

**A new configuration of power/knowledge in the realm of biopower: the cases of two patient-user organizations**

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## Introduction

Since Foucault's study of *The Birth of the Clinic* (1973) Foucauldian ideas have been widely used in the theorisation about and research on medicine, health and illness.<sup>1</sup> This paper studies the relation between power, knowledge and organizations of patients-users that take place within the realm of biopower via two case studies: the French Association Française contre les Myopathies (a patient-user organization that struggles against neuromuscular diseases, henceforth AFM) and Vivopositivo (a Chilean umbrella organization that gathers together people living with HIV/AIDS). We introduce the concepts of power/knowledge configuration, politicised collective illness identity, patient-user organization and biological citizenship. Our descriptions and analyses of patient-user organizations are based on the research of documents, websites, observation and a number of semi-structured interviews with key actors from each organization. We discuss the similarities, differences and trends that can be inferred from the cases and suggest that these are representative of the formation of a new type of socio-political identity and a new form of citizenship - biological citizenship - that have emerged lately in the realm of biopower. Furthermore, the practices of knowledge production of the AFM and Vivopositivo are illustrative of a new level of biopower due to the involvement of patient-users views and interests qua biological citizens.

Among other things, patient-user organizations are politically influential because they introduce a new type of power/knowledge configuration and new forms of subjectivation within the realm of biopower which is characterised by the empowerment of patients' positions, hence becoming proper patient-users. Accordingly, our main conclusion is that we are witnessing the emergence of a new configuration of power/knowledge in the realm of biopower. We claim that this new configuration of power/knowledge is complex, including, on the one hand, scientific discourses and practices such as medical discourse, genomics, public health and public policy and the(ir) respective regimes of truth and forms of subjectivation and objectivation and, on the other hand, radical political discourses and practices of patient-user organizations that put forward unprecedented understandings of identity, citizenship and politics that empower people through forms of self-governance.

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<sup>1</sup> A few examples are Armstrong (1995), the collection edited by Petersen & Bunton (1997), Novas (2006), Rose & Novas (2004).

Current changes in the field of medicine and disease are partly the result of a) the reframing of illness in contemporary world, b) the coming out of new technologies and advances in life sciences and c) the mutation of health social movements' and patient-user organizations' strategies, tactics and practices. We think that these three factors can be observed in the changing practices of knowledge production of patient-user organizations. As we will argue in more detail, involvement in research, especially biobanking<sup>2</sup> practices on the part of the AFM and the production of critical social research on HIV/AIDS on the part of Vivopositivo, the creation of public awareness, the provision of peer counseling, among others, are important knowledge practices that frame their respective roles in the realm of biopower.

### Health Social Movements, Patient-user Organizations and Politicised Collective Illness Identity

The study of contemporary patients' social movements and organizations has revealed that they are introducing important changes in the field of biopower. Foucault used the term biopower to refer to an array of phenomena that act upon human life, public health and population's existence, reproduction and decay and the state (Rabinow & Rose, 2006). Following Foucault's example, we think that the study of biopower has to be context specific, and very localised, both in time and space, rather than universalistic or general. The concrete and specific strategies of control and contestation that take place in the field of biopower is what we call biopolitics (Rabinow & Rose, 2006). The study of biopolitics requires a close case-by-case examination and the avoidance of quick and sweeping generalisations. Within the field of medicine, health and illness, biopolitics includes the management of reproductive rights and a politics of population control, a wide range of public health care policies, policies intervening in population's hygiene and, importantly, forms of classification, definition and control of populations. Indeed, the definition of vulnerable or risk groups, of disabled persons, of sick and healthy populations depend on classificatory systems that organise our understanding.

Patient-user organizations are part of the phenomenon of health social movements that take place within the realm of biopower.<sup>3</sup> Health social movements are "informal networks based on shared beliefs and solidarity which mobilize around conflictual issues and deploy frequent and varying forms of protests" that challenge established (medical) authorities, health policy realms, medical belief

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<sup>2</sup> Biobanking defines the collection, manipulation and usage of biological material, such as blood, tissues and cells, and its associated data (Cambon-Thomsen 2006).

<sup>3</sup> The following paragraphs draw on Brown & Zavetoski (2004) and Brown et al. (2004).

systems, and research practices.<sup>4</sup> In its turn, a patient-user organization is an association of people living with a similar health condition, diagnosis or disease. Organizations can include not only the sick or disabled, but also relatives, friends and other loved ones. Health social movements tend to evolve from the informal network into more institutionalised and relatively more bureaucratic formations when forming patient-user organizations.

Movements and organizations are expressions of collective identities and shared communities of understanding. They are the result of an imaginary, cognitive, moral, and emotional bond between individuals who feel they are members of a broader community. Forms of collective identity are ontologically political, and can potentially be politicised at any moment.<sup>5</sup> Collective identities require some sort of identity marker to identify/differentiate themselves from other identities. Illness and/or disability is/are key identity markers of collective illness identity (Brown et al., 2004). When illness is experienced and represented as a source of collective grievance and trigger socio-political demands to the political system, a particular identity is formed and politicised. Health social movements and patient-user organizations, as particular forms of politicised identity groups, frequently present broader social critiques against structural inequalities and identify outside *loci* of power putting political and social responsibility for their own grievances and suffering outside themselves. In a nutshell, it is crucial to realize that they do not only fight against disease; their struggles are against forms of exclusion, stigma and discrimination; their fight might be against uneven distribution of social power, uneven access to health services; medical authority or the dominant biomedical paradigm.

Politicised collective illness identities do not need to be directly experienced but can be imagined. In other words, the illness can be experienced as a fantasy formation of a collective bond that constitutes an imagined community. In its turn, collective illness identity (no matter if politicised or not) can be crucial in the formation of each individuals' identity that identifies him/herself with the broader community (collective identity) of the diagnosed, ill or disabled people. The transformation of a personal trouble, such as illness, into a social problem and then a political issue is due to an imaginary process: the personal trouble gets collectivised, this is, expanded to a wider totality through symbolic and imaginary means. Put differently, the personal experience of a particular health

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<sup>4</sup> This definition reworks the one put forward by Brown et al. (2004: 52). In their turn, they follow Della Porta and Diani's 1999 definition of social movement.

<sup>5</sup> For a detailed development of the argument see Laclau & Mouffe (2005) and Mouffe (2005)

condition can expand into a collectively alleged political problem through collective practices and imaginary means.

### **Biological Citizenship**

Nicolas Rose and Carlos Novas (2004) state that we are currently witnessing a new kind of citizenship which is taking shape in a biomedical era because “aspects of life once placed on the side of fate become subjects of deliberation and decision” and add that “a new space of hope and fear is being established around genetic and somatic individuality” (Rose and Novas 2004: 458). Their concept of biological citizenship emphasizes the “biological conception of a shared identity” and links “the conceptions of citizens to beliefs about the biological existence of human beings as individuals, as families and lineages, as communities, as population and races, and as a species” (Rose and Novas 2004: 440). In his later work, Rose (2006) expands his notion of biological citizenship beyond the purely genetic and somatic to include other identity marks. This newer concept of biological citizenship seems suggestive to us because it stresses the self-governing practices of patients and their refusal to accept the identity as “sick persons” as “fate”. Despite its merits, the category still remains undertheorised. Hence, we aim to supplement this view by covering what we think are their pitfalls and flaws through offering a stipulative definition of biological citizenship: We understand biological citizenship as an emerging dimension of citizenship that empowers people by entitling them to claim politically new rights related to the field of biopower. In other words, biological citizenship is not necessarily about biological conditions linked to certain rights, such as reproductive rights, but about politicising biomedical issues and group-based demands and interests by claiming a universal justification of the rights of the citizen that emerge in the field of biopower. This, normally against forms of negative biopolitics that aim at controlling the population.

### **The AFM and Vivopositivo**

Let us now turn to our cases, the AFM and Vivopositivo. The AFM is a French patient advocacy group whose mission is the fight against neuromuscular disease. According to Rabeharisoa (2003) the AFM had 4.500 members in 2003. It pursues two fundamental goals: “to help patients and their families in all areas of daily life” and “to support research on neuromuscular diseases with a view to eventually finding a cure for them” (Rabeharisoa, 2003: 2130). It is also important to note that the AFM is financially independent. Most of its budget (almost 80%) is raised thanks to Téléthon©, a

yearly festival. Since its inception in 1958, the AFM has followed the principle of turning “towards science” but refusing “to be controlled by scientists”. Its engagement in research, that has been depicted as a “partnership model” of direct civic participation with science (Rabeharisoa 2003).<sup>6</sup> This model emphasizes patients as equal partners of experts and scientists in knowledge generation. Secondly, it identifies patients as decision makers of their own research policy, which “does not delegate to them [the scientists] decision-making powers on the definition, management and evaluation of its research policy” (Rabeharisoa 2003: 2132), but instead claims the decision-making power for itself at all times. These features position the AFM as a very particular case of a patient organization’s involvement in research. Thirdly, the AFM is a private non profit organization. Focusing on rare disease patients, the AFM, began advocating a do-it-yourself approach (Rabinow 1999) and has developed a “partnership model” of equal partnership between the patient organization and the researchers. These features point out to the unusual nature of this patient organization, which can be especially considered particular in the French context.

As a matter of fact, the AFM is contested by many in France. The Syndicat National des Travailleurs de la Recherche Scientifique (SNTRS), for instance, argues that the patient-user organization’s research policy leads to a privatisation of research and a disengagement of the French state in public research (SNTRS 2003). The SNTRS’s criticism exemplifies the viewpoint that the state rather than private initiatives should foster and retain control over basic research.<sup>7</sup>

Having said this, let us move to Chile, to the description of some of the key features of VivoPositivo. In 1997 the Chilean state took the unilateral decision of cutting off the provision of bi-therapy for free. This created the conditions for organizing resistance among people living with HIV/AIDS. The result was the foundation of the National Association of Organizations of People living with HIV/AIDS (COORNAVIH), which a year later changed its name to Vivopositivo. Its goal is to “offer an integral solution the threats and challenges posed by the epidemic in order to improve the life quality of

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<sup>6</sup> Rabeharisoa (2003) presents the 'partnership model' in contrast to two other models: the 'auxiliary model', and the 'emancipatory model'. In case of the latter, a patient organization tries to put its specific matter on the political research agenda (e.g. HIV/AIDS activists in the 1980/90s) and rearticulates the traditional roles between patients and scientists. In case of the former, decision making power is delegated to a scientific council and the patient organization contains the role of a direct payer for the research conducted. The traditional roles are maintained.

<sup>7</sup> In the opinion of some French researchers, arguing in compliance with the French etatist culture, biomedical and genetic research, especially the one for rare diseases, is neglected by public funding. Although French governments have promised repeatedly to increase the overall research budget, which seems to align with heavy investment in the biotechnology sector, researchers remain doubtful about the effects of such announcements.

people living with and affected by HIV/AIDS.”<sup>8</sup> Its mission is to build in a participatory and representative manner an integral solution to the challenges of the pandemic from the perspective of men and women living with HIV/AIDS regardless of gender and age, and jointly with society. Vivopositivo’s activities aim to improve living quality and the social and affective milieu of people living with HIV/AIDS. Vivopositivo pursues such objectives through the defense of human rights, citizenship rights, sexual and reproductive rights, universal access to treatment, health promotion, prevention and the strengthening of the network of national organizations of people living with HIV/AIDS and their friends and relatives.

Vivopositivo is an umbrella organization that gathers together more than 40 grouping across the country. Although it is difficult to estimate the exact number of represented individuals, it is evident that it is the most important organization in the field in Chile.

Vivopositivo has a key role as spokes organization vis-à-vis the state and its policies. It takes part in important decision making processes, such as the acquisition of drugs and doses at a national level and the design of prevention national public campaigns. Thus, Vivopositivo has collaborated with the Chilean state in important matters. However, it has also sued the Chilean state for cases against human rights. Among the most notorious, are the cases regarding the limitation of reproductive rights of women living with HIV/AIDS.

These changeable strategies and tactics do not help us to accommodate Vivopositivo neither as a purely resistance organization nor a partnership organization. Furthermore, Vivopositivo’s case is complex also because it offers a series of services to its members, such as psychological counselling for individuals, couples and families; peers counselling and support; juridical counselling, nutrition advice or recreation. It also sponsors research in the field of HIV/AIDS studies focusing mostly on the problem of social stigmatisation and exclusion and, interestingly, it has also sponsored a 3 year applied research on the promotion of citizenship among people living with HIV/AIDS.

An interesting aspect in both cases is its “movement spill-over” effect (Meyer & Whittier, 1994). Frequently social movements work in coalitions, relate to one another and learn from each other. The trajectories and movement of important personnel from one to another and the transference of

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<sup>8</sup> <http://www.vivopositivo.cl/php/home.php.html> (01/05/2007).

activists knowledge and skill are very important. For instance, among the key founding members of Vivopositivo were political militants and sexual minority activists who transferred their skills to the new organization. Something similar occurs with the AFM, of which one key foundational member had gained knowledge in leadership and management as high ranking important labour activist.

All these previous observations on organization size, mission, finance, organization type, strategy and “movement spill-over” show patient-user organizations do not appear in a vacuum and, on the contrary, they operate within a social and institutional environment, are affected by power relations and even by personal trajectories.

### The French and Chilean Health Systems

Traditional views on power fall short in providing us with tools and a suitable account of patient movements and biological citizenship precisely because they overlook the relation between knowledge and practice that Foucault rightly emphasized. Contemporary Chilean and French societies –and arguably all contemporary societies- can be characterized, among other constitutive features, by certain power/knowledge configurations articulated in a biopolitical realm that revolves around issues of life and its administration towards making human life flourish and enhance populations’ productive capabilities towards an end.<sup>9</sup> It is in this context that forms of government yoked together with applied disciplines of knowledge begin to take seriously issues such as birth-rate, diet, longevity, sickness and hygiene. The welfare state in France and institutions of social security in Chile reflect this biopolitical preoccupation and are examples of the the management of life (both health and illness) itself.<sup>10</sup>

Nowadays, France has a universal health coverage system which has been implemented based on residence. The public system as a whole provides a high standard of care, medical technology and

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<sup>9</sup> Foucaults’ interest on biopolitics is a complement of his previous studies on discipline that aimed at studying the “conduct of conduct”. The inflection point between the two approaches can be appreciated in the period between his earlier focus on discipline and control as presented in *Discipline and Punish* (1977) and his later focus on biopolitics in *The History of Sexuality, Volume 1: An Introduction*. (1978).

<sup>10</sup> We do not refer strictly speaking to the state because there was a plethora of institutions that contributed to the aim of controlling populations. The history of social policy provide us with a few interesting examples. On this, see Arellano (1986) and Valdivieso (2006) In the case of Chile, the role played in such issues by the martyr president Salvador Allende ( 1908-1973) it was very significant. Being a physician himself he fostered and presented several projects to enhance diet and public health of the Chilean population. In one speech given for the promulgation of the law that established a state guarantee for every Chilean kid to receive a minimum of daily milk he argued that a child who has not have enough protein intake will never become a well developed and productive adult capable of realizing his/her complete potential.

develops quality research.<sup>11</sup> Although Chile introduced recently a system that provides explicit universal guarantees through the controversial Universal Access and Explicit Guarantees Plan (Plan de Acceso Universal y Garantías Explícitas, AUGE), the range of illnesses and conditions it covers, the type of interventions it consists of and its geographical coverage reflect the goal of providing a basic social security which does not threaten the continuity of the neoliberal social policy model introduced during the dictatorship (We will come back to this towards the end of this section).<sup>12</sup> Needless to say, there is an immense gap between Chile and France in public health matters. Take only one representative datum: France spends close to a 10% of its GDP in health, compared to only around a 4% of Chile.<sup>13</sup> Besides these differences, there are significant similarities between the two systems, which we want to focus in the following paragraphs.

First, voluntary mutual aid societies were the origin of both health care systems. Maybe due to this “private” origin, both cases are today representative of mixed systems that combine state service and private entrepreneurship (see Immergut, 2006 and Sabadier et al., 2004 for France and Castiglioni, 2005 for Chile). Secondly, nowadays, in both countries the health care system consists is dominated by of three types of institutions: public hospitals, private clinics and non-profit healthcare institutions.<sup>14</sup> Thirdly, in both countries, public institutions provide their service to the majority of the population.<sup>15</sup> Fourthly, they share a common emphasis in decentralization of their primary, secondary and tertiary care.<sup>16</sup> Fifthly, in recent decades both systems have undergone reforms to introduce either state regulations or de-regulations in order to maximize both efficiency and equality in systems characterized by a traditional state-centrism. In France this tradition is referred to as *etatism* and relates to the entrenched cultural belief that the state is expected to address (certainly to handle and

<sup>11</sup> “The French healthcare system has been in place and has continued to evolve for more than one hundred years, and was classified the “best health system in the world” by the World Health Organization (WHO) in June 2000.” <http://www.ambafrance-us.org/atoz/health.asp> (03/06/2007)

<sup>12</sup> This minimalistic approach to social policy in the area of health care can be illustrated by the fact that from July 2007 on, AUGE will cover only 56 illnesses. On the continuity argument, see Castiglioni (2005).

<sup>13</sup> France’s comparatively old population has a big impact in its health spending, compared to Chile’s relatively younger population.

<sup>14</sup> For general views on health care systems and their evolution until recent times see, for France, Immergut (1992, ch. 3) and Sandier et al. (2004). For Chile, see Castiglioni (2005, especially ch. 5) and <http://www.minsal.cl>. For updated information on Health Care public budget in Chile, see [www.dipres.cl](http://www.dipres.cl) and for previous years, [www.ine.cl](http://www.ine.cl) and [www.bcentral.cl](http://www.bcentral.cl). The standard literature in the field distinguishes a variety of health care systems. They vary along a continuum from private to public provision with a large space for different mixed systems.

<sup>15</sup> In France, there are three main health insurance schemes that cover little more than 95% of the population. In Chile, the public system covers a 75% of the population, the 25% left rests on the private ISAPREs.

<sup>16</sup> For this three-partite distinction see Turner, 1995. In both countries public hospitals include a diversity of institutions, that vary a lot in terms of size and facilities.

ideally to solve) citizens' social and political problems.<sup>17</sup> Reforms have included, on the one hand, the creation of central authority controls and special laws to regulate the private sector and, on the other hand, market-like incentives for public delivery, personnel and services' cut-backs and even privatization.<sup>18</sup> Other measures are clearly private-public joint efforts to foster the entrance of the private, as is the case of state subsidies of private health care initiatives (Immergut, 2006; Sabandier et al., 2004). These last features are characteristic of a neoliberal configuration of power/knowledge that revitalizes the old liberal themes of liberty, freedom of choice and market (Rose, 1996). This neoliberal configuration that also criticizes the social-democratic framing of citizenship as expressed in welfare regimes because of fostering citizens' dependency on state provisions has been implemented in Chile with relative success.<sup>19</sup> The state reduced its direct duties towards citizens under the neoliberal "mentality" of government and fostered autonomy, freedom of choice, the figure of the entrepreneur, the rational and self-interested consumer and the responsabilization of the individual. All of these have been conceived as resources for governing the conduct of populations without the state. Consequently, the neoliberal configuration in the field of (bio)medicine and illness aims at producing self-responsible, self-governing subjects able to care for themselves who are at the same time self-empowered clients of health services. Almost three decades ago, Foucault us the risks involved in this defense of state limitation and individuals' autonomy ().\* Instead of a pure gain for individuals' natural liberty, neoliberalism's kind of governmentality is functional to a pervasive social control that is post-disciplinary and produces an undesirable privatization and invisibility of public issues and fosters the atomization of the individual and his retreat from public matters. Furthermore, the neoliberal framing of citizenship as self-responsible is also functional to the logic of

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<sup>17</sup> On this see Kempf (1999) and Christadler (1999).

<sup>18</sup> In France, career in the medical field is mostly by seniority; nonetheless, even in France, with strong medical corporations (see Immergut, 2006, chapters 2 and 3) practitioners and establishments are evaluated nowadays and the public is informed through a nation-wide ranking system of hospitals and practitioners (see Sabadier et al. 2004 and <http://www.ambafrance-us.org/atoz/health.asp> (03/06/2007)). In our opinion, this shows the introduction of some sort of market-driven incentives in the work of the public sector. At the same time, the strengthening of citizens' health care guarantees and their empowerment as clients. In what regards to recent reforms in Chile, it is notable the Superintendence of ISAPRES (Private Health Care Institutions) that regulates the private health insurance market was introduced in the mid 1990s. The recent AUGE is the most ambitious reform. This is a compulsory health insurance system which guarantees 56 important illnesses. The reform was highly controversial. Organized medical doctors and health civil servants opposed the reform and according to a highly ranked Official in the Health Ministry. The reform is still obstaculized in its implementation in the local level of medical settings (personal communication).

<sup>19</sup> Evaluations of the system are very much ideologically driven still. By contrast, a balanced view can be found in Castiglioni (2005).

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privatization, to consumer-driven forms of social provision and to the expansion of the idea of the entrepreneur of one-self. All these are indirect techniques to conduct behavior.<sup>20</sup>

The brief survey of general features of France's and Chile's respective health systems shows that there is a political arena for health movements, patients' organizations and citizens to mobilize demands and to build up their own initiatives in areas only partially covered by the state and private market-driven health policies. The self-understanding and practices of self-governance of patients' organizations introduce changes in the field of health, medicine and the social acceptance and depiction of illness and, although they might have an affinity with the neoliberal configuration of power/knowledge. What dominates their contribution is the self-affirmative role of the ill individual who is depicted as an active and self-empowered person that becomes an active person rather than a passive "patient". He/she is empowered and takes care for her/himself, avid for information about her/his condition and able to judge for her/himself and give or reject treatment or even denying disease and embracing it as a choice of individual life style<sup>21</sup>. In relation to our cases, the AFM and Vivopositivo, this has not meant the retreat of the state but, instead, demands for further and deeper involvement of the state to get involved and/or public private partnerships to support their goals.<sup>22</sup> Having presented the institutional environment of our case studies, this is the right moment to move further to the consideration of the role of medicine in the formations of power/knowledge.

### Medicine and Configurations of Power/Knowledge

In *The Birth of the Clinic* (1973) Foucault showed that medicine is an applied and epistemologically weak discipline whose conditions of production are deeply rooted in social relations of power (Foucault, 1973). A key notion of that book was the idea of the 'medical gaze', a practice which is

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<sup>20</sup> In the same line of argumentation, Nikolas Rose has criticized some key aspects of the so-called "the third way" because of introducing neoliberal governance principles such as state retreat of policy areas and the combination of market and soft interventionist policies that give a central role to social collectives, voluntary work and the so-called third sector, and community based programs. However, against Rose, who thinks that "The collective logics of community are here [in neoliberal regimes] brought into alliance with the individualized ethos of neoliberal politics" (1999: 249), we think it is prudent to relativise his critique based on evidence we have produced observing patients' organizations, and in particular the AFM and Vivopositivo. We affirm that these organizations expanded the opportunities of freedom of patients. In this matter we agree with Novas (2006), Rabeharisoa (2003), Rabeharisoa & Callon (2002), Epstein (1995), Brown and Zavestoski (2004) and Brown et al. (2004). Rose seems more positive about the possibilities of freedom build up by patients' organizations and citizens in the field of medicine and illness in Rose & Novas (2004) and Rose (2006).

<sup>21</sup> A telling example is the case of a young bulimic girl who refuses to regard herself as suffering from a medical condition and depicts it as her right to starve herself to death.

<sup>22</sup> On Vivopositivo, personal communication. On the AFM, see its website <http://www.afm-france.org> (28/08/08)

both an art and a knowledge for establishing diagnoses. Based on this medical gaze illness and health get defined, and the healthy and the unhealthy classified. In *The Order of Things: An Archaeology of the Human Sciences* (1970) he developed that idea further and introduced the notion of the 'discursive-object'. This is a radical constructivist view of how disciplines define their fields of research and give meaning or even construct their objects of analysis through discourse.

In *Discipline and Punish: The Birth of The Prison* (1977) Foucault gave a step further stating that all forms of power rely on forms of knowledge and vice versa:

“... power produces knowledge (...) not simply by encouraging it because it serves power or by applying it because it is useful” but because “there is no power relation without the correlative constitution of a field of knowledge, nor any knowledge that does not presuppose and constitute at the same time power relations.” (1977: 27).<sup>23</sup>

In other important works of the same period he introduced the neologism power/knowledge to refer to this entangled and mutually dependent relation (Foucault, 1980; 2000a). It is important for us to retain the idea that there is no knowledge production or scientific practice, including medicine, which is independent of power. All forms of knowledge are somehow driven by a will to power and, therefore, claims of truth result from the productive features of power. Thus, beliefs associated with concepts like health, disease, contagion, risk group, healthy and unhealthy behavior, among others, are formed through power devices and are true in a certain context at a certain time. These concepts need to be addressed as discursive constructs or in Foucault's terms, as discourse-objects (1973) enmeshed in power relations.

Drawing on Foucauldian ideas, Deborah Lupton (1994) stated that illness “is not only physically experienced, but is spoken” and, hence, its meaning is socially constructed through discourses and practices that take place around sickness. Biomedical and patient-user organizations discourses and practices are central to the definition and framing of key concepts and experiences in the field of health and illness. Whereas the discourse of patient-user organizations is employed in the attempt to convey the pain or discomfort a person feels in relation to his/her condition, the aim of the biomedical

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<sup>23</sup> Although this quote is from *Discipline and Punish* (1977), Foucault was eager to state similar statements about medicine. See, for instance, his earlier work on *The Birth of the Clinic* (1973). Although both works are written in a similar critical spirit, the advantage of his later works (genealogies) is that they analyze with more refined tools the articulation of power and knowledge.

discourse is to define in objective terms health and illness and to determine what is the population at risk, to define the relationship between doctor and patient and to produce tools and techniques to manage these for the sake of the population's health enhancement. Regarding biomedical discourse, Lupton explains that

“...words direct the relationship between the doctor or nurse and patient; words nominate which kinds of people are considered to be at risk of developing an illness and how they should be treated.” (1994: 5).

How can we characterise further this discursive relationship between patients and physicians? Turner (1995) suggests that uncertainty is at the core of the medical paradigm and crucially shapes the doctor-patient relation. The patient's trust on the physician's expert judgement is the quintessential feature of the patient-doctor relationship. This trust is backed by scientific knowledge and the certification of the doctor as a professional.

Because of patient's ignorance, the patient is not in a position to judge the effectiveness of the service against other forms of treatment. (...) [T]he physician defines the clinical situation and controls the evaluation of the product. It is this uncertainty which underlies the notion of the docile patient role in relation to the doctor's intervention. (...) [U]ncertainty is an essential component of patient compliance within the sick role ... [and] has little control over the norms of treatment in terms of length, form and outcome of the service.” (194).<sup>24</sup>

In summary, discourses, their categories of thought, style, rhetorical tropes, discourse-objects and the different positions of enunciation and hierarchies they establish between different sorts of people seem crucial in the formation of the identity of the ill. This is the topic we explore further in the next section.

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<sup>24</sup> On top of the previous point, theories of the professions have emphasised the process by which “the medical profession became united into a single, recognizable profession, and how members of this profession were able to upgrade their collective status, achieving recognition from both governments and the public for their claims to expertise.” (Immergut, 2001: 16483, see also Immergut, 2006, ch. 2 and Turner, 1995).

## Subjectivation

Generally speaking, we mean by subjectivation the process of constitution of the subject, through an array of disciplinary mechanisms and techniques. The constitution of subjectivity is historically and context dependent and establish concrete regimes of the self. For instance, the sick conceived as patient is passive, a receiver of applied knowledge, an object of medical intervention, a carrier of an illness or detrimental condition. By contrast, a biological citizen is an active agent of self-promotion, creator or articulator of forms of knowledge, advocate of his/her own quality of life (*vis-à-vis* the idea of the patient qua sick person). Theoretically, these different formations of the subject relate to different regimes of the self and power/knowledge configurations. These typologies are merely analytical and can only partly resemble complex historical transformations which are never deterministic, are frequently slow and seem to combine aspects of the pure models.

It can be argued that the traditional biomedical knowledge and its power aim at constituting patients as able to follow directions and to act accordingly in an obedient manner sticking to treatment in order to change their behaviour according to social expectations and medical directions. Today, this approach is often combined (or even replaced) by the figure of the patient as self-responsible for his/her life. Furthermore, in today's era of biomedicalization, health has become a moral obligation, articulated as the moral responsibility of the individual to remain healthy (Crawford 1985) and to manage her/his own fate (Strauss et al. 1984), rather than to recover from illness (Parsons 1951). On the other hand the moral obligation towards ones own health implies both the will and capacity of self-transformation and self-governance that points to the possibility of experiencing disease as something that can be overcome and improved, rather than a matter of fate (Clarke et al. 2003: 172). Thus, the subject becomes a surface criss-crossed by opposing forces of control and self-government. This struggle takes part in the formation of the contemporary patient.

Our interviews with members of Vivopositivo and experts of the Chilean health care system show that various technologies of disciplinary control and pastoral power are relevant in the reproduction of the biomedical paradigm and experts' power. Among these, it seems particularly important free provision of medical information, emotional contention and counselling, condoms, medicine and anti-retroviral drugs. As pointed out earlier, all these are services provided for free, under the condition of undergoing regular checkups. Regular checkups are then instances where patients have to provide

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accounts and evidence of their conduct (a sort of confession), what also permits keeping an updated dataset of patients (a form of actuarial power).

The hierarchy of power expresses itself sometimes in dramatic personal experiences. We have come across accounts about complaints of patients living with HIV/AIDS against the derogative value judgement of some physicians and health workers. According to these accounts, some women living with HIV/AIDS have been told that they ought not to get pregnant, or should not have sex “since they are HIV positive”.<sup>25</sup> Their reproductive rights are limited (“beschnitten”) by the power of the practitioner. We came across one account about a woman who was sterilised without informed consent. And although a quantitative study run by Vivopositivo shows that health care personnel – both medical and administrative- is not discriminatory, a significant percentage of respondents living with HIV/AIDS were convinced that at least in some occasions they would need to wait longer than other patients of the health care system and would be treated in a bureaucratic manner (Zambra et al., 2004). In relation to the latter, we came across another illustrative account. The patient needed to wait until the last appointment of the day at the dentist without any reason given. S/he speculated about the possibility that the dentist would think that s/he could transmit the virus to other patients if treated in-between other appointments. This happened systematically over the period of his/her treatment, so that no accidental cause could be claimed in this case. The point is that as everybody knows a dentist is supposed to sterilise his/her instruments in-between patients and should throw away all disposable materials. In this regard, we agree with an expert’s view who explained that this sort of accounts shows how entangled personal value judgements of doctors are within the dominant biomedical gaze that still stigmatises patients. He insists in talking about “virus contagion instead of transmission”, and “aim at controlling the sexuality of persons living with HIV/AIDS”.<sup>26</sup> Thus, the effects of hierarchies established in the system seem to go beyond the realm of pure medical care.

In what regards to the AFM, we have posed the question of how much the practice of biobanking, with which we will deal in detail in later sections, relies on the (supposedly) objectifying gaze of science. As we have explained, the AFM has implemented a partnership model to work as an

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<sup>25</sup> According to one expert, this seems more common in rural areas of Chile.

<sup>26</sup> Here we are using the notion of the gaze (le regard) in its Foucauldian sense. The gaze relates to the power exercised by the observer over the observed because he/she has the “legitimacy”, the “right”, the “qualification” and/or consent to examine the matter. A more Lacanian notion of the gaze opens other possibilities that would lead us to consider the limitations of the gaze.

advocacy group together with medical teams and researchers. Accordingly, the AFM uses science's objectifying gaze, for instance, when deciding for fostering a particular research project. This is evident in the way it supports the implementation of the practice of biobanking that deals with taking, separating, classifying, storing and distributing human biological samples for the sake of advancement of research and eventually of patients' health. Thus, against some health advocacy movements that seek to confront or resist medical knowledge radically<sup>27</sup>, the AFM not only embraces but also forms it.

It seems to us that the particularities of the conditions that affect people from our case studies are relevant in this matter. This, because they have less incentives to exit scientific knowledge altogether. Consequently, these organizations are willing to use scientific evidence for promoting their own interests, but at the cost of either developing an ambivalent attitude towards medical expertise and authority as is the case of Vivopositivo, or they make all efforts to legitimise their own expertise vis-à-vis medical knowledge to promote partnership as in the case of the AFM. While they depend on scientific knowledge, simultaneously they challenge "its social, cultural and economic dominance" (Brown, 2006: 682).

This ambivalence towards the biomedical discourse leads us to reconsider the problem of the formation of the patient in a less deterministic way. This is, less determined by the hierarchies established by the biomedical system, its discourse and practice. Consequently, we agree with Nikolas Rose and Carlos Novas (2004) who argue that a new kind of citizenship is taking shape in the era of biomedicine. Let us move now to the analysis of the mechanisms that work in the level of the subject in the formation of his own identity.

### The Care of the Self

Foucault used the terms technologies of the self (and sometimes technologies of the care of the self) to refer to the strategies, mechanisms and various ways we relate to and conduct towards ourselves.

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<sup>27</sup> We have come across one Chilean organization, Chilean Real Citizenship of the Deaf Association (Asociación Ciudadanía Real de Sordos de Chile ACRESOR) that defined the deaf "condition" as a culture with a language on its own based on sign language. The association rejects the depiction of their members' identity as sick or disabled. Similar radical associations reject medical knowledge in the matter and affirm their right to perpetuate deafness as a community marker and the survival of their community alongside other communities of equal worth based on the idea that they are defined as a cultural linguistic minority similar to other minority ethnic groups. This resembles some of the arguments of multiculturalism (Taylor, 1993). On this see Blume (2000).

Some technologies of the care of the self are functional to the aim of governing the health of the population. Thus, they should not be seen as purely individualized. Among those related to health and illness, the development of self-discipline in diets, safe sex practices, regular sports, forms of meditation, psychotherapy and counselling support seem particularly important. All these are relevant in promoting self-control under an ethical gaze that, in most cases, does not contend the medical gaze but complements it. What is important to note here is that all these medical, biological and non-scientific knowledge that is translated into behavioural directions to be followed by the sick have a moralistic effect on the subject, which suggests that these forms of medical and para-medical knowledge and practices subjectify the sick (Coveney, 1998). These tactics of governmentality<sup>28</sup> express a combination of, on the one hand, an ethics in the idiom of pastoral power. This is a power that cares for the sick and its promotion for the sake of the whole of the community. On the one hand, it constitutes a form of self<sup>29</sup> and on the other hand, an individualistic ethics of self-care and responsabilisation. Both of these are functional to neoliberal governmentality.<sup>30</sup> However, there is also dispute about such matters and patient-user organizations such as Vivopositivo question dominant views about how to act and relate to oneself. Some interviewees have pointed out that the questions of morality, sex, and the control of pleasurable devices are of paramount importance for understanding HIV/AIDS, which cannot be reduced to a pure medical matter of health and illness. This contentious practice of questioning morality is highly political and has been a key step in the formation of the political identity of Vivopositivo.

Although most of Foucault's work on power and biopolitics has been used to understand processes of control of populations in modern societies, the late Foucault provides us with a more positive view on the matter, especially when writing about critique (1986a), the rights of the governed (2000b) and the life of the individual in relation to an ethos of self-formation through an "aesthetics of the self"

<sup>28</sup> In this respect we disagree with Coveney's interpretation. On "pastoral power", see Foucault, "Governmentality" (in the Faubion volume on Power, 2000c), in which he defines "pastoral" power as part of the genealogy of the development of governmentality.

<sup>29</sup> Foucault states: "Through ... different practices - psychological, medical, penitential, educational - a certain idea or model of humanity was developed, and now this idea of man has become normative, self-evident, and is supposed to be universal." (1988: 15).

<sup>30</sup> Nikolas Rose has been sensitive to political disputes around ethical issues (1999). In his more recent book calls ethopolitics to the "... attempts to shape the conduct of human beings by acting upon their sentiments, beliefs and values - in short, by acting on ethics." But instead of disciplinary, these are "...self-techniques by which human beings should judge and act upon themselves to make themselves better than they are." (Rose, 2006: 27; emphasis added). Although ethopolitics is wide in range, it revolves around questions of life such as quality of life, the right to choose, the right to life, among others.

(1986a; 1986c). This can potentially give a positive twist to the notion of biopolitics as the opportunity to free the subject from social controls, oppressive regimes of truth and forms of undesired government. It also opens new possibilities for working on ourselves creatively, expanding our horizons of experience and improving our quality of life. In our view, health social movements, patient-user organizations and the category of biological citizenship constitute good examples of this positive and liberating side of biopolitics. As we have seen, health social movements and patient-user organizations have successfully claimed a significant role in the field of (bio)medicine, health and illness. But how do they define the question of knowledge?

### Patients' Organizations Discourse: The Question of Knowledge

Patients' organizations articulate the meaning of health and illness discursively in a complex relation with hegemonic medical authorities. As we have seen, this relation cannot be described as simply rejecting such authority. Activists influence the production of knowledge "through amassing different forms of credibility" and "can in certain circumstances become genuine participants in the construction of scientific knowledge". Thus, "within definite limits" potentially they can "effect changes both in the epistemic practices of biomedical research and in the therapeutic techniques of medical care." (Epstein, 1995: 409).

The common belief about sciences' autonomy of other social spheres needs to be relativised. Although we agree with Foucauldians that science plays a crucial role in defining particular regimes of truth and causes important social outcomes through the disciplining effect of truth claims, this should not mean that regimes of truth are neither unchangeable nor immune to the blending of other discourses such as the activists' discourse. Our study of Vivopositivo and the AFM show that it would be a mistake to understand the role of patients qua lay people as passive individuals that can only count "as a resource available for use, or an ally available for enrollment" for the benefit of what is too quickly assumed as the true driving force of scientific knowledge: the "entrepreneurial scientist". Although science (and medicine) compared to other more public arenas (such as journalism) can be characterised as a less permeable and more enclosed system of communications. Vivopositivo and the AFM have advanced their own knowledge agendas and have influenced the constitutive rules of knowledge formation in medical science in their specific arenas. In other words, the participation of patients' experience-based knowledge and organizations' strategic goals and values in the

production of scientific knowledge has been effective. These are cases of successful patient-user organizations that are able to (or were forced to) overcome high entry barriers to scientific knowledge and debate, and have gained credibility within scientific communities and the wider public.

How does this happen? First, during our research we have learned that patient-user organizations websites, documents and declarations combine frequently scientific affirmations, experience-based statements, and advocacy statements and evaluations.<sup>31</sup> This discursive mechanism of hybridation allows them to redefine some key aspects of the field of medical discourse. The hegemonic biomedical discourse is forced to introduce new elements in its articulation, hence changing its identity. Thus, the sharp distinction established between specialized biomedical knowledge and lay knowledge is insufficient and is unable to describe the discourses of the AFM and Vivopositivo. The same can be said about the distinction between neutral objectivistic statements and advocacy statements.

Furthermore, the AFM and Vivopositivo have been critical of the biomedical paradigm, although to different degrees and as we have seen in different ways. This, because such a paradigm became a way of consolidating hierarchical relations in the field of medicine and illness. Consequently, this oppositional critique is a second mechanism by which the above mentioned sharp discursive distinctions become relativised.<sup>32</sup>

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<sup>31</sup> Consider the following long quotation from the AFM website, which we take for the sake of illustration: “Contrary to popular belief, rare diseases and genetic diseases affect more people than we may think. They affect 4 to 6% of the population, i.e 3 million French people and 25 to 30 million Europeans. Eighty per cent of these diseases have a genetic origin.[...] Actions to promote autonomy and citizenship of sick and disabled persons, such as the May 1999 demonstration which has achieved concrete results :the creation of the Autonomous Living Plan. In terms of management and citizenship, it is also necessary to gain a critical mass of knowledge, which is the only way to solve the problems patients experience in their everyday life. An overall strategy to provide information on rare disease problems, raise awareness and bring about changes in the health system. Today, a solidarity movement is taking shape and growing bigger, particularly within Alliance Maladies Rares (Rare Diseases Alliance) and Eurordis, and new synergies are developing within Plateforme Maladies Rares (Rare Diseases Platform). These years of struggle and action on behalf of neuromuscular diseases through a general interest strategy has found expression in significant advances for all rare genetic diseases and even for common diseases. We have come a long way – rare diseases are finally recognised as a real public health challenge and little by little research is being organised and new therapies are emerging. But many obstacles remain – diagnostic error, insufficient research, patient management difficulties etc. Although patients’ associations have a major role to play here, they cannot act alone. In this field, public investment is vital. At a time when a new political willingness is emerging to outline a national plan for rare diseases, we must ensure that this plan is structured and financed on a long-term basis.” [http://www.afm-france.org/afm-english\\_version/ewb\\_pages/d/decouvrirafm\\_maladiesrares\\_presentation.php](http://www.afm-france.org/afm-english_version/ewb_pages/d/decouvrirafm_maladiesrares_presentation.php) (28/08/08)

<sup>32</sup> On the AFM see Rebeharisova, 2003 and Rebeharisova & Callon, 2002.. On Vivopositivo, see Zambra, 2004. For useful considerations on lay and experts knowledge in the field see Epstein, 1995.

Related to the two previous points, a third mechanism is the acquisition of cultural competence on part of the patients. For instance, in order to advance knowledge and develop cures for neuromuscular diseases, the AFM built up on the knowledge of patients as active agents of their condition and co-participants in the process of knowledge creation as experts in experience. Today, they claim equal worth compared to scientific experts.<sup>33</sup>

A fourth mechanism is the use of scientific knowledge for the sake of the organization's strategic goals. The AFM uses science as a vehicle, something which can be seen in various instances, such as the following: it has created global-competitive funds for genetic research, and has formed Généthon, a private non-profit organization developing therapeutic products for the treatment of rare diseases and also involved in gene therapy. The latter is entirely funded by the AFM and promotes the constitution of a credible and experts' accepted medical sub-discipline specialized in the knowledge and treatment of muscles – myology, which they think should be equally accepted as, for instance, cardiology - and has sponsored and created the *Institut de Myologie*.<sup>34</sup> All of these bring together the efforts of researchers and patients.

The AFM, in concluding that the state would not act or was very inadequate in supporting rare disease research strategically decided to participate in genetic research.<sup>35</sup> Historically, the AFM decided to become actively involved in research policy and genetic research in the mid 1980s (Rabeharisoa and Callon 1999), which it sees as the pathway to cures. Although the AFM's devotion to genetic research is articulated for the benefit of its rare disease clientele, its research policy is not limited to this alone. The logic behind its policy is that all kinds of genetic research will prove useful for rare disease patients and therefore needs to be fostered.<sup>36</sup>

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<sup>33</sup> Epstein (1995) and Novas (2006) make similar points. The AFM clearly encourages this simply because it was a need for survival. Parents needed to take care of their children and learn to live with it since there was no cure and doctors were not knowledgeable or even aware of such rare diseases since some did not even have a name. (reference needed).

<sup>34</sup> With regards to Myology, the "AFM created the Institut de Myologie in 1997. A recognised center of international expertise on muscle, diseases, aging and accidents of the muscle situated at the Pitié-Salpêtrière hospital, Paris, it is promoting innovative collaborations between researchers, medical doctors and patients." [http://www.afm-france.org/afm-english\\_version/ewb\\_pages//larecherche\\_strategie\\_recherchefondamentale\\_dvtmyologie.php](http://www.afm-france.org/afm-english_version/ewb_pages//larecherche_strategie_recherchefondamentale_dvtmyologie.php) (22/08/08). On this see also and Rabeharisoa (2003).

<sup>35</sup> <http://www.afm-france.org> (20/08/05)

<sup>36</sup> The particularity of the AFM's research policy lies in the rather unique decision to foster all kinds of genetic research, regardless of whether it has direct benefit for its clientele. Usually, patient organizations tend to support disease specific research (for example, breast cancer research, such as the German patient organization Mamazone). Consider the following statement of the AFM website: "Since neuromuscular diseases have [a] genetic origin, AFM takes part in the development of scientific tools for the study of genetic and rare diseases in general, and provides scientists with new

Among many activities of the AFM, we would like to point out the practice of biobanking, which is best defined as collecting, classifying and managing biological data. This practice is depicted as crucial for biomedical research and pursued by the Généthon DNA and Cell Bank. Biobanking is not a new practice but has gained new significance in recent times due to the promises of genetics and genomics. This proves that the meaning and significance of a practice, here biobanking, is context dependent, contingent and changeable over time. The Généthon DNA and Cell Bank represents a rather particular category of biobank because it has been initiated, financed and is governed by a patient organization: the AFM (through Généthon). Furthermore, its activities are completely aligned with the goals, values, mission and biomedical research endeavors of the AFM. Believing in the power of genetics and genetic research, biobanking is depicted by the AFM as yet another means to fight disease and as an empowering practice. Thus, the AFM articulates genetic research as the key activity to find a cure. In addition, the AFM concluded that biomedical research lacked biological material (such as DNA and cells) in both quality and quantity and so started its biobanking activities in 1990. Since then, an AFM employee explains, it has organized sampling campaigns and started several DNA banks for the storage of human biological material (Mayrhofer 2008).

Consequently, the corporate identity of the Généthon DNA and Cell Bank is defined by the AFM's determination to find a cure for rare genetic diseases by all means and its refusal to accept disease as a fate. Ultimately, the Généthon DNA and Cell Bank represents an actualization of the concept of biological citizenship precisely because it puts into practice the refusal to accept disease as a final verdict, fosters hope and develops social struggle.

In contrast with the AFM, Vivopositivo seems more critical of the biomedical approach and research teams. In some of its publications and documents Vivopositivo has disapproved the inadequacy of the biomedical approach to HIV/AIDS altogether because of lacking an integral consideration of the person and his/her psychological and social milieu (Zambra, 2004; Vidal, ). Key members of Vivopositivo have told us that they have strategically fostered a policy of knowledge production of their own, without confronting drug therapy, because they have realized the need of getting public awareness and scientific credibility in matters related to psychological and social aspects of their condition. It has been difficult for them, being a socially stigmatized group, to get financial autonomy

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means and knowledge to accelerate our understanding of genetic diseases and open up treatment avenues based on an understanding of the genes". <http://www.afm-france.org> (27/0906).

for research purposes. The support provided by the Fondo Global de Lucha contra el Sida, la Tuberculosis y la Malaria (a UN fund for the struggle against epidemic illnesses has been crucial in this).

The knowledge produced by Vivopositivo has been mostly social scientific knowledge capable of addressing the psychological, social and even political (in the broad sense of the term) aspects of the experience of people living with HIV/AIDS, with a particular focus on problems of social exclusion based on gender/sex, discrimination, stigma and equitable access to health care, social and cultural representations of people living with HIV/AIDS, and the representation of people living with HIV/AIDS held by school teachers. Vivopositivo has a research team and its own research policy which, until now, has produced 10 book publications. They also publish an extremely high quality magazine that contains updated information on the condition, both medical and sociocultural. These media became important legitimizing mechanisms vis-à-vis government and health care service authorities. Plus, significantly enough, according to one interviewee these publications fostered a feeling of self-esteem among local leaders of Vivopositivo because they became experts in their own condition and were able to speak to medical doctors.

The two organizations considered in this study use science to democratize to some extent knowledge production and engage effectively in specialized debates. Our study cases show that there is no deterministic way of doing this. Whereas some organizations might support current medical research and establish joint efforts with biomedical teams as is the case of the so-called “partnership model” (Novas, 2006; Rabearisoa, 2003; Rose, 2006), others might challenge medical knowledge and authority (Epstein, 1995). Furthermore, Vivopositivo has been able to combine both tactics in a complex manner. Health social movements and patient-user organizations have developed a variety of forms of knowledge and social alliances in order to acquire a credibility of their own. The identity of these organizations is not only defined by the way they relate to medical knowledge. Also of paramount importance is the way they define the disease or condition, a matter to which we turn now.

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## Patient-user Organizations Discourse: A Struggle Against Disease

We have found a common discursive trope in both organizations: the representation of the disease as the enemy, the patient as the warrior and the experience of illness as an ongoing war that will be victorious in an undetermined future after a long struggle. We think that the symbolic field set up by both organizations is similar and is defined by this series of warfare-like figures that are used rhetorically to define and somehow give a picture of the agonistic experience of the ill.<sup>37</sup> This discourse positions patients as people who resist, as active citizens who demand, as warriors aiming at self-determination and autonomy (on the AFM, see also Rabeharisoa and Callon 1999). The goal to find a cure is to be achieved through self-governing practices that should liberate the patient from their biological determination. The following quotation is illustrative of this point:

The AFM is born from a new generation of patients and patients' relatives who have decided to take their destiny in hand and to put up a resistance to the disease on all fronts. Engaged in scientific research as well as in assistance to patients, it acts independently and is guided solely by the interest of the patient.

(AFM 2004: 3)

In the same line consider the motto of the AFM: Refuser, Résister, Guérir. Le don c'est tout l'année (Refuse, Resist, Fight. Donate all year long). This is not deployed only in natural language. The Logo of the 50<sup>th</sup> Anniversary of the AFM (see figure 1 below) also relates to the same notions through the idea of combat.



Figure 1. Logo of the 50<sup>th</sup> Anniversary of the AFM.

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<sup>37</sup> Here we mean agonistic as relating to agon, this is, to struggle and not to agonic as the state previous to death.

Similarly, Vivopositivo promotes the figure of the person living with HIV/AIDS as a proactive individual who fights against disease, promotes self-care practices and faces openly his condition in society in order to fight stigma. Each number of its magazine presents the biography of a particular leader from a local or national organization who has something to show in terms of his/her resistance and bravery. Particularly representative is one that presents on the front cover the portrait of a well known national leader and co-founder of the organization with the accompanying headline: A fighter for life (Gerrero por la Vida). We think that all these figures of struggle are sustained by an ethos of hope, a matter to which we turn now.

### Hope

Another aspect that has to be considered with regards to knowledge is what has been called the political economy of hope (Novas, 2006; Rose & Novas, 2004). Nik Brown states that “hope serves to designate a vocabulary of survival where survival itself is at stake.” (quoted in Novas, 2006: 291). We agree with Novas, who identifies an affinity between the language of activism and the language of science: both of them indicate a “willingness to overcome obstacles, transcend limits and explore new horizons.” Both language games point towards an achievable future through the use of imagination, including fantasy and dream work, scientific categories and research, and political ideas and transformative action. Both language games also aim at intervening in history and have a concept of a manageable future.

But maybe the crucial aspect is the binding together of personal suffering and hope through a collective project. In these discourses hope and suffering come hand in hand and contaminate one another. Simply they cannot be understood without the other and, although they might be seen as opposed in fact they are mutually dependent. The other aspect to be considered is the mobilization “personal biographies” tied together with “collective hopes for a better future” (Novas, 2006: 291). The following long excerpt from the AFM’s website is illustrative of these crucial discursive elements:

Why this disease? Why this apparent resignation of the medical establishment? After examining a child with reduced movements, how can a specialist condemn a child, admit that he cannot do anything, be incapable of making the correct diagnosis, of prescribing the correct equipment and adapted care in time? No explanation, no drug, no hope. In order to counter this unacceptable situation, a group of determined families decided to get involved in

a common project in 1958 to change their fate, fight diseases, support research and find a cure as quickly as possible. The solidarity of families progressively gave rise to a strategy: help patients affected by NMDs, understand the origin of the diseases and then try to find a cure. As a result of an innovative strategy, of the results obtained in genetics and of the partnerships developed, AFM has become a major player in the fields of health economy and scientific and medical research.<sup>38</sup>

The people and patients are mobilized relying on the promises of biomedical research to provide a better future and a cure. As will be seen, this element of scientific hope is also seen in public campaigns aiming at creating public awareness of the disease.

### Creating Public Awareness

Creating public awareness is a complex process that comprises concrete activities in order to a) make the illness visible to a wider audience, b) the interpellation of the public in order to gain its solidarity and foster their identification with the sufferers and c) promote the transformation of a personal or constituency-based trouble into a political problem of the whole of society in order to pursue common and/or more global solutions.

Vivopositivo promotes several activities to generate public awareness of the disease. It takes part in the design and decision-making process behind preventive public campaigns run by CONASIDA, the state institution in charge of the struggle against HIV/AIDS in Chile. Because these campaigns have been contested by the Catholic Church and conservative groups, Vivopositivo also promotes the use of condoms through its own campaigns. For instance, in 2007 posters and collectable postcards were distributed in three important regions of the country via free system of take-a-postcard shelves located in bars, restaurants and other public venues. Postcards depict through pictures images of overtly sexual content that became controversial precisely because of their open message. Visual messages were oriented to a variety of audiences between 20 and 49 years old, thus, not only

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<sup>38</sup> [http://www.afm-france.org/afm-english\\_version/ewb\\_pages//larecherche\\_strategie\\_interetgeneral\\_presentation.php](http://www.afm-france.org/afm-english_version/ewb_pages//larecherche_strategie_interetgeneral_presentation.php) (28/08/08)

addressing those who are usually stigmatised in Chile as groups under risk of contagion such as the gay community. The postcard reproduced below “Pontela en la Dura” is illustrative of this.<sup>39</sup>



Figure 2 One of the Postcards of the 2007 preventive public campaign “Póntelo en la dura, usa condón”.

Another interesting example of public awareness campaigning is a yearly Candlelight Vigil in memory of those who died of HIV/AIDS. We want to highlight that the action takes the form of a religious ritual: the vigil begins with a procession to a significant religious temple where usually an invited speaker makes a public address for the occasion. Since it began, vigils have had some public media coverage, especially in the local press. The following are some of the mottos used in the 2004-2008 vigils: “For those who died of HIV/AIDS”, “Illuminating the path towards a brighter future”, “Your remembering implies actions”, “Commit yourself to the memory of the dead of HIV/AIDS”. Most of these represent the fight of the organization against forgetfulness rhetorically, importing a positive sense of hope for a better future and the active commitment to remember. This, sometimes combined with visual references to the recognition and rights of the gay minority.

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<sup>39</sup> Pontela en la dura is a slang innuendo that suggests at the same time that the user should put the condom on the penis when it becomes hard (la dura, hard) and that he ought to because it is a true benefit in the prevention of HIV/AIDS. The latter, because in slang “en la dura” means also a real fact.

In what regards to public presentation, the situation of the AFM is quite different, because it does not fight against stigma, but mostly “against oblivion and indifference”. Indeed, this fundamental and foundational value of the patient organization is expressed in the “parents’ refusal to give up and to accept these diseases as their destiny”. It proclaims that the “AFM’s values are shared by parents and patients who are determined to take all possible steps to combat neuromuscular diseases.”<sup>40</sup>

Since myopathies are rare diseases the AFM promotes a global strategy to help raising “awareness of patients who are excluded from the social and economical life of society”. The AFM assists and supports sick persons and their relatives, informs the general public about neuromuscular diseases, about their prevalence, how disabling they can be, how important research is for finding a cure, how relevant solidarity is for raising public awareness and, least but not last, about the need for further involvement of all social actors including patients’ organizations, the citizenry and the state in the “fight” against myopathies.,<sup>41</sup>

Creating public awareness of this illness is a crucial step in the organization’s fund raising activities. Once such public awareness is reached, organizations can capitalise on it. The AFM both increases public awareness and raises money through a public event called Téléthon© that takes place “... on the first weekend in December, every year since 1987. This fund-raising operation, combining a 30-hour TV show and tens of thousands of local events across France, also aims to raise public awareness of neuromuscular diseases”.<sup>42</sup>

### Preliminary Comparative Discussion

We have seen that Vivopositivo and the AFM share many common features. First, both are constituted qua politicised collective illness/disease collective identities. Second, they promote an active involvement of patients using the language game of citizenship and rights. Third, they question biomedical knowledge and authority, although in different ways and degrees. Fourth, they mobilize a rhetoric of struggle against the disease to account for the experience of the predetermined individual (e.g. carrier of a particular disease gene), the active patient (self empowered) or ill person (refusing

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<sup>40</sup> <http://www.afm-france.org>(27/09/06). Emphasis added

<sup>41</sup>[http://www.afm-france.org/afm-english\\_version/ewb\\_pages/d/decouvrirafm\\_maladiesrares\\_presentation.php](http://www.afm-france.org/afm-english_version/ewb_pages/d/decouvrirafm_maladiesrares_presentation.php) (28/08/08)

<sup>42</sup> “The Téléthon© provides most of our donations and operates as a important vehicle for information, communication and education.” [http://www.afm-france.org/afm-english\\_version/ewb\\_pages/d/decouvrirafm\\_missions\\_strategie.php](http://www.afm-france.org/afm-english_version/ewb_pages/d/decouvrirafm_missions_strategie.php) (28/08/08)

any kind of treatment).<sup>43</sup> Five, they build their respective collective identities around and foster patients' identifications with the collective sharing of suffering and, most importantly, hope. This notion of hope seems to be a condition of possibility for the articulation of self empowered scientific and activist discourses. In its turn, this new discourse seems crucial in the formation of biological citizenship and the formation of politicised collective illness identities. Nonetheless, one should be cautious about over-emphasizing the positive aspects of hope in relation to an ethos self-empowerment. Indeed, this ethos of self-empowerment relates to two risks. One is the risk of falling for a progressive evolutionary narrative that presents the overcoming of the biomedical paradigm by a more humane one that fully recognises the human being, whereas as a matter of fact the latter could be just another more sophisticated way of optimising the systems' potentiality and maximizing its efficiency through forms of self-regulation (rather than through control). The second risk, related to the previous point, regards to the question of neoliberal governmentality and implies the move towards privatising public responsibilities and put the individual in charge for his/her own health. In this perspective patient-user organizations can be seen as functional to and supportive of market oriented policies and state rationing because what should be considered a social problem is transformed into a private, personal or familial trouble. Thus, for some it might not be surprising that health social movements and patient-user organizations are developing nowadays simply because there is a need for it due to the retreat of the state. Although this are very convincing arguments and we agree with them, these cannot be converted into general laws. Against these arguments we sustain that both our cases represent instances of empowerment that benefit patients rather than the systems functioning. Six, both organizations foster public awareness in order to gain public visibility, recognition and, thus, create political opportunities for pursuing their strategic goals. Seven, both organizations deal with the challenge of the constitution of the sick as a free citizen who has both the right and obligation to improve his/her own health through a variety of techniques that work upon his/her own body and psyche (which are not necessarily part of the hegemonic scientific discourse). Eight, in both cases we identify the preoccupation of the modern biopolitical programme with the management of life itself and populations' capabilities. This counts sometimes as the environment of

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<sup>43</sup> As it is known, sometimes people are just carriers of a certain condition. Is one ill when carrying a predisposition for a disease as, for instance, carrying its gene? Also, sometimes a certain gene is a condemnation of some sort since it is certain that the illness will break out at a certain point. One might be healthy until a certain moment of life. Lastly, being ill does not make one a patient. Some people refuse any kind of treatment and medical diagnosis, as is the case of some organizations of people with schizophrenia who name themselves as group of people hearing voices and not as mentally ill or some organizations of deaf people who call themselves a deaf culture with its own identity and language (sign code).

organizations. In other occasions, they seem more involved in the biopolitical programme. This is reflected in the formation of health systems, in the emergence of the field of public health, in the interest in life sciences and in the centrality acquired by health related political issues. Nine, in both cases we see a common trend towards constituting a new power/knowledge configuration. By power/knowledge configuration we mean the entangled and concrete form that the articulation of power and knowledge takes historically. There is a variety of potential power/knowledge configurations that can co-exist in the field of biopower in contemporary societies. Nevertheless, two such configurations are relevant for us. First, what we call a scientific-centric power/knowledge configuration that erects a deep divide between scientific and lay knowledge cultures and practices and, second, an emerging patients-centric and participatory configuration that relativises the distinction between, on the one hand, physicians, researchers and expert knowledge and, on the other, patients qua lay-people who develop their own forms of knowledge with diverse levels of articulation. Although we do not claim that the first configuration is dead and has already been replaced by the second, we think that both cases show a transformation in the hegemonic scientific-centric configuration. This transformation shows at least certain fissures where a patient-centric configuration seems to be emerging. This new configuration seems to be conflictive and criss-crossed by tensions that call for more detailed case-specific analyses. Nonetheless, it seems to us that we can already speculate about two main poles in this tension: first, scientific discourses such as biomedicine, genomics, public health and public policy and the(ir) respective regimes of truth and forms of subjectivation and, second, radical political discourses of patient-user organizations that are ready to articulate forms of scientific knowledge in their favour and put forward unprecedented understandings of identity, citizenship and politics that empower people through forms of self-governance and practices of freedom. Ten, in both cases we have found enough evidence of the emergence of what can be called politicised collective illness identity that has been formed through a web of relations, discourses, subjectivation technologies and institutional strategies. Eleven, the AFM and Vivopositivo have become key players in the realm of biopower in their respective immediate arenas and countries. They have been able to influence - or even sometimes change - the way patients understand their position and relation to their physician or research teams, knowledge and the rationale as well as context where biomedical research takes place, including issues of private and/or public research funding. They have been also influential in altering patients' strategies and tactics to increase public awareness through public campaigns, candle light vigils, public events

websites and blogs, amongst others. But most importantly, they have influenced communities of patients by gathering people with similar problems and experiences, providing mutual support, peer counselling instances, and establishing links and exchanges sometimes using innovative means such as the Internet. They have also become key political actors, playing the role of well informed and socially accepted representatives of both their clientele and the (bio)political establishment. Also they are now able to influence public health design, provision and funding for research and treatment. Last but not least, patients' organizations have developed new positive opportunities of self-understanding by re-framing the notions of illness and ill person, by detaching them from associations with suffering and fate, and by re-introducing the idea of hope and an open future for the person who suffers a condition.

All the previous are important similarities. Nevertheless, there are also significant differences between the two organizations. First and foremost, their respective institutional and financial strengths seem very different, being Vivopositivo in a far more vulnerable and less institutionalised status. Secondly, the particularities of the illnesses they are related to are very different as well. While the AFM is related to a non-stigmatised illnesses – what allows it to mobilize a wide-public solidarity for young children each year during the Téléthon(c)- Vivopositivo is related to a highly stigmatised illness. This makes it more difficult to get public support for its own agenda.

Finally, it seems to us that each organization analysed here pertains to different regimes of the self (see Novas, 2006). Although Vivopositivo has a wide range of strategic goals ranging from state recognition to public awareness, it seems to us that its emphasis is placed in relative terms more on the side of demanding state recognition, getting and improving equal access to treatment and getting state financial support for their activities. It is also more radical in its critique to external loci of power and critical of the structural determinants surrounding the condition, such as discrimination and exclusion of gay men and sexual workers. By contrast, the AFM seems to position itself as less critical to medical establishment. Both organizations have in common to turn towards responsabilizing the patient for the management of his illness, this happens rather differently in each case. Whereas the people living with HIV/AIDS are in most cases adults with moral capabilities, in the case of the AFM there is a lot of parents care, love and solidarity involved in the management of the illness.

## Conclusion

We have tried to demonstrate that there is an emerging configuration of power/knowledge that can be characterised as follows. First, it combines forms of scientific discourse with politically inspired discourses that tend to empower the patient qua biological citizen. Biological citizens are members of “imagined communities” (Anderson, 1993) that cohere around the experience of biological condition or illness; but their solidarity is also the effect of a hope for the future represented in the investment in medical and biotechnological innovation. Thus, this field is also characterised by the role of a “political economy of hope” (Novas & Rose, 2004; Novas, 2006; Petryna, 2002; 2004; Rose, 2006). Related to the previous point, there is a biopolitical imagination in which it is possible to put together science’s generally disavowed speculative prepositional fabric of medical thought that includes fantasy and dream work (Waldby, 2000: 136), with activism’s political ideas and imagined scenarios of plenitude. This is what some scholars in the field have called the political economy of hope in order to make sense of the way patients’ organizations intend to manage their relation towards the future as something lived not as fate but as partly manageable through different practices (Novas, 2006). The new configuration of power/knowledge is characterised by a tensioned relation between different logics and principles of organization that shape it. It has been claimed that the field of biomedicine is criss-crossed by, on the one hand, the logic of public welfare and, on the other hand, the logic of private profit-making and entrepreneurial activity (Waldby, 2006). Although we share such general description, we claim that the literature has generally overlooked the role of patient-user organizations that do not fit in this bipolar model. This asks for the consideration of a third logic of private non-profit organizations that pursue non-profit private and/or public goods, as exemplified by the AFM and Vivopositivo.

Also related to the previous, patient organizations promise to combine the diverse logics and interests in tension in the field of biopower. In general terms, our analysis shows that the new configuration of power/knowledge is characterized by the constitution of relations and forms of combination of interests between scientific institutions, patients, the state, biomedical industry and economic agents. However, only detailed case study analyses can show the concrete form taken in each case and what is (are) the organising principle(s) that dominate(s).

The aforementioned features are crucial in the understanding of the emergence of a new kind of political identity, namely, the patient organization. We claim that patient organizations are constructed through a web of relations that include the following factors. Firstly, discourses, such as scientific discourse, public policy discourses, common sense representation of groups in public discourse, and patient-user organization discourses. All these frame the identity of the patients' organizations. Secondly, we claim that the constitution of the socio-political identities of patient organizations are constructed relationally, this is, within a web of relationships and interactions with other organizational structures, such as: the state, the public health system, the media, biomedical industry, organizations of experts, medical science, the patients, the relatives, etc.. Thirdly, we have demonstrated that strategies or logics of interests involved are of paramount importance in the framing of the identities of patient organizations. Here we focus on the analysis of the principles and values of patients' organizations, such as self-help (i.e., mutual-help patients' groups), promotion of quasi political interest and practices of freedom (i.e., self-understanding and self-governance through activists' driven and participatory patients' groups). However, other logics are also relevant and should be explored in research to come. At least two other logics seem crucial to us: the profit-making logic of the biomedical market and private laboratories and the disciplinary and control oriented logic of the state. Also, complex combinations or articulations of these two logics might be important to understand the biopolitical regime.

Finally, we have concluded that the emergence of a biological citizenship is related – and somehow the result of- the work of patients' movements and patient-user organizations. Put differently, biological citizenship is a new expression of citizenship that takes place in the realm of biopower under these changes introduced by patient-user organizations (Novas & Rose, 2004; Petryna, 2002; 2004; Rose, 2006).

All previous points are crucial factors in our understanding of the changes affecting the realm of biopower done by health movements, patient-user organizations and citizens. This does not mean that health movements, organizations and biological citizens are responsible for all changes affecting the realm of biopower. Of course there are other factors, some of which can be regarded as very significant in the structuring of the contemporary field of biopower, such as the constitution of a bio-capitalist economy and the introduction and translation of new revolutionary technologies in biomedicine. What we claim is more subtle and at the same time humble. We propose to look at

patient-user organizations because a small but very meaningful part of current changes in the field can be explained by exploring the intricate articulation between the old configuration of power/knowledge and these new types of organizations that introduce new practices of knowledge, hence producing what we think is a more complex power/knowledge configuration.