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‘Europe of patients, Europe for patients’: the Europeanization of healthcare policies by European patients’ organizations

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‘EUROPE OF PATIENTS, EUROPE FOR PATIENTS’: THE EUROPEANIZATION OF HEALTHCARE POLICIES BY EUROPEAN PATIENTS’ ORGANIZATIONS

Vololona Rabeharisoa[*] and Orla O’Donovan[**]

Introduction

The last two decades have witnessed an efflorescence of European lobbying organizations, including European civil society organizations (Lahusen 2004). Lobbying activity is mainly clustered around enterprise and environmental policy, domains in which the EU has greatest regulatory competencies. However, health has been identified as the fastest growing lobbying sector (Coen 2007). Patients’ organizations have been part of the ‘rush to Europe’. This domain is of particular significance because healthcare is a major area of the welfare state in which the EU has in the past had little involvement, but one which has in recent years witnessed an increasing Europeanization of policy (Greer *et al.* 2008). To date, very few studies have explored the species of organizations that European patients’ organizations (EPOs) constitute, and the form of activism they develop. This article examines these two issues.

The notion of Europeanization has raised substantial discussion over the past years. For political scientists, Europeanization designates a process

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different from European integration (Featherstone and Radaelli 2003): European integration pertains to nation states transferring part of their sovereignty to a supranational authority, whereas Europeanization consists in the adaptation of domestic institutions and policies to this system once constituted. A large body of the literature on this process of *'societal transformation, pointing to a reconfiguration of cultures, identities and forms of governance'* (Sassatelli 2008: 225) focuses on the role played by the EU, either by exerting pressures through its rules and procedures (Radaelli 2003), or by promoting European policies (Shore 1993). Studies also examine the opportunities offered by the very existence of the EU to Member States for reorienting their own domestic policies (Putman 1998). Recently, however, research on the role of civil society organizations (CSOs) in the process of Europeanization has blossomed. Della Porta and Caiani's (2007) examination of 'Europeanization from below' stands as a remarkable contribution.

Della Porta and Caiani (2009: 25) define Europeanization from below as Europeanization *of* and *by* civil society. They identify two paths whereby CSOs, and notably social movement organizations (SMOs), Europeanize their claims and frames, the paths of 'domestication' and 'externalization'; the first refers to the targeting of national governments by SMOs to address EU issues, and the second to the targeting of EU institutions in efforts to pressurize them to intervene at national level. In cases of 'externalization', SMOs also 'go to Europe' to engage in a process of supranational network formation that cannot be done nationally (Montforte, 2009).

Della Porta and Caiani (2009) also discuss extensively the promises of Europeanization *by* civil society, especially democratizing Europe. Both pull and push dynamics drive CSOs to Brussels, as CSOs push their way into the newly opening channels of influence, but are also pulled in by EU institutions in search of democratic legitimacy (Putman 1998; Dunkerley and Fudge 2004). Della Porta and Caiani emphasize SMOs' potential contribution to the emergence of a truly European public sphere and a European demos. Establishing a 'social Europe' as an alternative to the 'Europe of markets' is another promise of Europeanization from below. Much analysis of CSOs (Bieler 2007; Storey 2008) focuses on how they might resist the neoliberal nature of the current European project manifested in the reliance on 'hard law'[1] for competition and other economic policies, and 'soft law'[2] for policies to defend and extend a 'social Europe'.

This article considers how EPOs contribute to Europeanization from below and its promises. Based on an analysis of the projects, pronouncements and politics of three EPOs – EURORDIS (European Organization on Rare Diseases), Alzheimer Europe, and ADHD Europe (Attention Deficit Hyperactivity Disorder) –, we investigate their role in the Europeanization *of* patient advocacy, moving it beyond national level organizing and acting. We also explore EPOs' role in Europeanization *by* patient advocacy, their contribution to debates and policies on healthcare at European level. Our argument is that

[1] 'Hard law' mainly designates the corpus of EU directives and regulation that Member States must comply with.

[2] 'Soft law' procedures include a variety of instruments whereby EU acts as a policy-coordinator between Member States. We discuss some of these instruments later on.

Europeanization from below does not consist merely of bringing national claims up to the European level, nor simply enriching national debates with EU issues. Crucially, it also entails a compounded multilevel process whereby EPOs give shape to health issues they deem important to address at European level, and build European communities of patients. This approach, which echoes Delanty and Rumford's (2005) questioning on the *construction* of Europe, is particularly relevant here. Indeed, healthcare remains the preserve of Member States, which implies that EPOs have to form European communities of patients and define the causes they stand for as European for them to effectively and meaningfully act at European level. This is what we show in the first section, drawing on interviews with representatives and staff members of these organizations, website and document analysis, workshops, conferences and events that they organized over the three year duration of our research project. In the second section, we turn to the forms of activism that EPOs develop and the *Europe for patients* to which they give rise. We highlight their intensive activity for producing facts, statistics and indicators in order to calibrate and justify their intervention at the crossroads of the 'Europe of markets' and a 'social Europe'. This 'evidence-based activism', as we may call it, points to the importance of metrological activity for the making of Europe, as Barry (2001) has demonstrated. In the conclusion, we revert to the promises of Europeanization from below and if and how they are advanced by EPOs.

1. European patients' organizations and the construction of a Europe of patients: from the 'patient-consumer' to the 'patient-sufferer'

For the EPOs we studied, building communities of patients and raising their capacity to act at European level are strategic missions. Indeed, the patient, as an individual with a disease, is not an ordinary European subject. This is due to the historical constitution of European patients as consumers.

Historically, the prerogatives of the EU were confined to the establishment and regulation of the European Single Market, whereas the principle of subsidiarity applied, and still applies, to sectors such as education and health. As far as health is concerned, Europe intervenes largely as a rule-maker in the health *market*, for example in the regulation of drug and private health insurance markets and legislation on the safety of bio-products. From the perspective of the European constitution, health is a sector of production, circulation and consumption of health-related goods and services. This is manifested in the title of DG SANCO – Directorate General for Health and *Consumers* (our emphasis) –, as well as in the first European initiatives in the domain of healthcare.

Jarman and Greer recall (2010) that these initiatives began in 1998 with rulings made by the European Court of Justice that healthcare activities are services subject to the EU's laws on the internal market. In an effort to legislate for the incorporation of healthcare into the general EU regime for the regulation of services, in 2004 the European Commission proposed the controversial Bolkestein Directive. Cited as an example of the 'externalization' path of

Europeanization of SMOs, Della Porta and Caiani (2009: 83) describe how the Directive was opposed trenchantly by many SMOs as *'an atrocious attack on public services, workers' rights and democracy'*, beginning with opposition at the national level and extending to European SMOs, networks and coalitions. Forced to abandon the Bolkestein Directive, a revised European Directive on patients' rights to cross-border healthcare that moved away from promoting trade in services to ostensibly promoting citizens' rights was put under the co-decision of the European Council and the European Parliament and passed in 2009, while the principle of subsidiarity continues to apply to the sector of healthcare.

In parallel to these regulations, soft law instruments were formalized over the Convention working groups that resulted in the Lisbon Treaty in 2000. Amongst those instruments, OMC (Open Method of Coordination) emerged as one major tool for fostering European construction in areas where Europe's initiatives were heretofore restricted. OMC draws on procedures that permit multilevel governance on issues for which Europe does not act as a rule-maker but rather as a policy-coordinator. It consists in:

> '(…) fixing guidelines for the Union combined with specific time-tables for achieving goals (…) in the short, medium and long terms; establishing, where appropriate, quantitative and qualitative indicators and benchmarks against the best in the world and tailored to the needs of different Member States and sectors as means of comparing best practices; translating these European guidelines into national and regional policies by setting specific targets; periodic monitoring, evaluation and peer review organized as

mutual learning processes'. (Presidency Conclusions, Lisbon European Council, 23-24 March 2000, Point 37)

OMC certainly paved the way for European actions in the sector of healthcare, such as the Europe for Patients Campaign launched by DG SANCO in 2008 as part of the European Health Programme 2008-2013. For the first time in European history, healthcare for patients with specific diseases, notably Alzheimer's disease and rare diseases, were featured amongst the eleven priorities of this programme. This programme *de facto* profiled a new figure of the patient as an individual suffering from a given condition. It is this nascent figure of the 'patient-sufferer', in contrast to the historic 'patient-consumer' and the abstract 'patient-citizen' that EPOs give rise to and consolidate.

Indeed, the EPOs we studied formed with an aim to gather European patients and to voice their concerns at European level. This however does not merely consist of grouping existing national patients' groups and pooling their claims at European level. Each EPO had to simultaneously give shape to a transnational community of patients, and define the disease or condition they are concerned with as a relevant European issue. Depending on how it formulated the cause it stands for at European level, each EPO adopted a configuration and a representational scheme it deemed appropriate and thus Europeanized in different ways.

1.1. Alzheimer Europe: representational monopoly and the scaling up of political advocacy

Alzheimer Europe holds a classical status of European advocacy group. It resembles many CSOs that Warleigh (2001: 622) describes as having Europeanized instrumentally *'to secure their objectives or in response to enticements by the Commission, rather than out of "European" zeal'.* When it formed in 1990, Alzheimer's disease (AD) was already considered a major challenge for Western societies. At that time, national AD organizations existed, some of them for up to a decade. However, although AD was recognized as a critical health issue and benefited from effective national activism, it was not an object of specific policies articulating research, prevention, care and support to patients and carers in all European countries. Alzheimer Europe was created by ten AD national organizations for motivating European engagement with AD in order to foster national public health policies.

This scaling up of political advocacy was narrated in a presentation at the 2010 Alzheimer Europe annual conference entitled *'Alzheimer Europe 1990-2010. Celebrating twenty years of achievements'*[3]. Recounting the origin story of the European coalition of Alzheimer's disease patients' organizations[4], the Executive Director cited the statement below made in 1990 by the founders of Alzheimer Europe:

[3] Notes from ethnographic observation of the 20th Alzheimer Europe Conference, *'Facing Dementia Together'*, 30 September – 2 October 2010, Luxembourg.

[4] The slides for this presentation are available on http://www.alzheimer-europe.org/

> ‘Because we are all satisfied that we will benefit from European co-operation, and together can put more pressure on the European Council, Commission, Parliament and other national and supranational organizations, we have decided to form a European Alzheimer organization’.

In line with this objective, it has expanded the number of member national AD organizations and positions itself as their unique legitimate and competent interlocutory representative vis-à-vis European institutions. Alzheimer Europe strongly emphasizes its representational capacity and monopoly. It publicly identifies itself as a European platform and umbrella organization of 34 Alzheimer associations from 30 countries (including non-EU Member States Iceland, Norway, Switzerland and Turkey) which is:

> ‘[…] the only organization which is both representative on a European level and able to provide a voice for people with dementia and their carers[5]’.

1.2. EURORDIS: heterarchical organization and the ‘politics of numbers’

EURORDIS shares similar features with Alzheimer Europe: they both have professional staff (27 for EURORDIS, 6 for Alzheimer Europe), substantial budgets (close to €3 million for EURORDIS, €0.7 million for Alzheimer Europe in 2009, to which the European Commission contributes), as well as headquarters at strategic locations (Brussels and Paris for EURORDIS, Luxembourg for Alzheimer Europe). However, EURORDIS, unlike Alzheimer Europe, has a heterarchical organization (Stark 2009) that is uncommon in the

[5] Alzheimer Europe’s Strategic Plan 2006-2010. See http://www.alzheimer-europe.org/

landscape of EPOs. It has member organizations, but it also welcomes individuals who are not affiliated to any patients' group. Formed in 1997 by members of four French patients' organizations[6], EURORDIS aims at constituting war on rare diseases as a European cause. Its Executive Director explained[7] that the organization defined 'the concept of rare diseases'[8] to demonstrate that its cause is even more relevant and legitimate at European level than at national level. The 'concept of rare diseases' denotes a series of characteristics shared by these conditions: they are numerous and all different[9]; some of them concern very few individuals who are either isolated or join organizations that are not primarily concerned with their particular disease; their prevalence varies from one country to another; expertise is unevenly distributed, if not lacking; specialists, when they exist, organize themselves differently in each country.

This 'concept of rare diseases' prompted EURORDIS to develop what we call a 'politics of numbers'. EURORDIS summarizes this 'politics of numbers' in its motto: *'Rare diseases are rare, but rare diseases patients are many'*. The organization estimates the number of individuals affected by rare diseases in Europe at 30 million. This translates into EURORDIS' first mission: building a

[6] With the active support of an official from the French Health Department who had been long involved in rare diseases affairs.

[7] Interview with the Executive Director of EURORDIS.

[8] This concept is delineated in a 14 page-statement published by EURORDIS in 2005, entitled: *'Rare Diseases: Understanding this Public Health Priority.'*
http://www.eurordis.org/sites/default/files/publications/princeps_document-EN.pdf

[9] Rare diseases have prevalence lower than 1/2,000 or 5/10,000. To date, close to 6,000 rare diseases have been recorded in the world. 80% of them are of genetic origin.

community of European individuals and families and becoming *'The Voice of Rare Diseases Patients in Europe'.*

Today, EURORDIS publicly identifies as a non-governmental patient-driven organization with 479 member organizations in 45 countries, including non-European countries. It actively contributes to the creation of National Alliances on Rare Diseases, which are statutory bodies of EURORDIS. Most importantly, individual patients who have either decided not to belong to any particular organization, or whose disease is not represented by any organization, receive full membership of EURORDIS if they apply. In addition, a few years ago EURORDIS started to build web-based communities of patients around diseases. Additionally, individual patients and families are invited to offer testimonies during conferences and workshops, including during institutional events like the Rare Disease Day held in Brussels on 1 March 2010[10]. The Executive Director of EURORDIS considers[11] that the organization is not content to be a conventional federation of federations: the individual patient, whatever his/her situation, counts, he says, if EURORDIS' s politics of numbers is to be credible.

1.3. ADHD Europe: mutual recognition between families and 'politics of experience'

Like EURORDIS, ADHD Europe has engaged in long-lasting work to legitimate ADHD as a relevant cause for Europe. However, whereas EURORDIS'

[10] Notes from ethnographic observation of Rare Disease Day *'Bridging Patients and Researchers to Build the Future Agenda for Rare Disease Research in Europe'*, 1 March 2010, Brussels.

[11] Interview with the Executive Director of EURORDIS.

preoccupation was to gain recognition for rare diseases as a major public health issue, ADHD Europe had first to state the fact of ADHD over the eight years prior to its official creation in 2008. ADHD is one of those unsettled conditions that Dumit (2006) called 'illnesses you have to fight to get'. ADHD still divides clinicians in terms of its etiology and appropriate therapeutic intervention. Often considered the result of bad parenting, the status of ADHD as a serious condition remains contested in many countries. In addition to stigmatization of children with ADHD, this situation led to the absence of appropriate care. These statements were at the origin of ADHD Europe.

In 2000, a mother of a child with ADHD living in Belgium recognized a need for greater awareness of, and services for, children with the condition. Acknowledging the dire provision for children with ADHD in schools in Belgium, *'she set out to find out what it was like in the rest of Europe.'*[12] As the Board member we interviewed explained, *'she got into talks with a colleague in the European Commission who had the same experience, because both he and his son had ADHD'.* The mother applied for funding from the European Commission Department of Social Affairs for a project called *'Knowing Me, Knowing You'*. Running from 2000 to 2002, the project aimed to map experiences of people with ADHD across Europe, and explore the needs of national organizations. Not yet formed as ADHD Europe, *'Knowing Me, Knowing You'* seemed to act as a springboard for the emergence of national groups and a growing European consciousness on the issue drawing primarily on the lay expertise of parents of children with ADHD. At a seminar as part of the project in Copenhagen in

[12] Interview with a Board member of ADHD Europe, 13 October 2010.

November 2001, parents came together to share their experiences of living with ADHD. This 'politics of experience' was instrumental in stating ADHD as a European condition that deserved coordinated action, as a press release on the event encapsulated in the following statement: *'There are no borders in Europe concerning ADHD*[13]*'.*

1.4. What Europe of patients do EPOs build?

For EPOs, the dual ontological construction[14] of communities of patients as European collectives, and conditions they are concerned with as European matters-of-concern, underlies the building of a Europe of patients. As described above, this process relies on, and contributes to the development of national patients' organizations. The EPOs we studied are of grass-root origin: in contrast to Warleigh's (2000) portrayal of European CSOs as often 'elite-driven rather than membership-led', representatives of national member organizations proactively engage in the building and running of EPOs. Conversely, EPOs contribute to the structuring of national patients' organizations, and impact therefore on the vitality of domestic patient advocacy. This intermingling of European and national level of patient advocacy stands as one remarkable feature of the Europe of 'patients-sufferers'. It pertains to the fact that healthcare still is the preserve of Member States and, consequently, that engaging the EU in healthcare policies cannot be done without close cooperation and negotiation between EPOs and their national member

[13] *Knowing Me, Knowing You: Diagnosis and Early Intervention*, undated: 21.

[14] We extend Laurent's (2012) perspective on the European regulation of nano-objects, by considering Europeanization as an ontological construction of subjects and objects, e.g. of entities that have to be generated as relevant and do-able for Europe.

organizations. We will see more about this multilevel action and the tensions it sometimes generates in the next section.

Moving from the national to the European level raises a specific representational concern: how to speak on behalf of individual patients who are dispersed across different countries, and whose experiences are embedded in diverse national contexts? This preoccupation with representation is critical for all CSOs' identity and legitimacy: as Lahusen puts it (2004: 67), they have to avoid a situation where their professional advocates become insulated in the *'cocktail circuits of the Brussels polity'*, and decoupled from their grassroots constituencies whose interests they claim to represent. EPOs may also face similar criticisms, some patients regarding them as *'qua-institutions, far away in Brussels'*[15]. As an organizational and a political answer to this challenge, EPOs seek to enroll individual patients in a variety of ways: EURORDIS offers them full-membership if they wish; ADHD Europe has long mobilized individual families, and still does via its member organizations; even Alzheimer Europe, which has no direct contact with individual constituencies of its member organizations, nevertheless publishes individual patients' and carers' testimonies on its website, portraying them as the ultimate beneficiaries of its actions. For EPOs, bringing individual patients to the fore, constantly recalling that their experiences matter, are at the core of their politics for transforming 'patients-sufferers' into European individuals.

A final significant characteristic of the EPOs we studied is that they all have members in non-European Member States, including associate members

[15] Interview with the vice-president of a small French rare disease patients' group.

outside the European continent. At the very least, it is fair to say that EPOs picture the Europe of patients as part and parcel of international networks of patients, contributing therefore to the globalization of patient advocacy.

2. European patients' organizations and the shaping of a Europe for patients: elaborating evidence on the relevance and legitimacy of EU health policies

The EPOs we studied seek to promote health policies and strategies in their condition-areas. To achieve this, they clearly endorse a position of 'insiders' rather than 'outsiders' (Della Porta and Caiani 2007; Greer *et al.* 2008) in the European political game and polity. This manifests in two ways.

Firstly, they position themselves within the complex and sometimes confrontational European CSOs ecology to defend their causes against other interest groups, as demonstrated by the long-standing controversies surrounding EU law on the patenting of biotechnological inventions. European patients' and environmental organizations first clashed on the issue in the late 1990s. In opposition to many European environmental CSOs, the European Alliance of Genetic Support Groups – with which EURORDIS has many ties – was a prominent and seemingly influential force in lobbying efforts endorsing the EU's 1998 Directive on the legal protection of biotechnological inventions (Balanya *et al.* 2000; Smyth 1997). The Directive sought to provide legal protection deemed essential for both techno-scientific research and economic development, but also to ensure that certain inventions remained *'unpatentable*

where their exploitation would be contrary to public policy or morality[16]*'.* Using for the first time its veto powers, the European Parliament rejected the draft Directive in 1995, but subsequently adopted it in 1997. During the 1997 vote, the halls of the European Parliament were filled with members of patient interest groups, wearing T-Shirts saying *'No Patents, No Cures',* and *'Patents for Life'*. Fights and debates do not only oppose divergent vested interests; they also question the very nature of the European project, notably how and to what extent the 'Europe of markets' and its techno-economic agenda can accommodate a 'social Europe'?

Secondly, EPOs contribute to the elaboration and implementation of collective actions, associating European institutions, national patients' organizations, European and national stakeholders in their condition-areas, namely consortia of researchers, clinicians, health professionals, and sometimes pharmaceutical and biotech firms. Additionally, they contribute to promoting the idea that there is a confluence of interests of these 'partners'. This is very much in line with the EU's multilevel soft modes of governance that were given a new impetus by the European Commission's 2001 White Paper on European Governance (Borras and Conzelmann 2007). The EPOs have progressively become experts and major players in this new EU governance, looking to ways whereby the EU can be brought into the sector of health that remains the preserve of Member States.

[16] See http://europa.eu/legislation_summaries/internal_market/single_market_for_goods/pharmaceutical_and_cosmetic_products/l26026_en.htm

These CSO interventions in the EU polity raise many concerns. Some scholars consider CSOs which play the EU multilevel governance game as just stakeholders among other stakeholders (Dunkerley and Fudge 2004; Della Porta and Caiani 2009), mostly engaged with the 'participatory engineering' that some critics allege characterizes the EU's approach to collaboration with CSOs, in which it tends to 'instrumentalize' them as service providers and co-producers of regulatory policy (Borzel and Buzogany 2010). Others warn against the depoliticization potential of the EU multilevel governance, picturing it as a version of democracy mostly preoccupied with 'problem-solving efficiency', with 'output' rather than 'input-oriented legitimacy' (Scharpf 1999; Mair 2005).

In what follows, we examine how these debates on 'Europe of markets' *versus* 'social Europe' on the one hand, and on the democratic promises of EU multilevel governance on the other hand, surface in the EPOs' pronouncements. More significantly, we investigate how they tackle these issues and contribute to their reframing through the concrete actions they undertake.

The EPOs we studied are engaged in a series of actions which aim at ensuring the development of medical research and care services, and access to diagnosis, medications and care for all concerned European patients. Looking at their projects and pronouncements, one is struck by their intensive work in staging, comparing, confronting, and circulating data, facts, and statistics on cure and care across European countries. Barry (2001) analyzed in great detail the importance of measurements in the construction of Europe: as a matter of

fact, this metrological work aims at proving evidence on the relevance and legitimacy of healthcare issues at European level. EPOs regularly conduct surveys of their members for collecting data on their needs and expectations, as well as information on the provision of care in their countries. It is through this 'evidence-based activism' that broader concerns with the neoliberal European project and with the deficit of democracy in Europe unfold in EPOs' discourses and actions.

2.1. Alzheimer Europe: soft modes of governance and hard facts to establish dementia as a EU priority

At Alzheimer Europe's 2006 annual conference held in Paris a *'Declaration on the political priorities of the European Alzheimer Movement'*[17] was adopted. This *'Paris Declaration'* called for dementia to be made a European and Member State public health priority and identified the four areas of promoting greater awareness and early diagnosis of the disease, greater coordination of research, sharing of best practices in dementia care, and advancing the rights of people diagnosed with dementia.

Three years later in 2009 the European Commission issued a Communication[18] to the European Parliament and Council on a European

[17] See http://www.alzheimer-europe.org/EN/Policy-in-Practice2/Paris-Declaration

[18] A Communication is an official document issued by the European Commission for advocating the EU support to initiatives it deems strategic. Such initiatives are prepared by the relevant General Directorates and/or EU working groups, in collaboration with various stakeholders. In contrast to hard law instruments, a Communication is not mandatory. However, it provides a crucial political impetus to areas like healthcare in which the EU has no regulatory competencies. A Communication is targeted to EU committees and political institutions, namely the European Council, and since 2009, the European Parliament too (a 2009 EU ruling requires the co-decision of the European Council and the European Parliament). After being examined by these institutions, a Communication may turn into a Recommendation by the European Council, and may sometimes result in the drafting of a Directive.

initiative on Alzheimer's disease and other dementias. This was welcomed wholeheartedly by Alzheimer Europe, because it encompassed the priorities of the *'Paris Declaration'*. In the organization's formal response to the Communication, it endorsed the soft law role of the EU as an empowerer, encourager and supporter of Member States, and advocated the use of the specific modes of the OMC, Joint Programming and public-private partnerships for securing official recognition of dementia as a European public health policy. Furthermore, indicating the organization's eagerness to continue its active involvement in such European modes of dementia governance, it asserted its own epistemic and democratic credentials, emphasizing that it provides *'robust and up-to-date information, engaging its member associations at grass-root level and facilitating the dissemination of the information'*.

The strategic importance attached by the organization to its metrological work and mobilization of research evidence was emphasized during a 2011 conference presentation by Alzheimer Europe's Executive Director in which he outlined various studies undertaken by the organization in *'building a case for political action'*[19]. One example of a study undertaken by the organization between 2006 and 2008 was partly funded by DG SANCO; this study, called EuroCoDe (European Collaboration on Dementia), sought, amongst other things, to develop *'consensual indicators'* on prevalence rates and guidelines for diagnosis and treatment. Indeed, the EU institutions have conferred epistemic authority to Alzheimer Europe. The European Commission's 2009 Communication on AD and other dementias extensively cited research

[19] Jean Georges, 'Dementia policy and planning in Europe – the NGO perspective', presentation at *Shared Priorities. The Dementia Agenda in Europe and Ireland*, 17 June 2011, Dublin.

evidence produced by Alzheimer Europe, such as its comparative analysis of legislation in Europe relating to the rights of people with dementia, and facts circulated in its *Dementia in Europe Yearbook*, a publication of the organization since 2006 that receives financial support from the European Commission. As noted by the chairperson of the European Alzheimer's Alliance in a foreword to the 2008 *Yearbook*, the annual publications *'have proved valuable tools for policy makers to compare the state of dementia care in their country to other European countries and I am convinced that this type of exchange of good practices can contribute to an improvement in the lives of the 6.1 million people with dementia across the European Union'.* (Alzheimer Europe, 2008: 12)

In December 2010 the European Parliament issued its Report on a European initiative on Alzheimer's disease and other dementias. This official document too includes multiple references to facts about dementia produced by Alzheimer Europe, but also calls for official recognition of Alzheimer patients' organizations as 'prime partners' of the EU and recommends that EU institutions should consider providing regular core funding to Alzheimer Europe and encourage Member States to do likewise for national Alzheimer organizations. Interestingly, when asked about the significance of the European Parliament's different political groups within the European Alzheimer's Alliance, one MEP who is the vice chair and a founding member of the Alliance said that 'It's very much a consensus'[20].

At the very least, one can reasonably argue that through its production and circulation of original facts and figures about AD, Alzheimer Europe has fueled

[20] Interview on 8 April 2011.

the EU soft modes of governance with evidence that has contributed to making the disease a non-partisan, regular and do-able object of EU policy-making.

2.2. EURORDIS: producing figures to align the 'Europe of markets' and a 'social Europe' in the area of rare diseases

Rare diseases too are becoming a regular EU health priority. EURORDIS first action was to promote a European Regulation on Orphan Drugs. This was published in 1999[21], two years after EURORDIS inception. From the end of 2000s onwards, EURORDIS has moved to another mission: motivating a global strategy on rare diseases in Europe, i.e. in all EU Member States, and in all areas that may contribute to the war on rare diseases, from research, clinical practices, health and social care, to medications.

The rationale for this mission, and discussion it raised, offer a telling illustration of the tension between the 'Europe of markets' and a 'social Europe'. Rare diseases posed particular challenges to the market, and this was why EURORDIS pushed for a specific regulation on orphan drugs to be issued. However, it was still necessary to ensure that all patients who needed those medicines had access to them. Some members of EURORDIS considered the European Directive on patients' rights to cross-border healthcare as one solution to this problem. However, other representatives of national patients' organizations and national stakeholders involved in the area of rare diseases strongly criticized this 'rights' option, which still vehicles, in their opinion, a neoliberal approach to the issue that they considered non efficient from an

[21] Regulation (EC) n° 141/2000 of the European Parliament and of the Council 16 December 1999 on orphan medicinal products, Official Journal of the European Union, 3.7.2009: C 151/7.

economic point of view, and unacceptable from a human point of view. The risk, they said, was that medical and health ‘deserts’ might appear in certain countries and regions if cure and care were available elsewhere. This warning helped EURORDIS to put an even stronger focus on what it saw as the critical problem: before accessing medications, patients must be identified, diagnosed and monitored.

EURORDIS began to lobby DG SANCO in the mid- 2000s, which, in 2007, started to consider the need for, and relevance of a global European strategy on rare diseases. On 9 June 2009, a Recommendation by the European Council of Ministers proposed that all Member States define and implement a national plan or strategy on rare diseases by 2013. This launched the EUROPLAN project. EURORDIS was then in charge of promoting the project at national level, in collaboration with National Alliances on Rare Diseases, and of following up its implementation. Moreover, at each and every step of this process, EURORDIS produced and disseminated facts and figures to advocate the need for a ‘social Europe’ if rare diseases patients are to be fully recognized by ordinary health and social systems. The following example offers a telling illustration.

Initially, DG SANCO launched a vast consultation, announced at the 4th European Conference on Rare Diseases on 27 November 2007 in Lisbon. Hundreds of stakeholders from across Europe were then invited, throughout 2008, to take stock of access to diagnosis, medication and care in their countries. EURORDIS played a decisive role in this consultation. It conducted a

survey of its members, called EurordisCare1, to collect data on experiences and expectations of patients and their organizations with regard to diagnosis and access to health services. Similar surveys have been repeated twice. The figures produced by EURORDIS allowed for cross-national comparison of health services, which was considered as truly added value of the EPO by EU and national authorities. It was on the basis of the results of this consultation that DG SANCO motivated the publication of a Communication by the European Commission, which was later turned into the above-mentioned Recommendation by the European Council of Ministers.

The EurordisCare surveys illuminate how the EPO accommodates the 'Europe of markets' and a 'social Europe' for advancing its cause. It produces evidence on the need for medical and social provision for patients' rights to be recognized, and for the market to operate. Indeed, in the area of rare diseases, the market cannot develop efficiently if patients are still out of the reach of health and social systems. By producing facts and figures on the extent of this 'out of reach' phenomenon, EURORDIS contributes to aligning the requirements of the market and the social needs of patients and families.

2.3. ADHD Europe: combining 'rights' talk and scientific evidence

Like Alzheimer Europe and EURODIS, ADHD Europe aims at developing cure and care for all European patients with the disorder. But unlike Alzheimer's disease and rare diseases, ADHD is still a contested condition in certain countries, which induces much more hesitation on the appropriate route for promoting a EU policy on the disorder.

These tensions surface in ADHD Europe' s own reflections on what ADHD is, and what it is to live with the disorder. ADHD Europe defines ADHD as a neurodevelopmental disorder which has a significant genetic component. As it reported in one *Knowing Me, Knowing You* document[22], this definition has been central to the organization's promotion of ADHD as a legitimate condition. In other publications however, ADHD Europe describes ADHD as a disability. This is consistent with its mission: drawing on 'rights' talk, it states that its aims is *'to advance the rights of, and advocate on every level throughout Europe for people affected by ADHD and co-morbid conditions in order to help them reach their full potential'*[23]

There are some tensions in this 'rights' talk, however. It is not obvious that the framing of ADHD as a disability is embraced by all national member organizations of ADHD Europe, and it is not clear whether the organization has attempted to build allegiances with disability groups or influence disability policy at European level. Instead, it became a member of Mental Health Europe. Its first key intervention was a contribution to the EC Green Paper on Mental Health in 2006. With the help of Mental Health Europe, the organization has also been participating in the DG SANCO meeting in the Commission on the European Pact for Mental Health since 2008.

But 'rights' talk has another facet: the fight for equal access to medications and care for all European patients with the condition. Central to the formation of

[22] *Knowing Me, Knowing You: Curriculum for Our Future*, undated: 26

[23] http://www.adhdeurope.eu/adhd-europe/objectives.html. Accessed 24 January 2010.

ADHD Europe and its development is the construction of national divergences in practices around ADHD as problematic, and the statement of a need for standardization in diagnosis and treatment approaches. For this to be achieved, ADHD Europe has progressively recognized the need for credentialed knowledge, which recently manifested in the election of scientific advisors. ADHD Europe also contributes data through surveys on its members. The organization conducted a survey published in 2009, entitled *'Diagnosis and Treatment of AD/HD in Europe: Differences, Problems, Progress'*, revised and expanded in 2011. The 2009 survey was conducted by sending questionnaires to the different national organizations about issues such as who diagnoses ADHD, treatments available, and existence of national policies. It also included tabular information comparing prices of different medications across countries, and treatment availability.

The surveys conducted by ADHD Europe contribute to reconciling a 'rights' talk and a medico-scientific framing of ADHD. Basic human rights talk alone is not enough to combat those who continue to deny the existence of the condition, like certain Italian anti-psychiatry groups for instance[24]. Data collected by ADHD Europe highlight different practices and create a picture of inequality that can be overcome only by a greater consensus on the diagnosis and the standardization of treatment strategies (Clark 2009), which ultimately imply a full recognition of ADHD as a serious disorder all over Europe. By combining equal opportunities talk and 'evidence-based activism', ADHD

[24] This issue emerged at the Annual General Meeting of the organization in 2009 (interview with ADHD Europe Board member, 13 October 2010).

Europe seeks to transform the abstract ‘patient-citizen’ favored by EU legal corpuses into an actual ‘patient-citizen-sufferer’.

2.4. What Europe for patients do EPOs build?

The examples of EPOs’ evidence-based activism described above illustrate that they are not simply lobbying for their interests; they are contributing data and statistics that also progressively map out health issues as economic, political and social concerns for Europe. Grounding a Europe for patients in facts, figures and statistics that allows cross-national comparison raises the question of commensurability between countries, and leads EPOs to balance between two options: standardization of health services *versus* diversification of solutions, according to the peculiarities of national health systems and specific desiderata of national organizations. The EUROPLAN project promoted by EURORDIS offers a telling example. One pivotal element of the plan was the organization of services for diagnosis, care and social support to patients with rare diseases. How to achieve this was a matter of intensive technical and political debates. Should centers of reference be created in every single country, or should networks of experts be set up across Europe so that ordinary medical consultations may call upon them in case they need assistance? This question points to major disparities between Member States: it is clear indeed that many countries do not have material and expert resources. Eventually, a mixed solution of national centers of expertise and European reference networks was decided upon. However, during a EURORDIS Membership Meeting entitled *‘The voice of rare diseases patients in national plans for rare diseases’* held in Amsterdam in May 2011, its Executive Director emphasized

the need for a sound evaluation of this option if the organization is to secure the national plans on the long run[25].

Linked to this issue of ‘standardization in a non-standard world’, to echo Epstein and Timmermans (2010), EPOs also contribute to the production of ideas about how ‘advanced’ or ‘backward’ various European countries are in respect of the recognition, authorization and provision for the various conditions or causes around which they mobilize. Significantly, these EPOs’ ‘development rankings’ vary across the conditions and do not conform with orthodoxies about which European countries are most and least modernized. For example, EURORDIS promotes the idea that France is ‘advanced’ and provides a model for the war on rare diseases, whereas for ADHD Europe, France is lagging behind. The designation of certain countries as models of best practice takes on a particular significance in the context of soft modes of governance such as the OMC, the aim of which is to promote the replication of those models in other Member States.

A final remark is worth being stated: EPOs’ ‘evidence-based activism’, and the Europe for patients they build thereof, put a strong focus on the metrological shaping of Europe as an important means for addressing issues of social justice and health democracy. What is particularly interesting is that these issues unfold differently within each EPO. Our fieldwork suggests that EPOs articulate in various ways these social issues with a techno-scientific and economic agenda firmly grounded in a series of indicators and measurements. At the very

[25] Notes taken during the meeting.

least, this points to the variety of conceptions that EPOs have on the ‘Europe of markets’ and a ‘social Europe’.

Conclusion

Reflecting on the promises of Europeanization from below, Della Porta and Caiani (2009: 47) regret that *‘The EU is rarely targeted from below’*; civil society actors seldom frame their object and issue scope as European and a national orientation of public debates and arenas continues to prevail. Our exploration of EPOs suggests otherwise: in the sector of health which still is the domain of prerogatives of Member States, EPOs which decide to ‘go to Europe’ cannot but construct a Europe *of* and *for* patients. Studying particular sectors such as the domain of health thus offers a fruitful locus for investigating the process of Europeanization from below and its effects on the shaping of European policies, and on the dynamics of national activism.

One may argue that the politics that EPOs adopt, engaging them as ‘euro-pragmatics’ (Mair, 2005) and as experts on various topics – ranging from European rulings and policy-making to the technicalities of national health systems –, contributes to the European project that some scholars depict as a technocratic one, based on a depoliticized democracy (Mair 2000; Storey 2008). EPOs are certainly experts on their conditions and on the functioning of health institutions, but, and this adds a significant value to their actions, their expertise mobilizes concerned people’s experience and knowledge. As a consequence, it is fair to say that EPOs bring European concerned people and voice their preoccupations in various ways up to multiple European arenas.

Beyond this, our fieldwork allows us to argue that EPOs engage in the on-going construction of Europe, and that this is a highly political endeavor of the sort. The disputes that regularly oppose EPOs and EU environmentalists on the regulation of bio-products, the debates that EPOs raise at national and European level on the issue of health inequalities, and most importantly, the evidence that EPOs bring to the fore to support their arguments, have removed politics from a classic partisan fight to an extended multifaceted collective experimentation. Studying the construction of Europe as a collective experimentation opens a research perspective that is worthy of exploration.

This being said, we must avoid romanticizing EPOs: they are particular civil society organizations, whose achievements must be appreciated in light of the efforts they put to impinge on the fabrics of Europe. This does not come without tensions and difficulties. As a matter of fact, the current financial and economic crisis that threatens the Euro-Zone and puts the EU governance under pressure, constitutes a serious obstacle for EPOs themselves, as witnessed by the adoption of the Portuguese Plan on Rare Diseases without financial support by the Portuguese government[26]. The EU agenda-setting and the budgeting of its priorities may well change the content and the scope of EPOs' politics and expectations.

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[26] Notes taken during the EURORDIS Membership Meeting entitled *'The voice of rare diseases patients in national plans for rare diseases'* held in Amsterdam in May 2011.

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