

# From representation to mediation: The shaping of collective mobilization on muscular dystrophy in France

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## Abstract

How, and to what extent, do patient organisations renew traditional forms of social participation and protest? This question is examined, drawing on a socio-historical case study of the Association Française contre les Myopathies—French Muscular Dystrophy Organisation (AFM). The originality of the AFM is that it has not been content to endorse the classic role of representation of people with muscular dystrophy (MD) and their families. It has also articulated and structured different social spaces that allow people suffering from genetic diseases and severe disabilities to be considered as fully-fledged human beings, persons, and citizens within those spaces. Based on quantitative data and methods, this paper aims to characterize this reconfiguration of social spaces that the AFM has undertaken. My contention is that it has given shape to a different form of collective mobilization, one in which the patient organisation is a mediator between different social actors, as much as a patients' representative. It helps a new issue, here MD, to emerge so that the largest possible collective designate it as a general public concern. As we shall discuss, this renews the question of patients' collective identity and citizenship.

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## Introduction

The emergence and empowerment of patient organisations has a long history in most Western countries, dating back to the 1940s and 1950s when the first organisations for people with chronic diseases were founded. This history has still to be written but a partial review of the literature (Rabeharisoa, Callon, & Demonty, 2000) has shown that it is characterized by three main claims. The first can be described as an identity claim. Patients with the same disease become aware of the similarity of their individual experiences;

they are no longer alone, for they have alter egos with whom they share a collective identity. To borrow from Rabinow (2002), they are “biosocially” linked to one another. The second claim is epistemological. Patients consider that their shared experience constitute knowledge of their diseases that is different from professional knowledge but essential for understanding and improving their condition. The third claim is political. With their special concern about their disease, patients consider it legitimate to have a say in decisions concerning their situation. It is the articulation of these three claims that makes patient organisations a particularly interesting subject to study. They involve a diversity of social experiments aimed at linking up the development of an identity, the production and mobilization of knowledge, and political action.

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To understand the nature, scope and effects of these experiments, one of the most frequently applied analytical frames is that of new social movements. In this brief introduction, we will not provide an overview of the vast literature on new social movements. Rather, we would like to highlight a few issues derived from this analytical frame, which better suit to the case discussed here—e.g. the collective mobilization around muscular dystrophy in France.

The new social movements consider the study of protest that develops in post-industrial societies not only around the means and organisation of the production of wealth, but also around the technologies that transform all aspects of social and cultural life (Touraine, 1985). Defending forms of life that some of these technologies threaten and resisting their tendency to colonize are the watchwords of the new social movements (Habermas, 1981). Use of this analytical frame enables us to highlight the influence of new social movements—e.g. civil rights, women's liberation and gay movements—on the development of certain patient organisations (Crossley, this issue; Hardon, this issue). It also allows us to grasp conflicts between patient organisations and professional authorities and, more generally, sometimes radical criticism of these organisations of medical knowledge and techniques. With this approach in terms of new social movements one is not confined to a description of patient organisations as ordinary organisations that can mobilize resources (financial, experiential, etc.) in order to establish their legitimacy and authority in the medical and health field, or simply as groups of individuals opposed, on principle, to any professional initiative. Crossley and Crossley (2001) show, for instance, how by denouncing professionals' power over the definition and treatment of their conditions, psychiatric survivors struggle for their recognition as actors in their own right whose experiences are valid objects of study and who can formulate their own projects. In so doing, these movements participate in the assertion of new collective identities (Johnston, Larana, & Gusfield, 1994). Questioning of medical power and knowledge, and construction of an identity are thus two analytical perspectives that emerge.

The present paper examines the project of the *Association Française contre les Myopathies* (AFM—French Muscular Dystrophy Organisation), an organisation of patients with muscular dystrophy (MD) and their parents, founded in 1958. This organisation has original characteristics as regards relations with professionals and the expression of a collective identity. Two salient features mark its history. First, it has applied a strong and lasting strategy of alliance not only with the medical and paramedical professions but also with a wide range of actors: researchers (biologists and clinicians), industry, public authorities, medico-social institutions, other patient organisations, the media, etc.

Second, it has played such an active part as a mediator between these different actors that describing it only as an organisation representing and defending the community of MD patients and their families seems inadequate. The AFM thus constitutes an organisation that fosters new ways of thinking: it calls for a renewed analysis of collective action and identity.

What exactly is the AFM? In what way does it challenge our understanding of patient organisations' action? To answer these questions we draw on research on the history of the AFM, its mission, its organisation, and its achievements. One of the findings of this research is that the AFM's project can be formulated as follows: not to create a community of MD patients, but to extend our common humanity to all people with MD. This approach was closely related to the status of muscular dystrophies, considered not as diseases but as defects. It was the awareness of that reality, the outcome of a long and painful learning process, which prompted the AFM to set out to ensure that the struggle against MD became a general public cause. The first section of this paper recounts the circumstances that led to the formulation of that project. It will become clear that the AFM mobilized many actors so that the areas of research, clinical medicine, pharmaceuticals, care for handicapped persons, and the media, would cease to ignore not only MD people, but also those individuals whose living conditions were altered by genetic and seriously invalidating diseases.

We describe the work undertaken by the AFM to reconfigure those spaces—work that has constituted the core of its action throughout the past few decades. The way in which the AFM has formalized its project, both in its discourse and its actions, is evidence of a reflexive capacity that we then consider in depth. This discussion focuses first on a description of its action. The notion of “demonstration” proposed by Barry (2001) is particularly useful here. Barry draws attention to significant similarities between political demonstrations and scientific and technical demonstrations. He rightly notes that “(...) to conduct a political demonstration can be a matter of making visible a phenomenon to be witnessed by others” (Barry, 2001, p. 178). Our argument is that the action undertaken by the AFM is precisely a demonstration of that sort. It consists of the configuration of spaces in which a particular object—here, MD—is designated as an object to be dealt with by the collective for the collective. This also enables us to examine a second essential point: the status of the AFM, both as an organisation of MD patients and their families, and as a social actor that is associated with and brings together other social actors around the same collective cause. We thus address the issue of patients' collective identity and representation in new terms. Finally, we conclude with an examination of the AFM's contribution to current debate on patients' citizenship.

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