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The Growing Engagement of Emergent Concerned Groups in Political and Economic Life

Lessons from the French Association of Neuromuscular Disease Patients

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This article discusses the notion of emergent concerned groups and explores how these groups contribute to shaping the relations between technoscience, politics, and economic markets. The first part presents the case of the French Association of patients suffering from muscular dystrophies. This history suggests that under certain conditions, emergent concerned groups are able to impose a new form of articulation between scientific research and political identities by directly linking the issues of research content and results to that of their place in the collective. The second part argues that the evolution of economic markets, combined with that of science and technology, leads to a multiplication of those emergent concerned groups. The study of the conditions under which these emergent groups become legitimate stakeholders as well as the analysis of their impact on market organization and technoscientific institutions are key research topics for the near future.

Keywords: patient organizations; emergent concerned groups; economic markets; social movements

Current questioning of the modes of governance of science (at least in Western countries) frequently highlights the limits of the delegation of authority from the political to the scientific system (Guston 2000; Callon, 2008).

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This delegation has not prevented researchers from being mobilized by large military programs, nor has it excluded them from participation in the innovation activities of industrial firms (Pestre 2003). What it has produced, however, which analysts have highlighted, is the exclusion of civil society that has only rarely been invited to take part in debate and decisions about the orientations of the technosciences and even less so in the process of knowledge production.

The notion of civil society may be useful for underscoring the limitations imposed by the prevailing institutional configurations, but it tends to be misleading in its assumption of a double divide, what Callon, Lascoumes, and Barthe (2001) have called a double delegation, between experts and lay people and between ordinary citizens and quasi-professional decision makers. It is furthermore meaningless for analyzing and understanding situations in which actors try to blur the distinction between the public and private spheres. There are probably several ways of avoiding being trapped in these dichotomies. The aim of this article is to explore one such possibility. We would like to show how the notion of emergent groups who are concerned by the development and effects of the technosciences could shed light on the establishment of a new type of relationship between science, politics, and economic markets.

In the first part we briefly present the history of a French association of patients with muscular dystrophy (MD), the Association française contre les myopathies (AFM). This history serves to illustrate what we mean by emergent concerned groups. It shows how patients were able to construct their individual and collective identities owing to the association’s intense engagement in scientific and technological research activities—an engagement that enabled them to change their ontological status. Considered for a very long time as freaks of nature, MD patients became human beings in their own right. Their disabilities and problems are now explained in terms of genetic faults that research has made it possible to characterize. It is the recognition of this new identity, constructed around genes and prostheses, that the association has fought for in the public sphere through intense political mobilization. The AFM’s history suggests that under certain conditions, emergent concerned groups are able to impose a new form of articulation between scientific research and political debate by directly linking the issues of research content and results to their role in the collective.

Is the AFM an exception? Or is it an extreme and therefore striking example of a wider phenomenon? To answer this general question we need to start by asking how such emergent groups appear. The second part considers the proliferation of emergent concerned groups from the point of view...
view of the mechanisms explaining their appearance. We argue that the
evolution of economic markets, combined with that of science and technology,
creates conditions for a multiplication of the emergent groups concerned.
These may be orphan groups that like the AFM strive to have their problems
taken into consideration, or they may be groups affected by unexpected
overflowing, the nature and effects of which they want to understand. Whether orphaned or affected, these groups are characterized by the fact
that they are concerned by technoscientific development and applications.
Like the AFM they might be incited to undertake investigations and research,
both to clarify the problems they face and to explore possible solutions.

In the conclusion we suggest that it is interesting to study these groups
and the course they follow because they could tend to induce the reorgani-
zation of double delegation and economic activities.

**Emergent Concerned Groups: The Case of the French Association of MD Patients**

In this section we use the case of the French association of MD patients
to introduce the notion of an emergent concerned group. The formation of
social groups and their reproduction are key questions for sociology.
Available answers are nevertheless unsuited to the cases of interest to us here. Generally, they assume that the identity of the group is based on values,
projects, practices, interests, or habitus shared by its potential members.
This type of approach does not apply to emergent concerned groups, whose
identity is an achievement rather than a starting point, a *primum movens*.
Moreover, the construction of this identity is the outcome of real research
in which the groups are heavily engaged and that leads to the production of
entities (in this case of genes and various sociotechnical prosthetic devices)
that participate in shaping their identity. The AFM’s history, briefly out-
lined here, shows how this transformation takes place and causes the con-
cerned group to articulate science and politics in an original way.

**From (Passive) Exclusion to (Active) Inclusion**

The AFM plays an original and important part in French society, in both
the medical and scientific fields as well as the political and economic spheres
(Rabeharisoa 2006). Through its annual television program *Le Téléthon*,1 the
organization collects increasingly large sums of money: €100 million in
2004 and a total of €700 million since its inception in 1987.
A substantial proportion of this money (about 70 percent) is used to support biological and clinical research. This has enabled the AFM to play a key part in genetic and genomic research (for a detailed analysis of the organization’s history, see Rabeharisoa and Callon 1999). The contribution of the Généthon, a technology platform decided on and financed by the AFM, has been crucial in the human genome sequencing project. The organization has also supported the creation and development of teams that have been highly successful on the international scene, and not only in the field of neuromuscular diseases. Compared to public research organizations that tend to shy away from new research areas, at least in France, it has proved to be highly flexible, as, for instance, in its decision to move into the field of genotherapies (Givernaud and Picard 2001). One study shows that the association has had a significant impact on Centre National de la recherche scientifique (CNRS) research orientations in the life sciences (Kahane 2000). The AFM has furthermore demonstrated the extent of its influence through its instrumental role in the government’s decision to launch a national program for the creation of Genopoles, and it has contributed directly toward the creation of the first of these Genopoles in Evry by donating facilities and equipment from the Généthon (Tambourin 2005). In the scientific and medical spheres, its intervention has encompassed more than genetics. It has also supported clinical research and built up an entire network of consultations devoted to MD patients. Through its technical publications for both professionals and the general public, and through the Téléthon, it has contributed toward the diffusion and popularization of genetic knowledge. It has also been directly active in the economic sector by supporting start-ups and entering into partnerships with industry. From the outset its frame of reference was international: in all cases, whenever it was unable to find scientific or economic partners in France, it looked for them abroad. Finally, the AFM has played a less visible but equally crucial part in the area of disabilities (Winance 2001). For instance, it contributed to the conception and implementation of a new form of assistance for disabled persons. It has been, and still is, at the center of political demands for the right to compensation (on all these subjects, see Callon 2006.)

This scientific and political activism has generated a great deal of hostility and countless accusations. Public research bodies have viewed the AFM’s growing influence with some anxiety and have repeatedly accused it of using its (additional) money to impose its own interests and priorities on scientists whose salaries are paid by tax payers. Some cabinet ministers have even tried to impose their regulatory authority on the organization, claiming that the funds collected could be considered as “public” money and that the
State therefore has to control its use (Barataud 1992). Scientists whose research options and advice were refused at some point by the AFM have mounted press campaigns to denounce its choices. In the early 1990s they criticized the risky technological investments of the Généthon and later the concentration of funds on genotherapies. For a long time intellectuals were indignant about the show put on for the Téléthon, with its display of suffering intended solely, they claimed, “to make grannies cry so that they’ll donate money.” Gradually, their criticism abated in the public sphere, but critics are still set to pounce at the slightest opportunity. The AFM has been undeterred by this criticism and jealousy. In 2004 Bernard Barataud, the organization’s charismatic leader who engaged it in this exceptional adventure, was awarded the annual University of California, San Diego (UCSD) and Nature Medicine prize for “people or institutions that have made a noteworthy contribution to the development of molecular biology for therapeutic treatment of human diseases” (November 2007). In the same year he also received the Ile-de-France Entrepreneur of the Year award as well as the national Enterprising Spirit award by Ernst & Young and the magazine Enterprise.

The AFM’s success, reflected in the organization’s active and influential presence in the scientific, political, economic, and media spheres, is even more impressive in light of its humble beginnings (Barral et al. 1991). The organization was created in the late 1950s by a few families with children diagnosed with MD. At the time, people with severe MD were hardly considered as human beings. Testimonies abound (Barataud 1992; Kepper 1988) showing how they were described as monsters or “errors of nature.” It was almost impossible to consider the affected individual as a person who could be separated from the disease from which she or he was suffering. In the absence of professional communities structured around this pathology, being an MD patient was a state and meant exclusion from society and culture (Callon 2006). Only a handful of professionals were interested in these diseases. There was no cure, no care, no research, no constituted facts, and no causal relationships on which to draw to find solutions—only matters of concern and questions. It was to fight against this exclusion and indifference that in 1958 some parents decided to create the AFM.

The changes in the past few decades have been striking. In 1950 MD patients were excluded from common humanity; thirty years later they were considered as human beings in their own right. They had crossed the border, back into the realm of human beings, where they were simply singularized by a few genetic particularities. In the late 1950s they were undifferentiated MD patients; since the 1980s they have been unfortunate human beings
affected by a particular disease, generally monogenetic, which explains why their bodies are so dramatically crippled and why they die earlier than other people. Uncertainties remain, especially on the possibility of preventing diseases and of finding therapies quickly. But many facts have been produced that make it possible to define options and to elaborate strategies. Professional networks—researchers, doctors, occupational therapists, and care officers—have been established, and patients with their families have formed groups to work together. Neuromuscular diseases are finally on the list of those covered by Social Security. People suffering from them have gone from a situation of *passive exclusion* to one of *active inclusion*.2

The association’s history is a clear illustration of what we call an emergent concerned group and of one of the trajectories that such a group is likely to follow. In 1950 the population of MD patients was fragmented and could hardly be considered as anything more than a juxtaposition of individuals and their relatives. Their status (quasi-nonhuman beings and, what is more, children) reduced to virtually nothing, they lacked the ability to define an identity and to perceive and defend their own particular interests. The families themselves were unsure, wavering between abandonment (doctors told mothers not to become too attached to their children because they were doomed to die), guilt (“we’re responsible for this mistake”), and revolt (“we’ve got to do something to save them”). The only things that federated these beings (relatives, parents, and sick children) were the shared concerns, worries, and problems that they could connect to the name of a disease provided by the medical profession for nearly a century but that seemed to be a death sentence, with no constituted knowledge and no research effort offering some hope of a solution or some way out of ignorance. Referring to a concerned group means underscoring the fact that beings feel bound by the matters of concern that they share and express with words common to them all, words that have meaning. Qualifying these groups as emergent means indicating that nothing is stabilized: identities are problematic and, in this case, in the most radical way possible (are they really human beings?). The interests to defend are inchoate, changing, and, above all, defined by third parties (parents and friends). Identity and interests are the outcomes, and not the causes, of the action itself (Callon and Law 1982).

Particularly interesting, in the AFM case, is the fact that a few decades later the situation has become much clearer and the uncertainties have lifted, at least partially. Expectations, interests, and projects have been formed and then stabilized, constituted, and entrenched in networks and communities where they belong and are recognized. The worries have not disappeared; these groups are still concerned, but in the meantime identities
have been shaped, asserted, and recognized; a form of acknowledgement has been obtained; and causal relations explaining their situation have been demonstrated, thus paving the way for strategic actions. It is this dramatic transformation that we would like to explain.3

To understand how this group created its own identity, we need to focus our analysis on patients’ and their families’ engagement in the research undertaking that was to spawn new entities: the genes responsible for the disease. These genes allowed the construction of a particular identity and provided the patients and their families with the resources and arguments needed to defend that identity in the public sphere. The dynamics of emergent concerned groups and the actions that they undertake are unintelligible without the nonhumans that their investigations bring to light.

The Two Paths and Their Articulation

How was an emergent group, consisting of individuals concerned by their own death and suffering or those of their children, able to construct a collective identity, be recognized, and transform their position of exclusion into one of inclusion? This shift was clearly more than a simple move: “our children were excluded; now they are included.” It was necessary for both the patients and their social environment to change. In short, we would say that it was possible owing to a dual movement or, rather, a dual detour, the first via research and the second, closely linked to the first, via political advocacy.

We claim that in order to understand how emergent concerned groups are sometimes capable of constructing stabilized identities, goals, interests, or preferences, it is necessary to examine all the investigations, inquiries, and research studies that these groups undertake to find solutions to the problems they face. From this point of view the AFM is an exemplary case, for it expressed its strategy in these terms very early on (probably due to the radical nature of the matter of concern: becoming full-fledged human beings). To describe this strategy it referred, from a very early stage in its history, to two paths to explore: the path to cure and the path to citizenship (two phrases coined by the AFM). The former led the organization to focus on genes, proteins, stem cells, and so on; the latter prompted it to fight for the recognition of all handicapped people’s rights and to propose appropriate compensatory sociotechnical prosthetic devices. These two paths constantly intersected, and the question of their priority in relation to each other was repeatedly debated within the organization. They helped to construct a genetic identity that was gradually transformed into a genetic citizenship (Heath, Rapp, and Tausig 2004; Rose and Novas 2005).
It is this twofold exploration that we will now consider, focusing essentially on the huge investments that had to be made, for stabilizing an identity and having it recognized required the mobilization of many actants.

The path to cure: genetic identity. What is striking in the AFM’s history is the intensity and variety of the modalities of engagement in biological and clinical research. Basically, these engagements have taken three forms, the relative importance of which has varied with time although they have always been present in one way or another.

From the outset, the organization was engaged in a process of problematization (Dewey 1916; Callon 1980a; Foucault 1994; Rabinow 2004; Miller and Rose 2008). For the families involved, the aim was to clarify matters of concern and to make them more explicit, that is, to identify problems and then to formulate questions that would be attractive to the few specialists likely to take an interest in the subject. This problematization entailed a primitive accumulation of knowledge that was to last throughout the 1960s and ’70s. In this process information was gathered about the different ways in which the diseases evolved and about the treatments, diets, physiotherapy, and prosthetic material that seemed to have beneficial effects. Very soon it enabled the AFM to disprove certain assertions by specialists, essentially on patients’ life expectancy and the evolution of their disease. Subject/objects, which until then were treated as invisible and unobservable, were subjected to observation and scientific scrutiny. Proto-instruments (that produced inscriptions) were used: films and photos taken by the families were shown and discussed; working groups were formed; inquiries were launched; white papers were drafted, circulated, commented on, and revised; and so on. The group became a producer of information and knowledge. The term “researchers in the wild” is certainly apt since there were no confined laboratories on which they could rely (Callon 2003).

This work of intense problematization at the beginning of the association’s life was never interrupted because the diseases and the patients’ living conditions (and especially the lengthening of their life expectancy) constantly raised new questions and posed new problems.

Once the first cooperation had been launched with researchers and doctors, the AFM did not withdraw from research as such. In this respect it diverged from the standard model in which laypersons alert researchers to a problem and then leave the monopoly of knowledge production to them. Nor did it deprive specialists of the right and ability to fulfill their role and make their contribution. In a pragmatic way, and before the notion had been conceived of to describe new modes of organization of research and innovation,
it contributed to the formation of a community of knowledge or what we prefer calling hybrid research collectives. These collectives consisted of researchers from different disciplines, practitioners, technologists, medical professionals, parents, and patients. But their description cannot be limited to such a list. To understand the functioning, dynamics, and modes of coordination of these collectives, it is necessary to take into account the active role of all the material, nonhuman entities that are part of them (see Amin and Cohendet [2004] for a successful combination of actor–network theory [ANT], distributed action, and a cognitive approach). With the development of the AFM, the growth of its financial resources, the multiplication of research agendas, and the survival of patients, these collectives (that the organization called interest groups) proliferated in various forms. Some were collectives constituted around a particular disease, for example, MD of Duchenne, spinal muscular atrophy, or myasthenia. Others were formed around an organ such as the heart, which is a muscle of a particular nature that may be affected when patients live longer. This required many observations, experiments, and interpretations to be developed and evaluated, especially by joint task forces. In the clinical domain, groups were formed, for example, around the tracheotomy or arthrodesis. The social sciences were included as well: groups bringing together psychosociologists, psychiatrists, and sick persons were constituted on subjects that are traditionally treated by patient organizations, such as accompaniment toward death, bioethical issues, and prolongation of life by medical means. On all these subjects the contributions by the patients and their families were highly innovative. For example, this collaboration between patients and specialists proved to be productive on “new” issues such as the organization of periods of respite, enabling families and patients not to be constantly dependent on each other.

These research collectives have varying life spans. In them the specific role of patients ranges from mere auxiliaries to researchers in their own right who even sign scientific publications in academic journals. In some cases patients act as intermediaries between disjoint specialties that were previously unaware of the others’ work. They compile information, translate articles, and write on the states of the art. In short, depending on the circumstances, the diseases, and their own education, they may become involved in any research-related occupation, from the laboratory bench to the dissemination of information, clinical observation, or the adaptations of therapies or prostheses. What counts here is their involvement in collectives that without them would not function in the same way or produce exactly the same knowledge, simply because they would focus on problems formulated differently.
The association has also played a key part in the orientation of research, that is, in the definition of a research and innovation policy in the full sense of the term. This is remarkable since France is one of the Western countries in which the delegation model was taken to its extreme. From the outset the AFM rejected this model. The governing board, composed exclusively of patients or their parents, constantly maintained its decision-making powers. It granted researchers the autonomy they needed, recognizing the value of their propositions, but kept a firm hand on the reins. This strategy was reflected, in particular, in dramatic decisions that turned a part of the scientific community against the AFM, such as the association’s decision to build the Généthon and, more recently, to launch out into genotherapies, thus discontinuing its support for teams working higher upstream that were accustomed to receiving its financial backing.

This type of political prowess is rooted in a remarkable understanding of the rules by which the scientific community functions (in several of his writings, Bernard Barataud [1992] has proposed sharp analyses of the research community and especially of the mechanisms of replication of results). It has also been expressed and reflected, above all, in the creation of governance structures and procedures of financing and support that were cruelly lacking in the French government and public research bodies. This level of reflection and strategic orientation requires that certain patients be capable of entering into the black box of knowledge. It was this strategic competence that prompted the organization to decide, against the advice of influential scientists, to build the research facilities that have enabled it to pursue and to control research activities and the choice of research thrusts.

The AFM also formulated a very precise doctrine on its own position in the French scientific community, defining its role in relation to those of public research bodies and firms and proposing original ideas on the boundary between public and private, general interest and particular interest.

This strategic work has been performed essentially by people without any specific university training, who sought no advice from experts in the social sciences or strategic management. In a merit-based country such as France, this mixture of respect and lack thereof is something exceptional and almost jubilatory: neither scientism nor antiscientism, just an immoderate passion for research and a keen awareness of the fact that choices have to be made and that those choices cannot be left up to scientists alone.

The AFM, by triggering the creation of research collectives, contributing to their development, participating in their activities, and ranking their priorities, did not limit itself exclusively to scientific or technical investigation. It embarked on another adventure: the construction and the defense of new identities. This is the point that we now wish to consider briefly.
The path to citizenship. The progressive construction of patients’ identity has been directly associated with the organization’s engagement in genetic and clinical research. Owing to this engagement, patients are “socialized”; they become stakeholders in scientific, clinical, medical, and social networks. As in classical ANT case studies, this socialization, which takes them from a situation of exclusion to one of inclusion, is mainly effected by nonhumans. They are the ones that by circulating and linking heterogeneous entities produce and determine the shape of networks of alliances and solidarity. For example, the gene, whose deletions are responsible for the spinal muscular atrophy (SMA) disease, links patients and their families to various actors, including the researchers at the Necker Hospital who took samples of their DNA and ended up locating and identifying the gene, the clinicians who performed prenatal tests, the researchers who published articles on the activity of proteins produced by the gene or worked on models of transgenic mice, and so forth. This sociotechnical network, with its ramifications all the way to North America, would never have existed without the activity of this gene that appears in cell banks, is expressed in the inscriptions produced by instruments, influences decisions during prenatal diagnoses, appears in articles published by researchers, and makes tracheotomies acceptable and bearable. Moreover, and this point is crucial, it would have had neither the same form nor the same distribution (or ubiquity) if the patients and families had not invested in each stage of the research, from the gene hunt, to the diffusion of knowledge, through the creation of research facilities. It is via this process of inclusion, in which one of the most powerful operators is the gene itself, that patients exist as recognized actors and progressively shape their own evolving multiple identities. As Strathern (1999) put it, it is through the mediation of nonhumans that the social proliferates and human persons are produced. The gene, hunted, inspected, tamed, or in the process of being tamed, participates in the construction of long and highly differentiated sociotechnical networks, transforming monsters into human beings in their own right, well integrated into constantly evolving webs of relations. As Rabinow stated, one could say that these constantly reconfigured collectives share genes and proteins. They also have “medical specialists, laboratories, narratives, traditions, and a heavy panoply of pastoral keepers to help them experience, share, intervene and understand their fate” (Rabinow 1996).

To be recognized, an identity, especially when it is unusual and departs from regular models, has to become visible and capable of making itself heard. This is where the path of citizenship and its constant articulation to the path of cure comes in. These two engagements (in research and in citizenship) are closely linked.
To guarantee their social existence it was not only necessary for patients to be considered as active participants of biological and clinical research, they also had to be recognized as full-fledged persons by the professions that normally cared for and helped patients and as citizens in their own right. In 1989 the combination of the path to cure and the path to citizenship was the subject of a general policy statement by the then president of the AFM. This policy was based on the International Classification of Impairments, Disabilities and Handicaps, published by the World Health Organization in 1980. The classification was based on the fact that due to medical advances, acute diseases were tending to become chronic, and these chronic diseases transformed the lives of patients and the role of medicine. It completed the International Classification of Diseases by recognizing that at the end of the twentieth century someone’s state of health could no longer be defined exclusively by the fact of having a disease or not, since the fact of living or not with impairments that could be the source of disabilities and handicaps was equally relevant.

The AFM was to adopt that classification, but with an amendment. To the original three categories of impairments, disabilities, and handicaps, it added the category of lesions to mark its will to fight against the disease from its organic causes to its social consequences. The classification as amended by the AFM clearly indicated that its two objectives—summed up in the slogan “Help and Cure”—had to go hand in hand. Above all, it enabled the AFM to match four areas of action to four categories of the International Classification of Handicaps as defined by it in Table 1.

This scheme associated the path to cure with that of citizenship, with a common goal: radically transforming the MD patient’s status. From a monster close to death, the patient became a human being suffering from a disease—the causes and physiopathological mechanisms of which were being sought in order to eventually be able to cure it—and a person with a life project aside from her or his disease.

To put this ontological change into practice, the AFM designed and developed a series of sociotechnical arrangements enabling patients to

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Table 1
The Two Paths and Their Articulation

<table>
<thead>
<tr>
<th>(1) Lesion</th>
<th>Domain of science</th>
<th>The path to cure</th>
</tr>
</thead>
<tbody>
<tr>
<td>(2) Impairment</td>
<td>Domain of medicine</td>
<td>The path to cure</td>
</tr>
<tr>
<td>(3) Disability</td>
<td>Domain of rehabilitation</td>
<td>The path to citizenship</td>
</tr>
<tr>
<td>(4) Handicap</td>
<td>Domain of social integration</td>
<td>The path to citizenship</td>
</tr>
</tbody>
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Source: Association française contre les myopathies scientific committee, April 28, 1989.
define and accomplish their life projects. A case in point is the Services Régionaux d’Aide et d’Information (SRAI), local services for help and information, which the AFM created in 1989. These services’ mission is to act as an interface between medicosocial networks and the patients’ families, whether they are members of the AFM or not. Each service, under the responsibility of a director, consists of four or five care officers, on average. These care officers usually have a paramedical background (occupational therapists, social workers, physiotherapists, specialized educators), although the work they perform in the SRAI differs substantially from their original occupation. An ethnographic study lasting more than two years in ten SRAIs enabled us to characterize this work (Rabeharisoa and Callon 2000). It consists of analyzing the situation jointly with the family that requests it, defining a life project for the patient and her or his family, and then helping them to carry out that project, even if institutional actors see it as unviable. The care officers are thus professionals who act on behalf of patients and their families, defending their needs and wants in the medicosocial networks. They are clearly representatives of the families in the medicosocial community, are perceived as such, and are committed to their work.

In parallel the AFM set up an individual financial support mechanism to enable patients and their families to buy the prostheses that they required, provided they also applied to institutional financiers. The organization furthermore designed and built dwellings offering the most disabled (those with SMA in an advanced stage) a social and technical infrastructure that made an autonomous individual life possible. Finally, the AFM played an instrumental part in drafting a law on disabilities, passed in February 2005, in which the rights of people living with disabilities were enshrined, including their right to compensation.

Articulation of the genetic and prosthetic citizen. In its quest to construct the collective identity of MD patients, the AFM followed an original trajectory. It did not simply unite individuals and make them aware of their similarities and common interests. Instead, it manufactured their identity by putting together heterogeneous elements. This can be described as a process of articulation that in the public sphere allowed the expression of and the demand for an identity shaped by scientific and technical exploration, an identity made of genes, proteins, and various sociotechnical prosthetic arrangements. We could say that it is a matter of articulating genetic and prosthetic identities as genetic and prosthetic citizenships (Heath, Rapp, and Taussig 2004). This sentence, which obviously simplifies the process, nevertheless shows the extent to which it is impossible to dissociate the
political and scientific dimensions of the AFM’s actions. We see why we would be wrong to limit this history to laypersons’ engagement in research. These emergent groups comprised of patients and their families carry with them the construction of new (genetic and prosthetic) identities that beg for recognition. It would also be wrong to conceive of the organization’s history in the same terms as that of a regular social movement (Hess, forthcoming). The detour via research and the integration of genes in the construction of an identity with an uncertain start cannot be dissociated from the struggle for the recognition of that identity.

In short, the AFM has managed to reconfigure the collective in which we, and MD patients, live. It would be more appropriate to refer to a common world, rather than a collective, for the result obtained by the AFM is not limited simply to the extension of the list of existing social actors. MD patients join the collective, entangled with their genes and prostheses, and impose new sociotechnical agencements (Callon 2007). Their inclusion redefines not only the constitution of the collective but also the boundaries and relations between society and nature, and the idea of a world does justice to that heterogeneity. This inclusion means that they are now able to influence both the industrial design and the commercialization of new therapies.

The AFM’s plan (Table 1) indicates precisely the road to take to achieve that reconfiguration: to structure and articulate scientific, medical, and social spaces so that they can host the gene and the enabling prostheses as operators of the link between patients and other human beings.

### Economic Markets, Technoscience, and the Production of Emergent Concerned Groups

Before addressing the question of the mechanisms that could explain the emergence of concerned groups, it would be useful to clarify the meaning of the term, based on the example provided by the AFM. A group is qualified as concerned when its formation is strongly contingent on the existence of matters of concern shared by its members. Initially, there may well have been no particular relations between the members of the still inchoate group. Then, owing to the activities of some of them and to the publicity given to difficulties that first seem to be individual, they gradually move closer to one another as they share their emotions and develop common actions. Provided they become visible and explicit, matters of concern then serve to link up and to bind the members of the group.
There are many different types of matters to be concerned about. The most interesting matters for us as far as this article is concerned share three characteristics that are clearly illustrated by the AFM case:

1. The patients and their parents who formed the association in the early 1960s were immersed in deep uncertainties: although their diseases had been given names, very little knowledge was available about the nature of the diseases, their causes, possible therapies, and directions to be explored.

2. Faced with such difficulties and uncertainties, they became engaged in investigations and inquiries that sometimes led them to invest in full-blown research and innovation. They then contributed to the constitution and organization of research collectives, mobilizing not only members of the group but also a whole range of professionals, including researchers and experts. They participated in the orientation of research and development and in the shaping and adjustment of the results obtained.

3. These investigations rapidly revealed a series of problems or issues that patients and their allies imputed to the technosciences and to their modes of development or organization. In the case of the AFM these problems stemmed from the low level of investment in research and innovation devoted to MD and, more generally, to compensation for disabilities. But, as shown below, technosciences, together with markets, can generate other types of issues.

In the following pages, we will consider only the groups that are concerned, like the AFM, with uncertainties related to technoscience and, in order to ease these uncertainties, have decided to launch collective investigations: the outcome will contribute to configuring their nascent hybrid identity.

Furthermore, groups that are concerned can experience many different evolutions and transformations. We must keep in mind that the history of the AFM is very peculiar. Through the years and owing to the actions undertaken by the association, MD patients have ended up forming a recognized group. Their cause has become legitimate, and they have gained the resources and influence that enable them to mobilize research, industry, and political power to support their actions. This type of success is fairly rare. Many groups concerned are not able to thoroughly and permanently establish their existence; they remain in a state of emergence and sometimes end up disappearing.

This diversity of possible developments raises two questions: one concerning emergence as such and the other concerning consolidation (or disappearance). It could very well have been the case that the scientific and clinical investigations developed and supported by the AFM failed to produce
any viable solution. Or the cause of disabled persons may never have resounded in the French society, the Téléthon may have been a total flop, industry may have refused to consider rare diseases, the AFM may not have had the political skills it has proved to have, and so on. The conditions of success and failure are at least partly distinct from those of emergence. In this article we concentrate on the question of emergence, not only because it precedes consolidation or disappearance, but also because (a) it matches a source of social dynamics that has received very little attention until now (the connection between the development of the technosciences and the proliferation of the social) and (b) it raises a series of specific questions related to the functioning of economic markets as well as scientific and political institutions.

The causes for the emergence of such groups that become concerned by uncertainties surrounding technoscientific developments are numerous. In the second part of this article, we focus on the role of economic markets. Economic markets play an important part in orienting the development of science and techniques and in selecting their applications. First, we show how, in general, they contribute toward the appearance of matters of concern and emergent concerned groups, which have the three characteristics mentioned above. We distinguish two categories of emergent concerned groups that we call orphan groups and affected groups. We then suggest that the growing importance of the network as a modality of economic coordination, coupled with the transformation of the objects on which science and technology work, tend to accelerate the production of emergent concerned groups by economic markets.

**Economic Markets**

The application of science and technology studies and, in particular, of the ANT approach to the analysis of economic markets has highlighted the importance of their technological and material components. In this perspective markets are better described as collective sociotechnical arrangements that (a) organize the design, production, and circulation of goods as well as the transfer of the property rights attached to them, and (b) construct a space of calculation allowing the assessment and especially the pricing of these goods involved in their commercialization (Callon and Muniesa 2005; Callon and Caliskan 2007; MacKenzie 2006). Considered as a collective sociotechnical arrangement, an economic market is caught between framing and overflowing; it is the constant tension between these two demands that explains the emergence of matters of concern and, in particular, the role of the technosciences in that production (Callon 1998).
To simplify, throughout the rest of this article we consider only a subset of all matters of concern produced by the framing of markets and the resulting overflowing, namely, those that lead to the appearance of orphan groups and affected groups, two categories of emergent concerned groups.4

**Framing and orphan groups.** The appearance of orphan groups is related to sociotechnical lock-ins, one of the most visible consequences of the framing, which allows economic markets to function as collective calculating devices. The phenomenon of sociotechnical lock-in has been studied from both the empirical and the theoretical points of view. It is a particular case of a more general mechanism: path dependency (Callon and Cohendet 1999; Abbot 2001).

Sociotechnical lock-in reflects the privilege progressively granted to certain technical and scientific options. Due to increasing returns to production and adoption, economic agents (designers, producers, distributors, and consumers) prefer investing in existing technologies rather than launching into the exploration of alternatives. As these investments are made, the framing of markets becomes more difficult to question. Sociotechnical lock-in thus results in the drawing of a boundary that creates a divide and introduces an asymmetry between those agents that can participate in the market and those that are rejected by it. The latter can feel excluded because existing markets do not meet their demands and fail to take them into consideration. In situations of well established lock-in (yet always exceptional and provisional), this exclusion is particularly striking and strong: only the supply and demand that fit into selected technological options can be expressed. Granovetter and McGuire’s (1998) exemplary analysis of the history of the U.S. electricity industry, with its irreversible choices concerning frequencies and production technologies, is a perfect illustration of this type of development. Another example is the French civil nuclear industry. As Hecht (1998) showed, the choice of the light water technology, made in about 1970 by a small number of actors, framed the development of the French industry for several decades and excluded other possible technological and economic options.

Because of the privilege given to a small number of scientific and technical options, some demands, needs, or expectations cannot be taken into consideration. The know-how and knowledge that would be necessary for them to be taken into account do not exist. This provides the grounds for the likely emergence of groups that, based on this fact, decide to embark on investigations that will enable them to explore new options, to define more clearly the problems facing them, and to seek possible solutions. We have borrowed the word “orphan” from David (1986) to describe these groups
that are excluded from the development of certain markets and that therefore explore alternative worlds.\textsuperscript{5} The AFM’s history is a striking illustration of such situations. In the early 1960s virtually no clinical or biological research existed on neuromuscular diseases. At the time of the genetic boom and without the intervention of patient organizations in the United States and Europe, and especially the AFM, these diseases would have been probably considered as secondary (or treated simply as exceptions).\textsuperscript{6}

Examples abound of such situations in which orphan groups mobilize. Their matter of concern is the fact of not or no longer being taken into account in the development of markets. By fighting against exclusion, they are struggling for a fairer allocation of resources devoted to the technosciences.\textsuperscript{7} Case studies attest to the diversity of the strategies followed and the forms of organization opted for by orphan groups to escape from situations of lock-in and the exclusions they produce.\textsuperscript{8}

The example of Linux (von Krogh and von Hippel 2003) shows that the engagement of what are known as lay people is but one prospect among many others. The frame imposed by Microsoft in the form of an economic monopoly based on sociotechnological lock-in was at the origin of the emergence of orphan groups closely concerned with this situation. Most of these groups consisted of computer scientists determined to fight against Microsoft’s economic and technical monopoly. The history of Linux shows that emergent concerned groups are not necessarily formed around laypersons (Linus Torvalds, the initiator of the movement, was a Finnish student) even if they soon include them. In the cases of both the AFM and Linux, there are orphan groups that are concerned and preoccupied by an ongoing framing that prevents their demands, expectations, and projects from being taken into consideration. In both cases these groups invent other forms of organization of research and innovation that are original compared to the open science or private innovation models. But in the case of Linux it is professionals who take the initiative, while in the AFM it is laypersons. In short, there are several ways of being orphaned and various strategic options for no longer being so.

One of the common characteristics of lockout strategies is the redefinition of the list of actors (the so-called stakeholders) who mobilize and coordinate to organize the exploration of new paths, to reorient research, and (possibly) to find solutions to the problems encountered and thus to overcome situations of exclusion. The inclusion of new actors and issues can eventually (although not necessarily) result in a reframing of the markets themselves that are strongly incited to take into account new preoccupations, as in the case of AFM. Callon’s work (1980b) on the electric vehicle...
and the research and innovations related to it in the 1960s in France and Steve Epstein’s work (1995) on AIDS and clinical trials could be reformulated along the same lines. What counts is not so much the fact that laypersons are active or that unexpected experts decide to enter the field; it is the forms of organization and coordination that these orphan groups promote: open hybrid collectives; distributed action and cognition; flexible coordination, often in the form of networks, and never in the form of paradigmatic groups; and the possible inclusion of laypersons.

Overflowing and affected groups. The framing needed for markets to function cannot be total. This impossibility does not correspond to what economists call market failure. It is the price to pay for a market to function, irrespective of its form as a sociotechnical agencement. Because they are framed, markets overflow. The hunt foroverflowing involves new framing that triggers new overflowing and so on. Market overflowing is a second source of emergence of concerned groups. Economists refer to externalities but, for reasons explained elsewhere, we prefer the more general concept of overflowing.

To draw up a systematic inventory of the overflowing associated with the functioning of markets, one needs simply to revert to the description of the sociotechnical arrangements comprising them (Callon and Muniesa 2005). Overflowing can affect—either independently or simultaneously—goods, agencies, or systems of relations established between agencies and goods. In the following, to simplify, we consider a limited subset of overflowing that is well documented from both an empirical and a theoretical point of view and is closely associated with technoscientific issues.

The first category of such overflowing consists of those that are generated by goods and their circulation. They correspond more or less to the externalities described by economists. Examples of such overflows include invisible prions that escape from firms and jump over species barriers, electromagnetic fields that frighten people living close to mobile telephone antennae, toxic waste, greenhouse gases, asbestos, transgenic plants that no one is sure can be confined forever, and so forth. This overflowing can entail costs for those who suffer because of it; it can threaten health and destroy the beauty of landscapes. But it can also have positive effects in all the sectors covered by the generic terms “culture” or “knowledge.” Goods encapsulating know-how and knowledge can overflow and make available to third parties resources that they use to develop their own lines of investigation and possibly to produce new goods. That is why it is preferable to refer to affected groups rather than hurt groups, the term used in some of
Callon’s earlier writings (2003). One can be affected by overflowing without necessarily suffering on account of it. What matters is that the affection triggers actions, explorations, and investigations. Collectives are formed that have the same characteristics of hybridization and distributed coordination as those previously encountered. Examples abound (Brown 1992; Brown et al. 2006), but we would like to mention a particular study by a Japanese colleague devoted to a disease called itai-itai that affected people living downstream from a mine. This story is interesting because it describes the creation of a collective (over a twenty-year period) that included the people living near the mine, university researchers and their equipment and instruments, lawyers, and then gradually engineers and researchers from the mine, politicians, and, finally, cadmium itself with its unexpected circulation and reactions. This collective not only solved the problem of cadmium overflowing (and the taming of it), it also contributed to innovations that made the mine cleaner, economically more efficient, and socially more responsible (Kaji 2004).

Economic agents can also be the source of overflowing. One of the best documented cases is that of engineers, researchers, or technicians who leave their firm or research center and put their competencies, know-how, or social networks to the service of new projects. Because of the framings that restrict their initiatives within the organization in which they work, they try their luck elsewhere. From the point of view developed in this article, this type of overflowing is particularly productive when these mobile professionals enter into partnerships with existing emergent orphan groups. It was indeed in cooperation with researchers marginalized by their institutions that the AFM was able to explore new research paths at the beginning of its existence.

The Proliferation of Emergent Concerned Groups

Economic markets are sociotechnical arrangements whose framings and overflowings trigger the appearance of groups (orphaned or affected) concerned by the development and applications of the technosciences. There is good reason to believe that the production of such concerned groups will intensify or accelerate. This acceleration is explained both by the introduction of new forms of organization of markets (networking) and by the evolution of the content of the technosciences themselves. Once again, to simplify we will mention only some aspects of this proliferation. To illustrate our argument we have deliberately taken examples only from the health field.
Increasing overflowing. Networks as a form of coordination and organization of economic markets are becoming increasingly predominant (Callon 1992; Amin and Cohendet 2004). Certain reasons for this trend are related to the emergence of what some call a new innovation regime (Joly and Hervieu 2003). This regime is characterized by the establishment of flexible cooperation between the multiple and heterogeneous actors who are often spread throughout different regions or countries (academic research labs, consultancy firms, public regulatory agencies, government services, firms engaged in subcontracting, local authorities, and consumers). Innovation is thus the result of numerous interactions between a growing number of diverse actors (DeBresson and Amesse 1991). These relations of cooperation, organized into techno-economic networks, are accompanied by competition that is no longer between firms but between networks fighting against each other to impose their own innovations. Techno-economic networks therefore have to demonstrate their capacity to react and adapt; the alliances that they enter into constantly change and evolve. This form of organization—characterized by both an intensification and a constant reconfiguration of connections, flows, exchanges, and circulations that take place gradually along with changes of configuration—has multiple opportunities for overflowing. It becomes quite difficult and even impossible for actors to monitor and control all the movements of all circulating entities. Leakages in markets organized as networks of innovation are more difficult and more costly to prevent than in traditional markets. These overflowings, always difficult to identify, generate matters of concern, especially due to their possible effects on human health. Many sanitary matters of concern are directly associated with the potential overflowing of networks (e.g., genetically modified organisms, bovine spongiform encephalopathy, and blood contamination).

The evolution of the technosciences and their content increases as well this propensity that markets have to overflow. First, the development of network technologies amplifies markets’ tendency to organize themselves in networks and accentuates the difficulties of framing their functioning. Second, private or public-sector R&D laboratories constantly produce new beings or entities that have to find a place in our societies. Rising R&D budgets, along with researchers’ greater productivity, automatically produce a demographic expansion of these new beings. To put it plainly, due to the growing investments in technological innovations, our societies are becoming more and more cluttered with nonhuman beings, so it is increasingly difficult for a new product or entity to find its place. This difficulty is all the greater since, as we have seen, the acceleration of innovation often goes hand in hand with the concentration of innovative activities on the exploitation of existing trajectories.
rather than on the exploration of new options (sociotechnical lock-in). Often this creates an incentive to slacken the requirements on new products or services: research intended to study their possible overflowing is carried out less rigorously, so they can be substituted more easily for existing products. A clear illustration of this trend is the pharmaceutical industry, where new drugs are intended mostly as substitutes for existing ones. This concentration makes substitution more and more difficult. As a result, there is a strong temptation for pharmaceuticals (and regulatory bodies) to launch and authorize products whose overflowing is less well framed (in this case they produce secondary effects that are disregarded: Pignarre 2003; Abraham and Lewis 2002). This laxness can trigger protest by affected groups.

Third, the technosciences contribute in an even more original way to the accelerated production of overflowing. One way of identifying this contribution is by underscoring the differences between disciplinary regimes and changes in their hierarchy. The physical sciences have a propensity to shape well-framed, purified entities and objects, in short, entities and objects whose behavior scarcely changes when they move from the laboratory into society. A CD-ROM driver acts in (almost) the same way in the laboratory as in a private home. With chemistry, by contrast, things start becoming more complicated. The chemical substances that share our lives and sometimes facilitate them are constantly acting, reacting, combining, and triggering chain reactions (chemical terminology attests to this activity). In short, they are less predictable, more difficult to frame, and the source of sudden overflowing or even explosion. Finally, with biology, biotechnology, and especially genomics, the difference is even greater. Entities are not simply reactive; they live their lives, even once they have left the laboratory. What happens within the laboratory does not make it possible to foresee entirely what is likely to happen outside. For a life science object, existing is overflowing (Bonneuil, Joly, and Marris 2008 [this issue]). A vector used to transfer a gene is alive; a cell in which a foreign gene has been introduced can become cancerous and proliferate in unexpected ways. The recent book by Kupiec and Sonigo (2003) has shown this proliferation by pointing out that with recent developments in genetics, the preceding model and its reductionism have been seriously challenged (see also Fox-Keller 1996; Rose and Novas 2005). It is increasingly difficult to liken the gene to a program and the gene’s action to the accomplishment of that program because of numerous interactions, interdependencies, feedbacks, and random events. Here again, the disciplinary repertoire is telling, with its distinction between in vitro experiments, experiments on live models, and in vivo experiments. These entities out of life science laboratories are thoroughly social, and they mix with us by living
their own lives, which we have to take into account (Rémondet 2004). With them, matters of concern and, consequently, emergent groups will undoubtedly proliferate.

Transformations of the technosciences coupled with the increasing prevalence of networks contribute to the proliferation of opportunities for overflowing and consequently to the proliferation of matters of concern leading to the emergence of affected groups.

**Stronger framing.** Competition between techno-economic networks multiplies the opportunities for overflowing. But network markets simultaneously produce strong framing for at least three reasons. First, they favor forms of externalities (network externalities) that generate increasing returns to both production and consumption and, consequently, lock in trajectories: techno-economic networks become irreversible and spread (Callon 1992).

Second, and more subtly, competition between techno-economic networks results in increasing singularization of products proposed to consumers. In this growing form of economic competition each consumer, user, or beneficiary of a service is differentiated from the others; each network tends to establish a (temporary) monopoly enabling it to harness a specific demand that it has actively coproduced with the consumer or user. In this strategic configuration, a network organization is a huge asset. It makes it possible to assemble competencies and know-how that allow for viable fine-tuning between supply and demand (Callon 1995). This trend affects numerous markets and, as highlighted by Nunes (2003), especially the health field where its effects are becoming increasingly visible. For example, even in the case of cancer, which is a well-known and widespread disease, “the set of diseases [under the label of cancer] can be defined as the outcome of polygenic dynamics, a range of factors acting on different levels or scales of biological organizations and multiple intersections of one and the other with environmental processes, social organization, life styles and consumer practices, available medical technologies and access to the latter, timely interventions of health professionals and the existence and effectiveness of adequate environmental and public health policies” (Nunes 2003).

The technosciences contribute to this growing tendency toward singularization, as is clearly the case in the health sector with the rise of genomics and proteomics: each human being can be characterized, at least in principle, as an ill being, in his or her own way that is different from other human beings. It follows that due to the very fact of this singularization, diseases are destined to become rare and consequently threatened, with the prospect of becoming orphans. Generally speaking, for the firm
the individualization of the offer allowed by the endless differentiation of customer profiles is a considerable asset since it implies close collaboration with its customers and consequently allows their attachment and loyalty (Callon, Méadel, and Rabeharisoa 2002; von Hippel 2004). But in exchange the firm, for the sake of economic viability, has to construct families of individual profiles that permit a form of rationalization (e.g., through modularization) of production and distribution. The result of individualization might be the exclusion of the most heterodox and heteronomous profiles, those that cannot be related to prevalent classes. To stick to the health sector example, therapies will perhaps—and here we are speculating—be targeted at certain genetic profiles or terrains, that is, the most frequent, the most similar, and . . . the most lucrative. Some empirical findings point to a strategic evolution of this nature. The AFM, for instance, recently introduced the concept of a model disease: faced with the endless differentiation of rare genetic diseases and especially neuromuscular diseases, the organization tries to reconstruct families of diseases that could possibly be treated by similar therapies (Callon 2006). This reframing intended to manage the proliferation of orphan patients inevitably leads to new exclusions: model diseases and the therapies they involve exclude certain diseases.11

According to Lakoff (forthcoming) the personalization of medicine (using the technological platform of pharmacogenomics) that gives pharmaceutical companies opportunities to market toward specific patients subgroups is frequently difficult to implement due to technical and commercial reasons. An alternative strategy, also based on pharmacogenomics, is the following: instead of considering that drugs and therapies have well-defined targets, one must define “illness in term[s] of that drug or therapy to which it responds: a successful response tells us what the person is suffering from. . . . The task is then to find the right patients, those on whom the drug shows demonstrable effects, and consequently to delineate the most salient population as [one] of drug responders” (Lakoff, forthcoming). This strategy is still a powerful device for drawing boundaries between persons who are included and others who are excluded. Thus, by personalizing medicine or by finding the right patient for the right drug, firms try (rather successfully) to overcome the problem of the increasing costs of clinical trials. In any case pharmacogenomics could lead to therapeutic innovations and to families of drugs that delimit the population and enact the identity of the patients who can be treated (see also Pignarre 2001). As Lakoff (forthcoming) notes, “These new pharmaceutical circuits function both to include and to exclude patients from medication.”

Under the effect of this coupling of markets as networks and the life sciences, we witness the proliferation of orphan diseases and consequently of
orphan patients who, whether enraged or not, will be ready for protest and mobilization. This rareness, constantly produced and extended by the joint action of sciences and markets, entails formidable problems of justice. It is no longer a matter of conceiving of an equitable distribution of existing goods between well-identified individuals and groups. The question is situated higher upstream, in the allocation of resources required for the conception and production of goods (e.g., new therapies) that do not yet exist and are intended for groups whose numbers and identity are not known with precision. This evolution and the mobilization it spurs have become visible. For example, the number of rare diseases, whose identification and diagnosis are partly related to the pervasiveness of genetics, is increasing rapidly and, along with it, so is the number of orphan diseases. The coprofiling of diseases, patients, and treatments seems inexorable. In France (as in other countries), this has resulted in the constitution of the Alliance Maladies Rares (Alliance for Rare Diseases) that aggregates matters of concern to groups that sometimes have no more than ten members. Their slogan is “diseases are rare but patients are numerous” (four million people are said to be concerned in France today).12

A third reason for which networks accentuate the force and debatability of framing is that the question of the limits to impose on the market constantly arises. The proliferation of cooperation and alliances has to be made compatible with the appropriation and distribution of profits generated by the delivery of goods and services to consumers. The more networks spread, become complex, and multiply, the more crucial issues of framing market relations become. This is reflected primarily in intense controversies and conflicts about the definition and attribution of intellectual property rights. Such debates are particularly visible in the case of the so-called commercialization (or privatization) of academic science (Dasgupta and David 1994). Apart from the tug of war between two institutions that try to maintain their own autonomy and decision-making capacity (open science versus private science), it is the balance between exploration and exploitation, between reinforcement of existing trajectories and maintenance of diversity, that is at play (Callon 1994). These questions that apply to all sectors are more acute in the biological field, where it is becoming increasingly difficult to draw a line between so-called basic (and therefore open) research and so-called applied (and therefore private) research (Sampat 2006). This demand for stronger and more controlled framing of property rights is a source of concern for groups that may believe they have been excluded by such frames. One of their claims concerns a revision of the modalities of allocating property rights: in the health field, patient organizations are increasingly aware of these problems.
To sum up, as a tentative conclusion to this section, we would simply like to say that as illustrated in the case of the health sector, the joint and intertwined evolution of the technosciences and economic markets leads, through the dual process of framing and overflowing, to the proliferation of matters of concern related to the orientations and applications of science and techniques. These matters of concern are characterized by strong uncertainties that might prompt the people concerned to embark on collective investigations intended to clarify problems, to identify possible solutions, and to elaborate an identity that largely depends on the results obtained.

**Concluding Remarks**

The first aim of this article was to present the concept of emergent concerned groups. Taking the example of the AFM, we highlighted some of the characteristics of these groups whose creation and trajectories are related by actors themselves to the appearance of matters of concern produced by the development of the technosciences. Faced with deep uncertainties and ignorance, they embark on investigations that enable them progressively to construct an identity that can be described as a sociotechnical assemblage. At the same time they try to arrange the collective as well as economic activities in such a way that they can find their place.

We then posited a possible proliferation of these emergent concerned groups. Economic markets, designed as sociotechnical arrangements, produce matters of concern related to the mechanisms of framing and overflowing. The upsurge and increasing pervasiveness of the form of market organization described as techno-economic networks triggers an acceleration of this process. The main result is a proliferation of affected groups and orphan groups, to be observed especially in the health field. The quantitative and qualitative evolution of the technosciences contributes toward this acceleration.

As the AFM example clearly shows, these groups are not simply an extension of the list of regular stakeholders usually referred to in governance literature such as public authorities, firms, academic researchers, consumers, and so forth. They disrupt the conventional definition of social roles and their division, and they highlight the limits of existing economic, political, and scientific institutions. First, due to the instability of constantly evolving identities, interests, expectations, and projects characterizing these nascent groups (instability related to the uncertainties surrounding matters of concern), the fact that established markets could take into account their demands and needs is highly problematic. For example, it was only after heavy investments in
research, over a long period of time, that MD patients were able to specify their demands and to frame industrial developments. Second, taking their existence into account politically is difficult in the framework of institutional apparatus that we have described as being structured around a double delegation: delegation of political representation to quasi professionals of politics and delegation of the definition of research and innovation activities to professional scientists. This double delegation indeed makes the existence of legitimate spokespersons difficult in their ability to express identities or interests that are still inchoate. What emergent concerned groups question, at least on the fringes, is the double-delegation model (Callon 2003).

These last remarks point to the necessity of developing more theoretical and empirical research in order to gain a better understanding of how emergent concerned groups could eventually contribute to the reconfiguration of relations between technoscience, politics, and markets.

To begin with, and this applies to all sectors, quantitative analyses ought to be undertaken. In the health field, the French case, for which we are starting to have substantial data, confirms the growing importance of emergent concerned groups in research activities as well as their presence in the public sphere to defend the new identities that their engagement in research enables them to construct. First, we have undertaken the compilation of a database on patient organizations and their investments in research. This database shows that 118 of the 213 organizations on which data were collected have a scientific committee and 84 finance research projects. Second, the creation in 2000 of The Alliance Maladies Rares is proof of the upsurge of emergent concerned groups in the health sphere and on the French scientific and political scene. The number of organizations that have joined The Alliance has more than tripled in three years, and current membership totals 141 organizations. One of the alliance’s objectives is to promote a research policy coupled with demands for full citizenship of people with rare diseases. Actions undertaken include the creation of an institute for rare diseases, intended to promote research in this area, as well as the organization of international congresses on rare diseases and handicaps, bringing together patients and their families, medical professionals, researchers, and representatives of the public authorities and pharmaceutical industry. It would be interesting to extend such surveys to other countries.

Furthermore, it would be useful to identify, from both an analytical and an empirical point of view, the economic sectors and technoscientific domains that (or which), like health are increasingly contributing toward the emergence of concerned groups. What is true for health probably also applies to sectors in which networked organizations exist and where the
level of unpredictability of goods is high and R&D is intensive (Bonneuil and Thomas 2004). Qualitative as well as quantitative investigations in these sectors have yet to be undertaken in a systematic way.

Third, the questions of emergent groups’ ability to impose their presence in the public sphere, to really reconfigure markets, and to weigh in on the orientation and organization of research and innovation are other areas requiring investigation. The question regarding the influence of national institutional contexts is worth asking. Comparative studies would be useful for determining the extent to which national frames amplify or curb these trends.

Finally, despite the increasing role of concerned groups, a romantic view of direct democracy and the historical revenge of laypersons on experts would be a serious misinterpretation. Concerned groups, both orphan and affected, are doubtlessly actors that contribute toward the constitution of research collectives of a new kind, collectives that are more open, flexible, and distributed. When they are successful, these collectives produce networks of alliances that generally result in a reorganization, and not in an upheaval, of the modes of functioning of markets (e.g., by amending the intellectual property regime) and/or of scientific institutions. Moreover, despite their openness, these collectives draw new boundaries; they re-enclose after opening up. When they are related to scientific and technical areas such as genomics, and when they articulate political advocacy to their research activities, they might impose new models of collectives and subjectivities. For example, the engagement of patient organizations in genetic research causes them to favor forms of collective life and subjectivity that some observers describe by means of concepts such as genetic subjectivity and genetic citizenship (Callon and Rabeharisoa 2004). In addition, as the case of the AFM shows, their success could cause them to turn into more conservative concerned groups with perfectly stabilized interests and firmly established power: emergence is a transitional property. A great deal of work is required to determine whether, as some people claim, the engagement of such (emergent) concerned groups into economic and political life will make the appearance of a new regime of innovation possible.

Notes

1. On the French Téléthon, see Cardon and Heurtin (1999).

2. This transformation is attested by the change of the association’s name. Initially, it was called the Association française des myopathes (French Association of Muscular Dystrophy Patients), but later it became the Association française contre les myopathies (French Association to Fight Muscular Dystrophy).
3. These changes may themselves be criticized and refused by certain patients who prefer their former status (Callon and Rabeharisoa 2004).

4. An exhaustive review of matters of concern should successively examine the effects of the actions of framing applied to the agencies, goods, and delimitation of the systems of relations that organize the encountering between supplies and demands and the different types of overflowing for which they are responsible.

5. David (1986) spoke of angry orphans to refer to those who had chosen the standard that was eventually eliminated, for reasons that had nothing to do with technical qualities or initial relative cost.

6. The term “orphan group” is particularly well suited to this situation because the diseases overlooked by research and markets are qualified as orphan diseases. It is under the pressure of patient organizations that in the United States and then Europe laws have been passed to remedy these exclusions.

7. The question of equity in the allocation of resources devoted to research (the question of which research orientations are favored) has hardly been studied. The idea that science is good for everyone (science as a public good) has helped to depoliticize this question.


9. As Callon (1998) has shown, the disentanglements necessary for framing markets inevitably lead to the production of new entanglements.


11. New biomedical conceptualizations might lead to a redefinition of disease categories that make more uncertain and more controversial the drawing of a boundary between potential victims, who should be included, and those who are excluded (Epstein, forthcoming).

12. It is interesting to note that even diseases that until recently were not considered to be rare are losing their unity not only because knowledge is advancing and showing their diversity but also because the treatments that prolong life expectancy favor the appearance of a wide diversity of opportunistic diseases. Note also, as Pignarre (2001) showed so clearly in the case of mental diseases, that the circulation of molecules and treatments increases the diversity of diseases due to the variety of reactions and responses by the individuals treated.


14. For a promising approach, see Hess (2005).

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