I don’t think I would. I’ve made a life for myself, my treatment is working and I got used to it, so I don’t see why I should go around changing that. Who knows what effects gene therapy might have on your body?”

The other woman picked up as soon as her friend was done: “I would consider it. If it had a high success rate, say 99%, then I would probably try it.” She checked her phone, and then kept talking. “I actually went to one of the centres where they are conducting experiments on it. I wanted to see if what they were saying was true, if it really worked. But I kind of didn’t really like what was going on. They weren’t really telling me things as they were; at least that’s how I felt. I didn’t like the way they treated me there, so I left.”

“What did you do there?”

“They didn’t really show any interest in me. Let’s just say they treated me like a number. I didn’t like that so I left.”

She was dismissive of my question in this response of hers. I didn’t push further. Although I was interested in gene therapy, I didn’t know that I would end up writing about it.

Our conversation on gene therapy ended with a note of pessimism: “Our doctors try to stay up to date with what’s happening, and they go to seminars and educate themselves about what’s new in gene therapy. But there’s still nothing here for us in Cyprus. We are depending on research centres from other countries to make the breakthrough.”
The problematically promissory industry of new genetics

The field of genomics and biomedicine is powerfully related to potentiality and imagination. Technological progress and intensifying flows of pharma-financialisation (Sunder Rajan, 2006; Ong and Collier, 2008) have transformed genomics into an unprecedented amalgam of scientific innovation and imagination. Talk of genes and cells, once restricted to scientific discourse, have now entered the public field of perception and conversation (Keller, 2010). We can observe how such widespread public discourses constitute an augmented form of genetic determinism; nowadays it is not only the capacity of genes to direct human behaviour that is significant, but also the capacity of scientists to profile and manipulate genetic and epigenetic influence (Lock, 2005).

Constant hyperbolic proclamations of scientific mastery over our genetic make-up have provided traction to the emergence of therapeutic and augmentative biotechnologies of radical potency, such as stem cell treatment, cancer vaccines, cryonics, regenerative medicine and gene therapy. One wouldn’t be wrong to assert that the majority of processes taking place in the biomedical sector operate in a dimension of future anticipation, rather than present preoccupation. As Charis Thompson points out, through her concept of “promissory capital” (Thompson, 2005), more than already existing treatments and technologies, it is future promises which today act as the motor of the pharmaceutical industry. The veneration of such promises often constitutes a form of implicit genetic reductionism by scientists and publics alike, since it obscures other, equally decisive political and social forces shaping biomedicine.

The gravity of such promissory futures should not be taken lightly, especially when put in the context of therapy, rather than enhancement. More than simply being bio-consumers awaiting the coming of genetic technologies for augmentation purposes, patients are presently embroiled in circumstances of pain, anxiety and suffering. The central role of
scientists dealing with the development of therapeutic technologies places them in a dialogic relation with those who carry the illness for which a cure is sought. The momentum gained by geneticists through copious amounts of funding and publicity has granted their activity and aspiration with ethical consideration as to what promises should be articulated in the context of therapeutic futures. Mary Jo Del-Vecchio Good shows how the promises made by pharmaceutical firms constitute a “biotechnical embrace” which envelopes the future expectations and therapeutic imageries of patients (Good, 2010).

Yet, one cannot blame the three thalassaemia patients I talked to for maintaining such a pessimistic stance regarding the coming of gene therapy. The problematic character of biomedical messianism is accentuated by the track record of promissory technologies, expectations and futures which never saw the light of day. Borrowing the term from one of her informants, Adriana Petryna dubbed the modern big pharma industry as the “science of expected failures” (Petryna, 2010). According to Petryna, the science of biomedicine is one of expected failure because, due to cost considerations, it tries to accelerate the widespread circulation of vaccines and medicines while bypassing important practical and ethical obstacles in laboratory research. Consequently, adverse side-effects and failures to deliver anticipated results have become normative. In the same vein, sociologists Steve and Hilary Rose (2013) have written a succinct review and at the same time critique of how genomics came to be perceived as a “promethean” field of expectations and hope. For the Roses, their perpetual failure to deliver such promises ultimately has granted pharmaceutical companies the excuse to transform the human body into a commodity to be appropriated, experimented and acted on as means to achieve their promises.

However, rather than as a case of ethical failure, bio-medicine should be examined through a lens of epistemological uncertainty. The anticlimactic ending to the mapping of the human genome perfectly summarises the often contradictory relationship of scientific
promises and actual results. The snippet from Eric Landers, a key biologist in the Human Genome Project, provided at the end of the mammoth thirteen-year project perfectly conveys the divergence of scientific expectations and eventual outcomes: “We’ve called the human genome the blueprint, the Holy Grail, all sorts of things. It’s a parts list. If I give you the parts list for the Boeing 777, and it has 100,000 parts, I don’t think you could screw it together, and you certainly wouldn’t understand why it flew” (Rose and Rose, 2013: 279). Philosophers of science and scholars of science and technology studies have also noted the gap which exists between the anticipation of scientific breakthrough, and the actual outcome of experimentation (Wynne, 1992; Stengers 1997; Rheinberger, 1997). For Lock (2010) such divergence is not only attributed to the incomplete knowledge which scientists have of genes, but also due to epigenetic factors which scientists often do not account for in their laboratory experiments. Relevant to this is also literature of sociological and ethnographic engagement which touches on the politics and contestations within science (Kuhn, 1962; Latour and Woolgar, 1979; Shapin and Schaffer, 1985). Such works show how science as a whole is not an objective and rational field, as it often appears in the public eye, but is rather a space permeated by uncertainty and ambivalence, enacted according to hotly contested disputes and politics between scientists, publics, governments and pharmaceutical companies.

Patient activism and the pharmaceutical industry

At the same time, such perspectives of scientific uncertainty and corporate immoralism, albeit problematic and worthy of the polemic stance of scholars of the likes of Petryna and the Roses, should not be considered as all-encompassing. In attempting to severely critique the field of genomics as a capitalist enterprise, we often forget to step out of the field of genomics itself. By remaining in the morally problematic frame of the biomedical
industry, one often forgets to attend to how the social field has similarly affected the epistemic cultures constitutive of genomic processes or how it is able and expected to do so in the future. As Michael et al. (2005) point out, epistemic cultures and scientific imaginations are not situated in a cultural vacuum but operate in a wider context which has the capacity to influence and alter the otherwise esoteric workings of biomedicine. Several scholars delving in the vein of patient activism have showed how patients have had a decisive say in epistemic practices of experimentation and innovation over the years (Epstein, 2007; Aymé et al., 2008; Rabecharisoa et al., 2014; Koay and Sharp, 2013). The rise of the pharmaceutical industry parallels the rise of another milieu of activity, that of patient activism and politicisation – what Roy Porter called a “medical history from below” (Porter, 1985). Such parallel activities of patient associations pinpoints the locales and events where pharma-capitalist imperatives are diffused, contested, suspended or simply ignored, not only by patients but also by scientists. The ambivalent progression of the future of genomics poses the ethnographic challenge of documenting how expectation, imagination and hope arise and relate, not only inside the laboratory, but also outside of it. Engagement with patients and patient associations unveils how technological expectations of therapeutic finality are capable of situating the politics of biomedicine in the public sphere.

To this end, a growing corpus of literature, aptly termed the “sociology of expectations” (Brown, 2003; Brown and Michael, 2003; Borup et al., 2006; Pollock and Williams, 2010; on relevant discussions on hope and potentiality see Novas, 2006 and Taussig et al., 2013 respectively) has extensively delved into the performative and pragmatic dimensions of public expectation, imagination and hope as formative forces in the enactment and shaping of contemporary biomedicine. Scholars operating within such fields align themselves with the aforementioned perspectives offered by Graeber and Latour in pointing
out that expectation and hope are not abstract and ideal but produce subjectivities and socio-political collectivities capable of partaking in the enactment of the modern bi-economy. Thus, as a foundational text in the sociology of expectations points out:

First and foremost expectations are ‘constitutive’ or ‘performative’ in attracting the interest of necessary allies and in defining roles and in building mutually binding obligations and agendas. At the most general level we can understand expectations to be central in brokering relationships between different actors and groups. Indeed, it would be hard to picture the formation of technology developments and innovations without some kind of shared, though flexibly interpreted, cluster of guiding visions.

(Borup et al. 2006: 289)

In this regard, for all those involved in the emergence of a new technology, being in a state of expectation does not entail being in a perpetual state of stasis. Rather, attending to the performative facets and activating capacity of expectations shows how they are dynamically embedded and enacted in the present, and how they give way to actions, events and happenings aimed at their actualisation. Imagination, in this sense, does not occupy a liminal space of lack as to something which does not yet exist, but is rather productive. Patients and patient associations are not docile observers of scientific mastery at work, but rather actively participate in such processes. By creating their own meaning and understandings, and by recruiting an imaginary excess deriving from promissory scientific activity, they actively appropriate such promises in order to achieve their own objectives (Wilkie and Michael, 2009; Langstrup, 2011). In such a way, the hyperbolic character of the biomedical industry is put to work by patients. The promise-filled field of biomedicine provides the resources to patient associations for politicisation and engagement with the institutions involved in producing the given technologies, as well with a wider political context of national governments, international organisations and funding bodies.
Technological innovation and scientific imagination are thus situated in and enacted according to a wider context of socio-political activity, comprised of heterogeneous actors of diverging, yet at the same time overlapping and related interests and objectives. In this regard, what one can perceive as “technology” extends beyond the normative definition of technology as an object or artefact. Rather, what we deem technology, or rather what ends up being called technology, is constituted and emergent of a socio-political and scientific milieu of interaction and relationality. Technological innovation, and also the results of imagination resultant of such innovative practices, are not confined to the scientific domain but rather overflow, mutate, and become appropriated by the rest of the actors involved in processes of technological production.

With this in mind, the capacity of patients to recruit and deploy expectation must be distinguished from a proposition of imaginative constructionism and idealism. The enactment of expectation and hope within the wider bio-economy is not a linear, unproblematic process, but one permeated by conflict, ambivalence and uncertainty. The entanglements of patient associations, medical institutions, pharmaceutical companies and national states often give way to processes and effects which greatly diverge from presumed expectations. Such contested dimensions of patient expectations present the ethnographic challenge of attending to their temporal and spatial “situatedness” (Brown, 2003: 10). By engaging and adopting the perspective of those who expect and imagine together, one can document the ways, spaces and channels by which imagination, expectation, and hope are concretely enacted, collectivised and politicised, but also the cases where they become blocked (Graeber, 2012). It is to this political version of expectation and imagination that I now turn to. If for the women I talked to the uncertainty surrounding the development of gene therapy was considered a hindrance, the argument I make in the
next part is that in a political register such uncertainty is one of enablement and production.

**Gene therapy and the PTA**

My experience with gene therapy would soon enter into a new, more positive trajectory, when I would get involved with the thalassaemia patients’ association. I say more positive because these were individuals who, unlike the three women I talked to before, were actively implicated in the political context of thalassaemia in Cyprus. Under such circumstances, expectations of gene therapy literally assumed a more positive potential and character. This initial distinction, of what constitutes a “positive” trajectory, might initially seem quite blunt and dichotomising, but I think it is one required for the argument I make: in order for imaginings of better-worlds and expectations of techno-therapeutic finality to be meaningful and powerful, they must be enacted in a political key. Although the distinction I make between the political and the non-political register is equally rigid, I maintain that it is not merely an analytical and heuristic concept introduced by me in order to analyse my findings, but an ethnographic reality. My definition of politics as an intentional practice of presenting yourself publicly, building and maintaining connections and alliances, and mobilising relations as pertaining to a matter of concern is one which continues from Chapter 3. These, then, were specific practices and activities that certain thalassaemia patients were involved with, while others were not. Towards this, the remaining chapter will adopt a decisive, yet important, distinction between those who are political and those who are not – a distinction between those engaged in practices necessary to imbue imagination, hope, expectation and uncertainty from contemplative to pragmatic and those who do not.
Attending a European conference on blood disorders (see Chapter 4) at the end of October 2012 allowed me to make contact with individuals and board members implicated with the Cypriot thalassaemia patients’ association, and at the same time witness how thalassaemia is enacted in a political context of mutuality and also contestation between patients, doctors and scientists. Soon after the conference I found myself speaking to the president of the PanCyprian Thalassaemia Association (PTA) at their headquarters in Nicosia. The office space itself was quite small. Two sofas on my right as I entered through the door and a desk on the left where the association’s secretary sat made up the setting of the interview.

K, the president of the association with whom I had arranged the interview, seemed to be knowledgeable about the prospect of gene therapy in Cyprus, as well as about the organisations and institutions involved.

We have a whole department working on it over at CING, and they’re on very good track. They have already created vectors which are capable of entering the human organism and fixing the faulty genes. They are still in an experimental stage but very close to making a breakthrough. There are four labs in the world working on thalassaemia gene therapy at the moment: one in England, one in Italy, one in Greece and then us, at CING. These centres are networked together and operate through a common platform. The platform is called ITHANET. This is good, because if someone makes a breakthrough then everybody gets to hear about it and reap the benefits.

“There’s no competition involved? No patent race?”

“No, as far as I know they work together. In their experiments CING are using vectors developed in a laboratory in Italy. For another example, we have a PhD and a post-doc
programme here at CING, and the students are taught by scientists from those other centres.”

She went on:

What we want as a patients’ association, what we hope will happen … and this might sound a bit grand, but what we hope will happen is that, along with the state – and this is important because the state has to be the dominant entity in this plan – we will have set up the infrastructure capable of receiving gene therapy as soon as it becomes available. So as soon as a breakthrough happens, we can take advantage of it. This will be made through the help of haematologists and geneticists. But we can’t do this with the current infrastructure – this procedure cannot take place in the existing general hospital. You need a lab which will be close to CING, and which will be specialised in carrying out this sort of treatment. Plus, the amount of money required is huge. It is estimated that the cost of treating one patient with gene therapy will be more than one hundred thousand euro. And there are six hundred of us around the island. It’s not easy. But we think the state is positive as to this prospect. As long as it secures the funds to do so…

K directed me to a few other people that she thought might be helpful to my research: a couple more patients involved in the association, and the aforementioned Dr. V.

These two patients also expressed views on the role of the Cypriot state regarding the potential implementation of gene therapy in Cypriot healthcare, as well as the need for constant politicisation from the PA. One of them said to me:

The state has generally been helpful and responsive. There still is much room for improvement, but they’re not deaf to our demands. But we have to stay active. One of the reasons the PA has a good relation with the state is exactly
because we have been in constant communication ever since 1973, when the PA was founded. So we need to keep this up, we need to stay next to the state and to keep asking. Not because we are greedy, but because thalassaemia changes: technology improves, our needs change, therapy methods improve...

Like his counterpart, the other PA member also made explicit the role of the state, He continued:

Now I’m almost forty, and no cure has yet been found. But we remain hopeful. We don’t expect miracles, we know it takes time to achieve results. The people at CING know what they are doing. What’s important for us as a patients’ association is to keep reminding the state that we need to be ready once the therapy becomes available. We can’t waste time. If they manage to get GT [gene therapy] tomorrow and then we need five or ten more years to set up the infrastructure for it, it’s no good, we can’t risk that…

After a pause he went on to add, “Many of us are already old, who knows if the therapy will work on us.”

Uncertainty in political and non-political registers

I was moved by the sentiment of my last interlocutor: “We remain hopeful.” It is not just the fact that he kept a positive attitude, but that he spoke in the name of many. Like the three women, the attitude of the three PTA members towards the coming of gene therapy also maintained traces of scepticism. Expectation oscillated between optimistic ambitions of techno-therapeutic realisation, and pessimistic acknowledgements of the uncertainty and obstacles at hand: a history of repetitive promises which were never actualised, as well as the financial magnitude of the task.
Such appropriations of imagination and expectation took place with regard to what Tiago Moreira and Paolo Palladino termed the regimes of hope and truth. For the two, the relation of truth and hope is one of tentative equivocation and, at the same time, affirmation. If truth and hope in the coming of speculative technology is collectively enacted by those involved, then the two regimes in their interaction open up a space of possibility and deliberation as to what the relation between truth and hope is, and how this should be articulated in political terms. As the two write, “If the regimes of ‘truth’ and ‘hope’ can then be said to include each other in the very same moment that actors articulate their differences, the relation between the two is one of ‘mutual parasitism’” (Moreira and Palladino, 2005: 74). The relation between truth and hope is thus one of ethical and political primacy. Taking his cue from the work of Mary Jo Del-Vecchio Good on oncologists and patients, the aforementioned Crapanzano goes on to pose the questions at the core of this chapter: Should doctors and scientists “Instil hope? False hope? Unrealistic hope? To what extent does their own hope - their wished-for hope - colour their ‘realistic’ evaluation of their patients and lead then to encourage a hopeful attitude in them?” (Crapanzano, 2004: 113).

The urgency of his question is pertinent and, at the same time, benevolent. I say benevolent because in many ways the question of whether hope should be instilled on patients by scientists is predicated on the assumption that the former are passive. Who says that hope is only to be found from the perspective of the doctors? Constellations and productions of hope extend beyond patient-doctor relationships. As shown by my interlocutors, hope and expectation are enacted in a wider context of institutions, associations and governments, and are influenced not just by medical, but also social, economic and political conditions. Another question: why should patients need doctors to instil hope in them? Instillment implies a passive vessel to be filled. With regards to a plurality of patients, it
implies an unconditional and uniform acceptance. Talking to patients, it was made evident to me that they do not unproblematically accept, recycle and regurgitate the promises made to them by scientists. Rather, patients consciously and intentionally accept therapeutic promises, and embed them into personal and political narratives. Choices of patients to accept such promises should be explored within a conceptual frame of conscious intentionality and practical purposefulness. It is not only the fact that patients accept to engage with scientific rhetoric that is important, but also the reasons and the objectives in mind by which they choose to do so. Such recruitment of expectation is translated and diffracted through personal and collective understandings and experiences of illness.

It is important that we acknowledge the differences between how the politicised patients handled the uncertainty of gene therapy in comparison with to the politically apathetic women I first talked to. I believe that this comparison can unveil the differences by which imagination, expectation, and also pessimism and uncertainty, are handled on an individual, non-political register, and a collective political one. The question of whether promissory statements should be made by scientists does not deserve a singular, definitive answer, but should be explored within the relative contexts - cultural, technological and political - in which such promises are articulated. To return to the connection Moreira and Palladino make on the two regimes of truth and hope, it must be pointed out that these two regimes are not static and holistic. A certain epistemological and ethical diffraction occurs, according to whom you talk, which mutates the relation between truth and hope. Narratives of illness and also expectations of future worlds are “shaped by the pragmatics of the social relations” (Good, 1994: 161) they are enacted by. According to these relations, the relation between truth and hope is constituted through a process of connecting information at hand. That is to say, patients entangle and weave be-
tween hope and truth according to their individual and also political objectives and alignments they belong to and partake of within the nexus of the extra-pathological space out of which thalassaemia is emergent of. As Byron Good writes, contrasting the narratives of those who maintained hopes of change and those who didn’t,

Stories of illness and healing experience which represent quite distinct and often competing forms composing the illness are present in narratives precisely because they maintain the quality if subjunctivity and an openness to change...Those who had simply accepted their illness as a chronic disease to be treated with medication also maintained little of the multiplicity that was present in the narratives I have been describing…however, the multiplicity of perspectives was particularly evident in the narratives of persons in the early stages or the “middle” of the story, whose still actively engaged in reevaluating the past and seeking to open their future to change (Good, 1994: 156).

Gene therapy as a potential future and also as a current development is thus differently enacted and utilised in the two different contexts I describe above: on the one hand, in the case of the women I first talked to, and on the other hand in the context of the members of the PTA. There is something to be said about entering a politically activated organisation, like a patients’ association. Much like Good writes, in such a political register, gene therapy was more than simply a speculative technology, and the future was more than a nefarious entity. Rather, involvement with the PA propelled me in a trajectory of movement (TIF Conference > M > PTA members > CING> Dr. V) and ethnographic encounters which allowed me to discern the actors involved in the coming of gene therapy and the construction of potential futures. As an ethnographer conducting research you become implicated, you itinerate and become entangled with a milieu of activity enacted much differently from that of individuals who do not traverse such networks. The potency of expectation and hope, as well as what passes and matters as
“truth”, differs in such a register. Unlike the case of the three women, engagement with patients who were politically activated consisted of acute narration and description of political forces at work.

Moreover, in the case of the PA members, the distinctions between patients, scientists and politicians are not dissolved but are rather put on a mutual, cooperative terrain. Unlike my initial non-politicised interlocutors, for the PA members the relation of thalassaemia patients to scientists, or the Cypriot state, is not one of diametric opposition. Gene therapy was not enacted according to an esoteric, scientific modality, but rather according to a network of heterogeneous actors, which included the PA. In the case of the individual non-politicised subject, the uncertain future of techno-therapeutic finality is perceived and treated as contemplative. On the other hand, in the case of the body-politic, or an individual belonging to a body-politic, the future is not merely terra incognita but, in addition, terra mutaris: a shifting process, enacted according to interactions between the numerous institutions, organisations and individuals which constitute a deliberative assembly of voices at work. In such political milieus, the uncertainty and ambivalence regarding the coming of a technology does not constitute a factor of imaginative blockage but, on the contrary, a factor of enablement and urgency, and an impetus for further politicisation and empowerment.

The uncertainty experienced by the PTA regarding the coming of gene therapy can be thought through Isabelle Stengers philosophy of practices. This is a philosophy which is rooted on the notion of constraints as productive and creative of new collectives. According to Stengers, the uncertainty intrinsic to conducting politics is a not a constraint which limits, but one which enables the production of relations and alliances or what she calls, taking her cue from Deleuze and Guattari, acts of “reciprocal capture.” When it comes to the promise of radical technologies such as gene therapy, for Stengers the true
act of creation is not the technological object itself, but the formation of collectives which can deliberate over and create the given technology in an ethical manner for all those involved in this process. As she writes,

The notion of constraint invites us to situate the question of reciprocal capture in a landscape in which what should be satisfied is on the order of ‘holding together with other’…to follow the way a new idea materialises is first and foremost to follow the operations of recruitment an alliance that will produce the real ‘material’ of innovation, the heterogeneous set of those who agree to be shaken up, modified, interested by it (Stengers, 2010: 43).

In the case of political forums, such as the one enacted by the PTA, CING and the Cypriot state, imagination, expectation and hope do not entail a state of stasis but of movement and construction. Such congregations of heterogeneous political actors actively situate themselves inside the trajectory of technological experimentation and construction. A final distinction must be made in the way technology is differently envisioned in each of the two registers. In a non-political modality, technology is perceived as a cold, physical object; it is taken as ready-made, and is imbued with a predetermined purpose: to heal. Yet, by simply “anticipating” therapy (Adams et al., 2009), patients exclude themselves from the constructive activities which contribute to the production of future-worlds and the actualisation of such expectations. On the contrary, a politicised patient actively situates him or herself in the trajectory of technological constitution. In its political modality the technological object is not perceived in its seemingly unitary appearance. Rather, technology is perceived as an end product emergent of multiple political and deliberative processes.

Technology will always be political in one way or another, even if that entails that technological trajectories are enacted according to a simply scientistic domain (exclusion, the
political act par excellence). Yet, the real challenge for patient associations is to exactly pinpoint the nexuses and nodal points of scientific and political entanglements, and also how such relations can be more meaningfully and productively reconfigured. With this task in mind, it is not just imagination and hope which are important, but also the mannerisms and locales in which they are produced. One must not only inquire into the potency of expectation and hope, but also the infrastructures of imagination which give way to such processes, as well as the difference in potency modalities of such infrastructures carry (Galloway, 2010). Entanglements of imagination, technology and politics direct us to multifaceted dimensions of engagement: imagination as a political technology, but also to technology as an entanglement of politicisation and imagination itself. This is a challenge for patients, publics and anthropologists alike: not to take imagination as ready-made, but to pinpoint the practices and settings in which imagination is connected to collective anticipations of therapeutic futures, and how such collective anticipations are imbued with political relevance and potency.

*Populating the laboratory*

In my case, it was CING which provided the setting for the politicisation of imagination, expectation and hope. CING proved to be the grounds and assembly where political forces implicated in the coming of gene therapy in Cyprus would meet to deliberate. This is something to take away: the distinction between society and science is first and foremost spatial.

It’s around 6.30pm on a late Friday afternoon in CING headquarters. I’m sitting on a white stool, playing with an empty petri dish. Dr. V.’s voice comes from the room adja-
cent to this one - “I’m wrapping up some things, got some deadlines to handle, give me a couple of minutes.”

“Yes.” Then without me asking him anything else he went on. “Part of my job it to build new stuff – new tests, new experiments.” I remember this statement clearly because, on first impression, it rang out to me as a very honest assessment of himself and his work.

When I told him about my research V went on to give me a complete rundown of how the thalassaemia programme formed over time. He was very knowledgeable on the sequence of events by which the prevention system came together, as well as the specific
time periods when new technologies became available to existing patients. After that he proceeded to give me a detailed description of the genetic processes by which thalassaemia transmits; he made it easy for me to understand and every couple of minutes he would stop and ask, “Are you getting this?” I would nod while taking notes, and he would proceed.

Discussion went on to CING’s experimental research programmes currently in progress, and it wasn’t long before V. mentioned gene therapy.

“So what happens is that you introduce a healthy gene into the thalassaemia patient. How is this done? You have viral vectors. One thing a virus can do is transmit its genetic material very efficiently into its host. The virus utilises the host’s cell mechanisms to reproduce. It can’t reproduce by itself - it needs some sort of medium to do so. Using these viral properties you can introduce genetically engineered vectors into a host. The vectors will integrate itself into the host’s genomic material and block their regular functions, instead transmitting their own. So the purpose is to use a vector as a mode of transfer to introduce DNA into the host. In the place of a pathological gene it can introduce and transmit a therapeutic gene.”

“So gene therapy works by introducing a sort of virus into host?”

“No. You don’t use a virus, you use viral vectors as a mode of transmission, and there’s a difference. Once again, this is very crudely put. It’s not easy, interfering with a cell’s DNA can be dangerous. You might try doing one thing and cause damage somewhere else. You can have complications - cancers, you might destroy other genomic mechanisms or whatever. So targeting is very important.”

He went on:
“So right now we’re part of a network of research centres working together to make a breakthrough. There’s some competition from some other centres and research clusters but that’s healthy, in many ways.”

I asked him about what the patients told me: “Some people I talked with mentioned that it’s important for Cypriot health care to invest in some sort of infrastructure, so gene therapy can become readily implemented as soon as it becomes available to the public.”

V. concurred: “Yes, that is correct. Here in Cyprus we have a good thing going. CING is a thalassaemia reference point by the WHO. And the PA is active too. So yes, the aim is to have an infrastructure ready for gene therapy to become integrated in.”

“So you have a good relation with the PA?”

“There are always conferences happening where scientists, clinicians and patients come together to discuss things. And then you have scientific conferences which are also open to patients. Or some other times patients invite us to talk in their own conferences. Or there might be some sort of middle ground, with us discussing with patients about the latest news from scientific conferences. And the other thing which is quite impressive is that many of the patients have incredible knowledge as to what happens in our field, that is to say science. I would say that we are a community. CING might be part of the research, of experimentation, of therapy, but we are still part of this community: you have us, the PA, the thalassaemia clinic in Nicosia. And then you have larger projects – TIF and ITHANET. I would say that by now all of us are complementary. We can’t function without each other.

And then you have the need for funding. We are lucky to have a good relationship with the Cypriot state; they fund most of our projects. So what I’m trying to say is that research is always interactive. There’s no point locking yourself in a laboratory saying that
you’re going to conduct research, or discover a gene, or something along those lines. To do research you need ‘friends’ to put it that way, you never do research on your own.”

“Would you say that the PA in certain ways influences CING’s research agenda?”

“I would say research sets its own agenda. You need to keep your ears open as to what is happening around you. A lab, especially one of the calibre of CING, cannot be static. You need to keep moving, and stay attuned to what happens around you – new information, new technologies, new breakthroughs and so on. You need to evolve. Thalassaemia in Cyprus is something alive.”

Dr V. concluded our conversation with what can be interpreted as a nod, intentional or not, to Heraclitus: “This whole thing, thalassaemia, is a living organism which evolves. We can’t stay static. If you stay static, you’re done.”

By the time I had to leave, the austere persona I first talked to on the phone had transformed into a mature and willing interlocutor. While leading me to the elevator V. extended an invitation:

“If you want to learn more about what CING and the PA are doing come down next weekend, we have a conference with lots of speakers – doctors, scientists, patients.”

I accepted: The laboratory must be populated: by publics, and their expectations, anxieties, hopes and imaginings of better future-worlds. The laboratory must also be populated by anthropologists. Not only to deconstruct its inner workings (Latour and Woolgar, 1979), but to also affirm its importance and participation in a broader relational milieu of imaginative enactment and political activity.

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The conference took place on May 12th, 2012. It was part of the annual thalassaemia week, which has been taking place every year ever since 1973. While the first editions of the week were aimed at sensitising the Cypriot public and integrating thalassaemia into Cypriot society as an acceptable condition, the event has by now acquired a more political character. As said on several occasions, of importance now is not that patients are accepted into society, as that is a task that has long been achieved. Rather, the week is aimed at raising funds for better treatment and facilities, as well as making the public aware of the political dilemmas surrounding thalassaemia in Cyprus.

In the previous chapter I discussed the role of conferences as events of collective deliberation. As argued in that chapter, conferences, if properly organised and designed, can act as technologies of revision for political entities such as the PTA. Although I cannot attend to this conference as meticulously, I will emphasise a particular occasion which will help me clarify the key points of this chapter. Walking into CING’s three hundred or so capacity amphitheatre, where the conference took place, I remember it being packed. Some of the people I knew, but most of them I didn’t. Throughout the day I got to talk to several of the attendants, including patients, scientists working at CING, clinicians working at the thalassaemia clinic, as well as family members of patients. Several presentations took place in the duration of the conference, some given by scientists, and others by patients.

Amid the presentations give, a session was given on advances made in the field of gene therapy regarding thalassaemia. The presentation was led by one of the scientists in charge of the team conducting research on gene therapy at CING. At the end of the presentation some time was allocated to questions. A discussion ensued between scientists and clinicians on whether the therapeutic DNA injected into patients during gene therapy should be frozen and unthawed, or whether it should be directly injected. The
discussion alluded to the benefits of each method. On the one hand, freezing therapeutic genes acts as a test on whether they are robust enough or not, and consequently whether injecting it into the host will prove successful. On the other hand, freezing and unfreezing the material potentially decreases its potency by killing off a certain amount of therapeutic cells. The presenter, in favour of freezing, conceded that this was still a sensitive, unresolved subject, requiring further tests and even actual implementation: “You can’t really know until you actually put it in practice - you can’t control everything in the laboratory.” The debate carried on for several minutes. At stake were logistical matters which extended beyond the actual issue of freezing and unfreezing genes. As one of the patients in the audience said, should an unfreezing route be implemented in the future, then it must be made sure that the place where the unfreezing takes place is in close proximity to the place where the injections would occur, otherwise the potency of the genes would be further damaged. Once again, this went back to the issue of a new blood centre being built near CING headquarters, and from there to financial considerations – the role of the state, and its apathy concerning EU blood regulations.

The outside milieu of the laboratory manifested in the room; an imagined extra-pathological space was revised – “unfolded and refolded” (Stengers, 2005: 190) differently - courtesy of such deliberations. If one is to take away one thing from my conversation with Dr. V, and also from the above discussion on gene therapy, it is that modern science and biomedicine is not a rationalised enterprise but is rather enacted according to epistemological lacunae of epistemic, political and economic dimensions. Much like the thalassaemia patients I talked to before him, CING doctors also maintained elements of uncertainty and scepticism regarding the coming of gene therapy in Cyprus, elements which by and large eluded his immediate milieu of the laboratory and instead diffused into the wider space of the enactment of thalassaemia in Cyprus.
Can such uncertainty indicate that the purpose of science is not to narrow down and, with overt conviction, articulate the future in a single trajectory of undisputed clarity but rather, on the contrary, to multiply such trajectories? Or that ambivalence and deliberation are actually the vital forces of scientific and technological progression, rather than objectivity and certainty? Much like patients, scientists too have to face the uncertainty inherent in experimenting with technologies of speculative character by becoming implicated with enigmatic iterations of genetic behaviour. This is why every scientific breakthrough is accompanied by surprise and delight, even by those who achieved it and had long been working on it. The work of science has never been to “succeed” or “to deliver”. The work of science and experimentation has always been that of proliferating spaces of possibility as to the actualisation of potential futures; the breakthrough is corollary of such modus operandi. In this respect, science and the modern industry of genetics are not different from practices of divination. The diviner and the subject of divination are not separated in purpose and knowledge. Rather, the purpose and knowledge of the diviner and the one who visits the diviner are mutually put to work in assembling existing elements, recombining these in potent combination and verbally articulating them with the aim of enriching the sphere of the possible and, at the same time, of the actual (Werbner, 1973).

By conceptualising the relation between science and polity as complementary, we upset and rearticulate a common misconception which even patients often adopt: that patients and the scientists working on their cures are diametrically opposed in terms of purpose and political alignment. What I hope I have conveyed thus far is that thalassaemia in Cyprus is not merely an illness suffered by many. Nor is gene therapy a technological messiah for thalassaemia patients, who are passively waiting for it to appear and cure them. Rather, thalassaemia and gene therapy as processes and projects are actively constructed,
enacted, deliberated and contested over by a multiplicity of actors: patients, clinicians, politicians and scientists. Rather than simply being emergent of the laboratory, it is interactions between these actors which bring together networks under which thalassaemia and its therapeutic potentialities come to be negotiated and actualised.

Perceived as an assembly of voices rather than as merely a widespread pathological condition, illness is not a liminal space of abjection and withdrawal but, on the contrary, an activated space of politicisation and imaginative production. Amongst such assemblies, technology is not merely an object but a hotly contested issue. In contesting technology in its future articulation, such congregations pull technology apart: they are able to treat and conceptualise technology not as a soulless artefact, but as an animated network of deliberative and political processes, out of which the given artefact is emergent of. Such congregations are what in the next section I regard as techno-collectives.

**Technology as a collectivity, technology as a collective**

Michael Fischer recently argued that STS scholars and anthropologists should turn away from Bruno Latour’s object-oriented approach of Actor-Network Theory, and instead focus on “the peopling of technologies” (Fischer, 2013: 356) to understand the ways by which technology acquires social and political character. Instead of wholeheartedly partaking in such radical inversion, in this part of the chapter I would like to examine Fisher’s position as complementary and in continuity to Latour’s. While, following ANT, I initially regard technology as a network or, to use my language, a collectivity of heterogeneous actors, I also regard it as a collective of peoples, each apprehending and utilising technology through their own perspective and standpoint. My task is not to separate the collectivity from the collective, but to examine the political processes by which
the former transforms into the latter. I suggest that the main difference between a collective and collective is that, while both are realised on an ontological level, only the latter is realised on a level of politics. While the process of technological progression is predicated on an ontological collectivity of human and non-human actors, it is only once it acquires a dimension of human intentionality and awareness that a leap is made from a technology as a collectivity to technology as a collective.

Heidegger was perhaps the first philosopher to conceptualise technology as a collectivity: not simply as a singular object but as a “gathering” (or Gestell to use his term) of multiple elements (Heidegger, 1977; see also Latour, 2004b). In his *The Question Concerning Philosophy* Heidegger describes technological essence as a process of “enframing.” Enframing entails thinking of technology not in its indisputable objectivity - that is to say, not as an object tied to an objective cause - but through the frame of how such objectivity is achieved. Technology is not a given object, nor a practice which involves the particular machine in question once it has been produced. Instead, technology, or rather the essence of technology as he makes clear, is the assembly of the various elements required to construct and give way to the object known as technology. Thus for Heidegger, the philosopher who came to be perceived as the phenomenologist par excellence, technology is not be apprehended phenomenologically, but structurally - or, as he puts it, in the processes which allow technology to be “brought forth” (1977: 10). For example, the essence of the technology of the car is not the car itself or the act of driving the car, but rather the elements, human and non-human, tangible and non-tangible, out of which a car is assembled: the raw materials required, the labour put it, the factory machinery involved and the design required. In this sense “there is nothing technological about the essence of technology” (1977: 35).
A technological ethics of enframing involves apprehending technology from a different perspective: not in its phenomenological finality, but in its relational, erratic and often ambivalent process of construction. The “essence” of a technological object is not an unchanging metaphysical given, but a chain of deliberative and political events productive of debate, revision and evaluation within the ongoing process of technological construction (consider the current debates surrounding nuclear energy, climate change or GMO foods). By making the mind conscious of the several processes of enframing by which a technological object comes together, one is able to participate in the given processes of enframing: of influencing it, of making it otherwise. Thus, technological enframing is not merely a metaphysical heuristic of interpreting the world but, more importantly, a concept which can provide an ethical mannerism of acting, thinking about and more importantly constructing technology. By actively situating ourselves in constitutive processes of technological trajectories we becomes aware of the multitude of actors and relations involved in the process of technological enframing, and become capable of tactically (see Chapter 3) partaking in them.

What Heidegger calls enframing, I decided to call a techno-collective. I decided not to keep the same concept because Heidegger does not push it to its political limit. Although he succeeds in describing technology as an ontological collectivity, he does not take the leap in describing technology as a political collective. Although he takes a step in the right direction by suggesting that we perceive and treat technological objects in their construction, rather than merely in their application or appearance, Heidegger, much like Crapanzano, chooses to situate this endeavour in the individual and, additionally, rational register. Yet, in every case, a technology is a technology of many in two ways: it is a technology constructed by many and, at the same time, it is a technology in which many have a claim and stake in. More than a “matter of concern” (Latour, 2004b) emergent of the
gathering of a network of heterogeneous actors, the technological artefact is a conductor of imagination, hope and politics. If the technological artefact is brought forth from the gathering of the multiplicity of elements then a subsequent political rather than ontological question is: What does this gathering bring forth in return? On the one hand, and similarly to Heidegger, a techno-collective is a lens for understanding a technology not merely as an object tied to an end, but as a collectivity of elements, interactions and relational processes which give way to the technological object itself. At the same time, the given concept takes us a step further: it can direct us to the processes of enframing and technological construction not as singular and conducted by individuals, but as ones situated in political milieus of imaginations, hope, deliberation and uncertainty, enacted by many. In this regard, the technological object, imaginative or not, becomes a knot of its past and of its future, of its actual and potential form. In becoming a loci of relationality and also of politics, the technological artefact acts as a mediator and nexus of the two faces of the techno-collective: of the ontological processes, elements, actors and arrangements which give way to the construction of the technological object, and also of its “peopling”: The deliberative and political processes of negotiation, contestation and the creation of new assemblies the given event of enframing made possible.

“The machine is always social before being technical. There is always a social machine which selects or assigns the technical elements used” (Deleuze and Parnet, 1987: 70). In many ways the challenge lies in constructing the correct social machine, rather than the technical machine, since the former anticipates and gives way to the latter. The process of assembling a techno-collective is not to be taken as ready-made. A technology only becomes a political collective once this given collective becomes aware of its existence as a collectivity. A technological assembly makes the leap from collectivity to collective once it starts understanding, unravelling and also experimenting on the relation which bound it together on
an ontological scale as a collectivity of elements, and starts examining, contesting and re-articulating these relations on a collective dimension by doing politics. Moreover, a technocollective as a mechanism and forum of politicisation and evaluation requires effort and work to be constructed and thereafter maintained. Let me once again invoke Dr. V’s words: “You need to keep moving. This thing is alive. If you stay static, you’re done.” In short, a collectivity becomes a collective once it intentionally and continuously starts participating in its own process of enframing.

The ambivalence permeating techno-collectives becomes more evident when we deal with technologies of promissory natures. In such cases, imagination, hope and expectation are at the forefront of processes of techno-collective deliberation and technological enframing; more than any other tangible element, expectation, imagination and hope are active contributors to such a technology’s coming into existence – into its “coming forth” to once again revert to Heideggerian terminology. A techno-collectivity as a squad of heterogeneous actors bound together by a given project of technological construction and imaginative deployment does not entail functionalism or lack of conflict. This is something to further complement Heidegger’s meditations: the process of enframing can never be complete, it can never be certain of itself; it will always be permeated by epistemological lacunae of unanticipated experimental outcomes, political disputes and financial considerations. The dynamics and contours of the interactions of a techno-collectivity can never be completely rationalised, understood or controlled, because the actors involved in a techno-collective often have divergent yet at the same time complementary objectives in relation to a given technological field.

However it is exactly these tensions and agonistic relationships between the elements of a techno-collective which fuel its ever perpetual process of enframing. The leap from a techno-collectivity to techno-collective demands - presupposes - the procurement and
collective recognition of an element of uncertainty, doubt and conflict within a field of technological progression. Unlike in the case of the individual, non-political and contemplative register of imagination, such intensified uncertainty is not necessarily a disadvantage. A lack of a definitive trajectory as to the coming of a therapeutic technology has the potential of imbuing a techno-collective with a political and deliberative vitality of considerable dimensions. In this respect the uncertainty permeating the coming of a techno-therapeutic future is not a hindrance, but a mechanism of urgency and politicisation; uncertainty, in its political guise, does not restrain but rather unleashes. This because, although such collectives have their as their ultimate aim their disbandment through the achievement of techno-therapeutic finality, they also recognise that the road to this telos is not predetermined, but must be collectively and politically constructed.

**Taking care of the possible**

A year and a half has passed since the events and conversations described above took place. When writing I try and maintain the memories in my head. I visualise them and go through my recordings again and again. I diffract and complement such memories and audio files through concepts, ideas and ethnographies conducted by others. On the 29th of September, while writing this chapter, I email a contact.

<Hi.

*Long time no speak.*

*I am writing a chapter on the social dimensions of gene therapy in Cyprus. I’m interested in how the expectations of patients about the coming of gene therapy bear potential for politicisation - of how expectations are not abstract and ideal, but participate in the social and political present.*


What do you think of this? Has anything substantial taken place regarding gene therapy since I left?

A reply, five days later.

<Hey,

Sorry for the delay, I hope this finds you well.

Truth be said, our expectations for gene therapy might not be abstract, but they are pretty ideal. CING is doing a really good job on the experimental front, and we try to help them as much as possible, but there’s not really much we can do. As an association we try and keep pressure on the state to build a new transplantation centre, ideally in CING. We put pressure through CING - we have one of ours in their committee - and also collectively as an association.

That being said, there’s not much response from the state.

That’s all I can think of now, I hope it helps.

Best.>

I am not pleased by the response. I am writing about the political dimensions of expectation. Although my contact tells me how expectation is used by the association, he also tells me that the state is not responsive. Is that the end of it? I write back, in an attempt to procure a more spirited reply.

<Thanks, that was really helpful.

Let me ask you another question. Since the state is not really responding to your demands for a new transplantation centre, what motivates the association to keep pushing for it? I am guessing that many members in the association are nearing 30 or 40 by now, and that even if a breakthrough is made in the case of gene therapy no one really knows if it’s going to be applicable in middle-aged patients.
So I am just wondering what keeps you pushing, given that the state is not really responding to your demands and the technology is still on a pretty speculative and experimental level. Is it a matter of altruism for coming generations of thalassaemia patients? Is it a tactic of applying pressure on the state - of keeping thalassaemia in their agenda?

Thanks once again.

Best.>

A response four days later.

<Hey, sorry for the late reply, I’m not around the computer much nowadays.>

Yes, you could say that for many putting pressure on the state for gene therapy is a matter of altruism and responsibility. But we have other stuff going on as well - lack of blood, access to medication, treatment costs, etc. So we can’t really focus all of our attention on gene therapy, there are other more urgent happenings that we need to keep addressing the state for.

We bring it up from time to time because we also need to adopt a long-term strategy. Besides, who said that all those involved in the association have lost their chance at being cured? Maybe when the bloody thing finally arrives it won’t have any age restrictions. Hope dies last!

Best.>

I ponder his response for a couple of days. The claim that I have been making in this chapter is that imagination, expectation and hope as to the coming of a technological future of therapeutic finality are enacted differently, and carry different potencies, on an individual politically-inactive level on the one hand, and on a techno-collective level on the other. On an individual level, unfulfilled and perpetual expectations of technological futures remain sterile because technology is perceived as a singular object, tied to a spe-
cific cause, which more often than not remains un-actualised. On the other hand, on a techno-collective level, expectation, hope, uncertainty and even pessimism (Tutton, 2011) are integral parts of the process of enframing; they are active ingredients in the way by which anticipated futures come into existence. This exchange introduced a new tangent. Namely, what happens when there isn’t enough “fuel” to mobilise and politicise expectations? Capital is ultimately the means, the fuel by which expectation and imagination come to be produced and circulated within the pharmaceutical industry. This is not to say the patient activism and imagination are capitalist in nature. A distinction has to be made between capital and capitalism: while the latter operates by an ethic of accumulation, the former provides the means of creation though the funding of scientific and political initiatives. It is unavoidable that all attempts at politicisation and activism become implicated in a nexus of financial activity and governmental agendas. The Cypriot economy has been subject to an intense politics of austerity imposed by the IMF and the EU for almost three years now. How are political groups, such as patient organisations, meant to navigate and deploy imagination in such highly fragile and uncertain terrains?

I follow Isabelle Stengers in saying that “pragmatism is the care of the possible” (Stengers, 2011). To take care of the possible implies pinpointing the elements which give way to the possible - the tasks, objectives at hand and the actors involved. Techno-collectives are ways to take care of the possible because for them technology is not a singular compound but rather the result of a myriad of articulations. Taking care of the possible entails pinpointing modal points of connection between the possible and the actual, examining them, and rearticulating them in more powerful and potent combinations. Techno-collectives do not take illness, technology or the future as ready-made, but are rather concerned with forces and processes out of which these as singular compounds are constructed: the relations by which they solidify and attain consistency as objects of public
discourse, knowledge and practice. By enacting illness, technology and the future on a collective, deliberative register, they are granted with a democratic, ethical and moral agenda as to how the production of expectation and imagination should be conducted and managed within a social field.

In this regard, more than being technologies of politicisation, techno-collectives are pragmatic technologies of imaginative sobriety and calibration. They are technologies of sobriety because they prevent imagination from running rampant, and they are technologies of calibration because they continuously adjust the relationship between expectations of future worlds and the circumstances of current ones. Techno-collectives instigate, navigate and negotiate the tense relations between truth and hope, desire but also priority. I believe this is one aspect that the sociology of expectations can be more attentive to: the ways by which technological forums can act as a way of adjusting the expectations of imagined futures to the circumstances of actual presents. If patients themselves do not fetishise the prospect of an ultimate cure, if they do not single it out of all the conditions according to which an illness in its multifaceted enactment takes place, then neither should ethnographers. By situating expectation and imagination in a broader extra-pathological space, what becomes apparent is that hopes for a therapeutic finality are not always catalysts of patient activism. Rather, such hopes and expectations are enacted in relation to a more extensive milieu of financial flows, political activity and governmental agendas. In techno-collective forums of deliberation the prospect of therapeutic finality does not act as a central organon nor a telos, because it is thought of in relation to a wider context of pathological enactment and distribution of agency. Patient associations often must attend to other more urgent matters which if left unattended could have severe and immediate repercussions.
This is not to say that the future is unimportant, or that the present is more important than the future, but rather to realise that the relation between the two should be enacted and adjusted according to an evaluation of the circumstances at hand. The collectivisation of imagination precisely depends on a political and institutional infrastructure capable of recruiting both sides of the same coins - contingency and strategy, hope and pessimism, certainty and uncertainty - and feeding them into collective mechanisms and mediums of macro-representation and politicisation. This is no easy task. I agree with sociologist Barbara Adam that the actualisation of potential futures is not only a matter of imagining them but, at the same time, of planning. As she writes, “[The future] imagined as an abstract, open territory is amenable to colonization and control, plunder and pillage. Devoid of content and meaning, it is a realm to be filled with our desire, to be formed and occupied according to rational blueprints” (Adam, 2010: 366). Yet, I would be cautious about adhering to Adam’s overtly rationalist and linear perspective of making sense of such processes of future making. As discussed earlier, the field of genomics is an ambivalent and unpredictable one; planning in such milieus does not take place according to ethical and moral clarity. The heterogeneous and unpredictable dimensions of how therapeutic futures are created and negotiated often cut through, disrupt and muddle the crystal-clear moral categories of good and bad, right and wrong, as well as the epistemological certainty and all-knowing knowledge of a Godly tactician.

Planning, with regard to biomedical futures, is not a predetermined trajectory but rather a constant process of carefully adjusting to and managing the contingency and unpredictability of shifting circumstances in order to maintain a tactical disposition as to what futures can be imagined, and the ways by which such futures can be brought into fruition: a process of bricolage, rather than engineering. To once again quote Dr. V., “In many ways research sets its own agenda.” A techno-collective is in a process of constant revision -
tracing, examining and reconfiguring knots and nodes of subjectivity, politics and technology – and questioning how to make these more useful and powerful. Acting as a survey of possibility, techno-collectives unravel the relations by which a technological milieu is created and perpetuated. In doing so, it promotes an evaluation and productive re-articulation of the given relations through deliberative processes of collective dimensions. Engagement with individuals and institutions situated at heterogeneous positionings pertaining to anticipations of realisations of therapeutic horizons unveils this ambivalent, uncertain and, most importantly, political and collective character of expectation, uncertainty, imagination and hope, as well as their means and channels of negotiation, contestation and deployment.
Conclusion: Activating Illness

The production of connections implies a milieu that could be described as activated

(Pignarre and Stengers, 2011: 89)

Pending the establishment of the thalassaemia prevention programme, it is not far-fetched to claim that the rise of thalassaemia as a social and political matter of concern for the Cypriot state and public parallels the founding and, increasing over the years, mobilisation of the PTA. As a patient organisation and a patient collective it has managed, over the course of its inception, to transform thalassaemia from a widespread chronic blood disorder into a collective issue of public and governmental deliberation. The key objective of the thesis was to examine such activities of the PTA on historical and contemporary perspectives, and to gesture to the political work of the association as integral to bettering the lives of thalassaemia patients in Cyprus as a whole. On an ontological level, the thesis aimed at exploring the processual nature of thalassaemia in Cyprus and how this is reflected in terms of experiential, social, political and technological change. On a political level, the thesis attempted at exploring the tactics through which the PTA accrues political leverage and participates in this ontologically processual enactment of thalassaemia. Finally, I attempted, through exploring the PTA’s activity, to develop tactics of my own, which could contribute to the practice of conducting politics of illness.

Because of these objectives the thesis put particular emphasis on the politics of thalassaemia in Cyprus. As argued in chapter two, using Margaret Lock and Nancy Scheper-Hughes’ work, while the experiential and social bodies do have a say in the enactment of illness, the body politic is the one which bears an affective hierarchy over the rest in terms of how public understandings, practices and experiences of illness can be collectively bettered for patients. The predicaments faced by thalassaemia patients in Cyprus on
a regular basis such as lack of blood, lack of hospital space or inadequate transfusion scheduling, although largely deriving from the country’s political landscape, would be left unresolved and unattended if not for the actions of the PTA. Nevertheless, as repeatedly made explicit in the thesis, the links between the political and everyday social and experiential dimensions of illness are not to be taken for granted. Rather, the task of doing politics for patient collectives is exactly to illuminate the relations between illness, society and politics and to render these visible to the wider public. By doing so, by alerting others to the political character of their illness, patient associations actively situate themselves in the processual becoming of their illness. By becoming politically relevant patient associations gain the capacity to partake in the contestation and reconfiguration of their illness since, unlike static biomedical, symptomatological models, the political and social landscape of illness – what in the thesis was referred to as an extra-pathological space – is prone to modification and change, according to deliberative practices of negotiation and contestation by all those concerned and affected. This shift in collective perceptions of illness, from a biological disease of one to a socio-political matter of concern of many, signals the event of activation.

I would like to revisit the opening questions of the thesis: What modality of politics does illness, in its collective manifestation, give way to? How can illness translate into a political modality of organisation and activity? If I were to sum up the five chapters in one sentence it would be: the political dimension of illness is not a given, it must be achieved through politics. If throughout the thesis I have contrasted the two terms, it was not to point to an irreconcilable difference between them, but to demonstrate the potential and demand for their connection. Opposing Pignarre and Stengers’ proposition of “another world” (Pignarre and Stengers, 2011: 3) philosopher Alexander Galloway writes:
That silly slogan of the left, “another world is possible,” should be scrapped. Another world is not possible. The political is that thing that cannot happen. It cannot be produced and it cannot take place. But why? Because “production” and “taking place” are the domain of anti-political forces. The political does not arise from the domain of production, nor does it exist in any place or situation. Another vocabulary is required. So like Badiou we might speak of the political in terms of the event. (Galloway, 2012: 139)

Yet, if the political cannot happen, it is because it always is. In other words, one can critique Galloway for not making the distinction and thus conflating the political and politics, as well as ignoring their potential connection. As argued, the distinction between the political and its politics is that, while the political dimension of illness is an ontological given, politics is the means and practices by which this ontological given is constructed, maintained and made explicit in public perception. In this sense, while politics and the political overlap in their effect, they are distinguished by the former’s strategical dimension as pertaining to a specific matter of concern.

The political is exactly an ontological dimension which partakes and is reproduced in the individuation of illness at any given instance. Yet, while the political is part of the ontological realm of forces out of which illness largely emerges in everyday experience, only through the intentionality of politics can one accrue the potential to achieve a re-organisation and re-articulation of these forces. As made evident on several occasions, conceptually and ethnographically, conducting politics of illness – making another world possible - does not merely demand that a patient organisation attains adequate political representation in relation to a biopolitical apparatus. More importantly, patient activism always emerges in relation to one or more matters of concern which negatively affects patients. In the case of the PTA, these matters of concern initially took the form of social discrimination and lack of medical provision, and later shifted to achieving better quality
of life and achieving therapeutic finality. Thus, more than achieving political representation, doing politics for illness demands that patients conduct practices capable of establishing a link between the everyday, political experience of illness, and the macro-mechanisms of representation according to which politics of illness take place.

The distinction between politics and the political also bears some methodological implications for anthropologists. Insofar as the practice of politics (as distinguished from the political as a state of affairs) is not a metaphysical certainty but an intentional practice of public communication, deliberation and contestation, then the ethnographer’s task is not merely to verify the political character of illness through social analytics, but also to pinpoint the events, locales and means by which such political character manifests in human perception on a collective scale. By interpreting illness as inherently political ethnographers risk erasing the efficacy and very purpose of doing politics by patient associations. Anthropological insight must move beyond an “intellectual recognition” (Osterweil, 2013: 39) and the “intellectual common sense…to insist that everything is political” (Brown 2015: 10) and engage in the more pragmatic project of pinpointing the sources of such recognition - in other words the practices, channels, words, gestures and technologies through which matters of concern acquire a political character. In the case of medical anthropologists, this entails attending to the practices by which political entities such as patient associations do politics.

Throughout the thesis, the manifestation of the political dimension of thalassaemia in Cyprus was not treated as assumed and all-encompassing, but rather an exceptional circumstance which arose out of a problematic engagement of illness, society and politics (or lack thereof). Such circumstance took the forms of demonstrations, newspaper articles, television appearances, conferences, and workshops which made explicit the political dimension of illness, as well as the need to reconfigure it. The political character of
illness is thus not to be assumed as ethnographically ready-made, but rather one which has to be verified through events and practices conducted by patients. By exploring such practices, anthropologists can attend to the ways by which patient associations attain and maintain political momentum. The political character of illness, at once a process and project, demands “work” (Latour, 2005: 39) to emerge and persist.

The name the thesis gave to this work was “tactics”. As developed and referred to in the thesis, the terms “tactics” denotes channels, mediums, practices and events capable of achieving continuity and establishing a feedback loop between the ontological dimension of illness and its politics. As mentioned in the introduction, the potency of the given term stems from an open-ended conceptual character which evades closure, instead denoting a more general horizon for connection, enrichment and application. A tactic in its conceptual guise thus adopts a fuzzy form, which is defined and clarified by the particularity and urgency of a given situation a collective finds itself in. In other words, the term tactics does no attain potency through a definitive set of practices and guidelines, but rather through the indetermination and hence plurality of its potential combinations: the multiplicity of ways by which the gap between the ontology and politics of illness can be bridged, as well as the plurality of conditions under which this demand arises.

In the thesis the terms tactic adopted various modalities. In Chapter 1 it took the form of “slowness” as a mannerism of forging productive relations between science, state and public. As argued, the setting up of the Cypriot thalassaemia programme proved successful because the medical practitioners who set up the programme did not treat the specificity of Cypriot culture as something to be negated in favour of a scientistic regime of prevention. Rather, such cultural specificities acted as points of pause – occasions of deliberation and connection which aided in the setting up of a prevention system which was culturally attuned to the logics of the Cypriot population. In Chapter 3, both the ontology
and politics of illness were explored through Bruno Latour’s concept of “matters of concern.” On the one hand, the change matters of concern undergo serve in showcasing the processual nature of illness. On the other hand, the given concept also attends to the tactics by which patients succeed in politicising their illness. The purpose of such tactics was to connect the ontology of illness – the everyday practices and experiences of patients – to its politics. Such tactics took the form of the connective and politically powerful character of speech, comparison, counter-knowledge, as well as the perpetual necessity of alliance and relative autonomy. These were practices which made explicit and rendered visible the problematics of thalassaemia in the Cypriot public sphere, and succeeded in granting the PTA with political momentum and authority. In Chapter 4, the event was explored as a tactic of revising a patient association’s organisational essence. As argued, events such as conferences are able, through occasions of internal dissensus, of revising a PA’s political objectives, and keeping them in track with political, technological and economic changes. The gravity of such events becomes more and more important if one considers the extensive network of alliances set up with PAs around the world, a development which makes possible the achievement of mutual projects such as the ENERCA White Book, but at the same time gestures to the need for attuning such projects to the particularities of patient lives.

More than making explicit and participating in the political life of illness, the need for tactics links to an essential aspect of extra-pathological spaces and patient activism which permeated the thesis as a whole, and which was further made explicit in Chapter 5 – that of having to face uncertainty. An activated milieu gestures to the potential for creation, but at the same time hints at the uncertain, volatile and precarious context which the urgency and opportunity to activate is predicated upon. Uncertainty figured in the thesis on several occasions: in the past as the uncertainty of parents of thalassaemic children having
to face social discrimination and poor treatment conditions, and as the uncertainty of Cypriot medical practitioners to having to deal with the prevention of thalassaemia under conditions of war and social discontent. Ever since thalassaemia has become socially integrated in Cyprus, such uncertainty has attained contemporary form: it manifests in the form of patient concerns over lacks of in lack of blood, financial hardship, and ambivalent therapeutic horizons.

As argued, such uncertainty, if managed and deployed correctly, need not be a restraining factor in conducting politics of illness. In other words, uncertainty itself can acts as means of activation. Uncertainty is intrinsic to patient activism – it acts as the life blood of a patient collective, and should be thus affirmed. The tactics deployed by patient organisations to utilise and manage uncertainty direct us to the ontological modus operandi of the contemporary extra-pathological space, this being an oscillation between unpredictability and strategy. The milieus where illness is enacted are always reshaped and upset by forces of unpredictable, negative character, such as scientific ambiguity as to the coming of therapy, or economic meltdowns. In this regard, the extra-pathological space where illness takes place is indeed one of uncertainty. At the same time, however, the extra-pathological space is informed from the inside out. It is informed by those whom the extra-pathological space affects and concerns the most: patients. Politics of illness are thus always enacted according to a circumstance of urgency and uncertainty, but also intentionality. Thus, more than erasing uncertainty, tactics as means of politics entails acknowledging, recruiting, and tactically deploying it. For example, a slow modality of conducting policy as detailed in Chapter 1 precisely depends on an element of uncertainty which one does not disregard in order to reach a predetermined ideal result, but rather employs in order to trigger deliberative processes which open up new spaces of possibility and trajectories of action. Likewise, uncertainty is an essential ingredient in conducting
politics of illness and maintaining a matter of concern insofar as it is a dimension of an extra-pathological space which demands one to “stay ready”, as suggested in Chapter 3.

If uncertainty is to acquire political character and potency for patients, it must be elevated and enacted according to a collective. If in Chapter 5 I drew a sharp contrast between the patients involved and those not involved with the PTA, it was not to criticise the latter, but rather to showcase how the uncertainty intrinsic to illness acquires a pragmatic efficacy in the case of the former, through their alliances with scientific and governmental bodies such as CING, TIF and the Cypriot state. The enactment of uncertainty on a collective, institutionally heterogeneous level is what powers its transformation from contemplative to practical and from constraining to enabling. This political deployment of uncertainty is capable of transforming the milieu according to which illness is enacted, since it explicitly addresses the epistemological and political blind spots which permeate an extra-pathological space, not in order to defeat them, but in order to transform them into spaces of contestation and action. Once the uncertainty of illness becomes a modality of doing politics, it becomes a positive force which drives the formation of alliances and collectives which would not otherwise be possible. At the same time, the singular and cold nature of technology as a means of achieving techno-therapeutic finality is transformed into an animated network of deliberation, enacted according to a heterogeneous infrastructure of institutions which are exactly glued together from the uncertainty and ambivalence intrinsic to collective future-making: A techno-collectivity in its unexpected ontological gathering, but also a techno-collective in its intentional, tactical operation.

What kind of work do such collectives do, and how do they differ from traditional forms of doing politics? To return to Galloway, another deficiency one can pinpoint in his definition of the political is that he reserves the slogan “another world is possible” (Pignarre and Stengers, 2011: 3) for the “left”. Although the thesis prioritised the perspectives of
patients, it also gestured to the heterogeneous composition of alliances and collectives according to which politics of illness are currently conducted. Elsewhere (Kyriakides, 2015), I explore the “unnatural” ways by which such alliances and collectives amass at particular points of time, according to particular matters of concern. Such a modality of conducting politics is predicated on occasions emergent out of abnormality - what Viveiros de Castro calls “demonic” alliances between those involved in a matter of concern (Viveiros de Castro, 2013). Such alliances are not based on traditional forms of representation and ideological alignment (left, right, etc.) but according to the gravity and particularity of circumstance.

Ever since I finished my spell of fieldwork in Cyprus some changes have taken place. CING, in cooperation with a scientific research centre in Italy, started trials of gene therapy on human subjects, including Cypriot thalassaemia patients (Kathimerini, 2015). TIF and the PTA have forged yet another alliance with the newly established Medical School of University of Cyprus in order to promote research aimed at treating haemoglobinopathies in Cyprus and elsewhere (Ikypros, 2015). Austerity measures are still in effect, albeit in a recuperating yet still fragile Cypriot economy. Courtesy of this emphasis it grants to tactics, I believe the thesis showcases an enduring character which can keep it relevant even in light of technological, social, economic and political change. If, both, illness and its politics are a process – a continuous trajectory of extra-pathological differentiation - then, for patient associations such as the PTA, the only constant in these two unfolding trajectories is the need to build and maintain a connection between them. Extra-pathological spaces might change, but the need for tactics as a means of managing and navigating the onto-political axes of illness amid such spaces remains. Although the thesis was situated in the vein of patient activism, my impression is that through the ethnographic descriptions and conceptual work provided, one may be able to draw wider con-
clensions regarding the objectives of not only patient associations, but also other activist groups and social movements which find themselves in perilous conditions.

With this more general orientation in mind, another objective of the thesis was to indicate the potential anthropological concept-work has for political activation. The constant need for tactics for these collectives and organisations gestures to a potentially fruitful question for anthropologists: In addition to an anthropology of exploring tactics, what would a tactical anthropology entail? If the term “activism” is often described in terms of frustration by those ignored by a certain political arrangement, then how can this frustration be anthropologically infused, described and analysed through intentionality and strategy, rather than simply uproar and discontent? If the term tactic is largely restricted to the vocabulary of warfare and the indication of cunningness, how can we reclaim it in the name of political connection, the assembly of heterogeneous assemblies, and the creation and maintenance of matters of concern on a collective and political scale? These questions point to a potential connection between anthropologists and collectives they do research with: on the one hand, collectives such as the PTA use tactics as means of activating illness. On the other hand, what can the anthropologist do when he or she comes in contact with such collectives? How can she or he inform the attempt of activation?

The increasing demand for anthropology to be more socially and politically engaged is often interpreted and understood as ethnographically grounded in mutual projects between anthropologists and the people they do research with while engaged in fieldwork. In addition to this, I suggest that a politically engaged, tactical anthropology on the conceptual level is predicated on the dictum that there is no dichotomy or opposition between conducting fieldwork and doing theory. Instead, much like the case of politics and the political, it would decree that there is only a distinction and an initial separation between these practices and their spatial milieus, which provide the impetus for connection
in multiple combinations, the proliferation of relations between the two, and as such the enrichment of space of possibility for political action and movement (Kyriakides, 2014; Martin and Flynn, 2015).

A tactical anthropology stems from an ethnographic examination of tactics, but also attempts to enrich such an examination through anthropological concept work. More than providing “theoretical foundations” or a “making sense” of ethnographic material, concepts carry an ethical dimension and a vitalism which provide a mannerism through which one can think and act in the world. Every chapter in this thesis placed one or more concepts at its core, whose utility and exploration oscillated between ethnographic and theoretical treatments. My intent in borrowing and devising terms such as “slowness”, “extra-pathology”, “comparison”, “counter-knowledge”, “techno-collective” was not merely to describe the PTA’s political activity but to isolate, and construct out of the effects of these practices, a concept-as-tactic able to enrich, when needed, the space of possibility out of which it is deployed. Concepts-as-tactics do not simply describe, but rather connect to, and inform the social field out of which they emerge. Much like the relation between the ontology and politics of illness, anthropological concept-work can also achieve a “looping effect” (Jensen, 2008: 310, Fortun, 2014: 323) between the potency of the concept and the conditions of its emergence. The concept as tactic and answer to the challenge of inventing an “anthropological concept of the concept” (Corsín-Jiménez and Willerslev, 2007): This is a useful road to pursue and one which anthropology has barely started to touch.

An ethics of theorising tactics itself demands an ethics of theorisation: Pignarre and Stengers caution not to use the language of alienation in thinking and writing about the predicaments of collectives, organisations and movements around the world. As they write, “To theorise alienation is to use words that are made more for the use of those who pose
the problem about others, than for communicating pertinent practices” (Pignarre and Stengers, 2011: 106). Should the subjective experience of illness be anthropologically restricted to a malfunctioning political apparatus, then the possibility of action and movement as allowed by the practice of doing politics is ethnographically and conceptually negated. As such, the emerging field of patient activism as an anthropological and ethnographic site of engagement is of integral importance, since it explicitly focuses on and affirms patient attempts to reconfigure political dimensions of illness. By portraying patient collectives in activist light, ethnographers aid in “thickening their reality” (Puig de la Bellacasa, 2011: 89). By pinpointing locales and attempts of activation, ethnographers grant patient collectives with a political standing and ontological robustness of their own, rather than simply thinking of them through faulty workings of state, financial and pharmaceutical institutions.

I gave the thesis its title from the quote of Philippe Pignarre and Isabelle Stenger which appears at the epigraph of this conclusion. Why did this book prove so important to me while writing? Elsewhere, Eduardo Viveiros de Castro deemed the given work to be a direct descendant of Pierre Clastre’s anthropology, with the same question at its core: “how to make room for others?” (Pignarre and Stengers, 2011: 63; Viveiros de Castro, 2010: 23). To make room for others is an entirely practical, pragmatic and thus political, in the context of this thesis, question which evades the language of abjection and alienation. The result of employing the language of alienation is that agency, intentionality and ethics are suspended at the level of the patient. The object of a tactical anthropology and anthropology of tactics is that ethics and politics, as mannerisms of navigating the uncertainty and peril of extra-pathological spaces, are reclaimed in the name of the patient. If the thesis was not written on a line of alienation I would like to think it was written on a line of pragmatism. This spirit of pragmatism was not restricted to me, the figure of the
ethnographer, but was already present in the people I wrote about. How else can one explain that the PTA has the constant objective of preventing future births of thalassaemia while at the same time maintaining an acute stance of politicisation for existing patients? That is to ask: how can they affirm and negate the importance of their illness at the same time? It is a paradoxical treatment of illness can only stem from a pragmatic perspective and modality of conducting politics.

The language of pragmatism does not only mean abandoning the language of opposition and alienation and adopting one of affirmation, connection and potentiality. This second language also means treating political entities which were previously thought to be the sources of such sentiments of opposition and alienation in a more a strategic manner. In such sense, the language of pragmatism does not simply entail opposing capital and state. If in the thesis the Cypriot state appears, at times, as a figure of opposition for the PTA, this was not in the name of denunciation, but connection. “To connect” exactly presupposes that one fosters and nurtures alliances which extend beyond one’s traditional milieu of operation, and to seek new associations and resources in spaces previously thought of as hostile and/or sterile.

This is no easy task. The language of pragmatism might initially present itself as naive. If anything else, it is a language which makes both, the anthropologist and the patients’ work harder, since the potential for meaningful political connection is not omnipresent, but rather requires effort to achieve, and arises at specific instances of collective mobilization. To think in terms of pragmatism demands that anthropological theorisations move beyond the conceptualisation of the politics of illness in terms of monodimensional dialectics between entities and forces such as “state”, “capital”, and “science”, and instead attend to the shifting institutional cartography and the multiplicity of relations, circumstances and events according to which the politics of illness are globally...
and locally enacted between these entities. The questions which lead to meaningful practices are: How is illness embedded into the relations and political processes of such actors? How do these processes and relations change through time, thus providing spaces of alliance for patient organisations? Tactics as related to such processual cartography entails pinpointing means of activation: the creation of spaces of possibility for connection and movement, and the opening up of state, financial, scientific and pharmaceutical apparatuses previously thought of as monolithic. Although these are seemingly rigid they are nevertheless porous, receptive to alliance, and politically promising for patients.
Footnotes

1 More specifically, births of infants with thalassaemia still take place, but only through the parents’ consent. Although I could not locate any figures, during an interview with a genetic counselor I was told that around 3-6 births occur yearly.

2 For a comprehensive review of the Cypriot thalassaemia prevention system see Cowan (2008: 181-222).

3 Being a carrier of the mutation can sometimes present mild, temporary symptoms of anaemia, such as a low red blood cell count and tiredness.

4 Although it can, at times, lead to withdrawal. Exemplary in this regard is the story I heard from a woman in the field. Asked by her then boyfriend if she had the stigma she proceeded to split up and never meet him again, since she perceived the question as indicative of the man wanting to have children with her.

5 As Woolgar and Lezaun recently wrote, for STS the ontological motto is “it could be otherwise,” as compared to the “it actually is otherwise” of multinationalist/ontological anthropology. (Woolgar and Lezaun, 2015: 465, emphasis in original).

6 The organisational essence of the PTA is only disrupted in Chapter 4. As I argue there, events such as conferences can act as impetus of disruption but also revision of organisational essence.

7 In this instance Paris refers to the method of splenectomy, one of the earliest methods of treating thalassaemia. This involved the removal of the spleen.
On another occasion I was told by the mother of a thalassaemic child of how people in the 1960s and even early 1970s would perceive thalassaemia contagious and would not let their children play with anaemic children.

According to Dr. Hadjiminas, Dr. Gillespie recommended the introduction of obligatory premarital testing as early as 1957, in a letter to the then British administration (Hadjiminas, 2008: 96).

Although a moral argument can be made that, although the prevention system does not directly promote abortions, it indirectly encourages them. For an overview of the bioethical debate surrounding thalassaemia in Cyprus see Hoedemakers and ten Have (1998).

Inconsistencies of blood transfusion scheduling are also caused because of thalassaemia patients from the occupied, Turkish part of Cyprus crossing over to receive treatment. Much like Greek speaking Cyprus, the northern part of the island also has high thalassaemia prevalence (Bozkurt, 2007), and similarly lacking healthcare (Rahmioglu et al., 2012) (although the fact that patients cross over to receive treatment might indicate an even more wanting healthcare system). Moreover, thalassaemia patients from the north part of Cyprus are prioritised, meaning that should they request a transfusion they jump to the front of the transfusion “queue”. Although this is an arrangement which might cause frustration and inconvenience to Cypriot thalassaemia patients it is a sensitive point which carries subtle dimensions of national politics between the two sides, and is thus unconditionally accepted from all.

A normal haemoglobin level for an adult is between 12-18 grams per deciliter.

A distinction developed by military and social theorists is that between strategy and tactics. An acceptable distinction between the two is that while strategy is a certain predispo-
sition which aids in developing a battle plan, a tactic is a specific practice which unfolds, adjusts and also is influenced by the conditions in a specific locale (Clausewitz, 2008: 74; de Certeau, 2011: xix). For my part I will not adopt this distinction, not only because I find it to not necessary in the context of the theoretical claim I am trying to make, but also because it affirms a vocabulary of warfare. On the contrary, as I try and convey in this chapter, tactics in the context of patient activism are not aimed at defeating an opponent, but rather achieving political collection.

14 For his part, Tarde takes his cue from Leibniz – see Tarde (2012).

15 The White Book has been recently published. See (Vives-Corrons et al., 2014)

16 Although I cannot pursue this route here, it is worth pointing out the relevant literature focusing on the negotiation and contestation of the notion of expertise by patients and publics (Rabeharisoa et al., 2014; Brown 2009). The fact that TIF actually pursues such negotiation and contestation - of making the title of expert available to not only doctors but also patients - in my eyes makes its organisational structure all the more interesting and productive.

17 Lévi-Strauss uses the term “floating signifier” to denote a symbol which has “zero symbolic value, that is, a sign marking the necessity of a supplementary symbolic content over and above that which the signified already contains, which can be any value at all, provided it is still part of the available reserve” (Lévi-Strauss, 1987: 64). For example, the category of “patient” provided to the delegates of the conference can be conceptualised as such: as a sign which has a set form, but no meaning, thus, in its use, being able to reconcile diverging patient circumstances.
Thalassaemia patients often use the Greek term *paschondas* to refer to each other, as in this occasion. The term translates to English as “sufferer” or, alternatively, “one who is affected”.

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