Viewpoint

Challenges for patient organisations: focus on Europe

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The challenges facing patient organisations in Europe are unique only in part, but that part is both critical and daunting. The core problem involves what "Europe" is and is not. It is a collection of nation states. It is not a nation. Consequently, people are "Europeans" after they are Danish, German, French, or whatever their nationality, and their healthcare and policy is National (with a deliberate capital), not European. Their access to treatment differs with their nationality. Where they exist, their patient organisations are National, not European.

At the European level, there is need for dialogue to inform the decisions of policy makers and to use patients as a resource to define societal and service needs. Organisations such as the European Parkinson's Disease Association (EPDA), the European Federation of Neurological Societies, and the European Brain Council have an important role in initiating and sustaining a dialogue between medical science and society to improve the quality of life of patients and families living with Parkinson's disease (PD) and other brain diseases. The mission of these organisations is to educate Members of the European Parliament and European Commissioners about diseases of the brain and their impact not only on patients, but also on the workplace and society.

To achieve this end, there must be a united voice, and this requires both horizontal and vertical alliances and integration as illustrated below (fig 1). It is crucial that there is a consistent message that reflects the needs of patients and focuses attention on how those needs as well as those of society generally can best be met with the resources available.

The immediate challenge, therefore, is to find the means to support pan-European organisations to make them credibly independent of their sources of funding, and open and transparent in all their financial affairs. As a result, they can agitate or even, when necessary, antagonise those who have the power to execute changes that meet patient needs.

In many respects, this challenge differs only in scope from the problems faced by each of the similar National patient organisations. Historically, these organisations have focused on access to treatment, but this is no longer adequate and no more so than in brain disorders, where treatments are, at best, helpful in the majority of cases, temporarily effective in others, or, at worst, essentially non-existent.

Of course, everyone would prefer prevention or cure, but faced with 21st century realities of stressful lifestyles and aging populations, neither prevention nor cure is on the horizon for many brain disorders. The World Health Organisation, which historically focused on communicable disease, now recognises the importance of the overall "burden" of illhealth in the world, and estimates that 35% of this burden is due to brain disorders.¹ This proportion is likely to increase, because many brain disorders are more common among the elderly, the proportion of which is increasing in most populations. Considering such realities, it is imperative that the patient's needs, not wants, are given a voice that is not only heard, but also results in action.

Figure 1 Alliances and integration. EFNA, European Federation of Neurological Associations; FENS, Federation of European Neuroscience Societies; EFNS, European Federation of Neurological Societies; EANS, European Association of Neurological Societies; ECNP, European College of Neuropsychopharmacology; EBC, European Brain Council; EPDA, European Parkinson's Disease Association.

In PD, something akin to a parable exists, which illustrates not only the need to hear the patient's voice, but also the difference between "needs" and "wants." In 1817, James Parkinson, an Edinburgh educated general practitioner in London, published a remarkable essay based on observation of just five patients. He described very clearly their slowness and poverty of movement, and their curious, uncontrollable tremor. Having written this seminal essay on a disorder yet unnamed, he contributed, so far as we know, nothing further on this subject, perhaps because he had no means to ameliorate their illness. His work did not escape notice and what he began was taken up by Professor Jean Martin Charcot (1825–1893) in Paris, who suggested the disorder be called Parkinson's disease. However, it is the work of another remarkable man that completes the picture with the impact of PD on daily life. Wilhelm von Humboldt (1767–1835), a man of letters, elder brother of the renowned naturalist Alexander, founder of Berlin University, and friend of Schiller and Goethe, was keeping a diary in which he set down the great difficulties he had living with what was clearly PD. He noted the trouble he had doing up his buttons; he speaks of the tremor that wracked his body. He wrote particularly poignantly about the difficulties he had with his handwriting. No longer able to manage the elegant German script, he wrote instead in Latin. While the doctors and academics could put a name to Wilhem's syndrome, they could do nothing for it, and there is little or nothing to suggest that they considered or suggested means by which patients might live more easily with their disease.

Certainly, there has been great progress, especially in the past few decades, but the point of this quasi-parable is that it underpins the ethos that drives not just EPDA but any patient organisation. For optimal management of a disease, it is essential to bring together on the one hand knowledge (the doctors, the academics, the scientists) and the healthcare industry with the policy makers and, crucially, the patients who must live with the disease. Understanding a disease is more than defining its mechanisms or delivering treatments, it must involve also the "living with". It is only when all these are brought together that the real challenge of PD and other brain disorders can be fully recognised and addressed. This inclusive concept underpins the EPDA charter²: that people with PD have the right to: (a) be referred to a doctor with a special interest in PD; (b) receive an accurate diagnosis (research

has shown that satisfaction with the explanation of the condition at diagnosis has a significant impact on the patient's quality of life)³; (c) have access to support services; (d) receive continuity of care—that is, to see the same doctor as necessary; and (e) take part in and have joint responsibility for managing their illness.

Health technology assessments (HTA)⁴ represent an important example where consultation with patient groups should be central to decisions concerning the contribution of any new or revised treatment toward overall management of a disorder. However, to have any real impact, organisations such as EPDA and EFNS require resources. These groups are essentially charities. With the best will in the world, they cannot raise from their patient members the funds necessary to sustain concerted activity year on year. It is necessary therefore to form alliances with those who have the means to finance such groups. There are only two: the EU Commission or industry. Public funding is fickle and hardly comes without strings attached. Industry funding received from many companies, with clear understanding that a patient organisation is not an advertising agency for anyone other than patients, is by far preferable. There are precedents for unrestricted support such as the grants to support meetings of many professional bodies such as the European College of

Neuropsychopharmacology, Collegium Internationale Neuro-Psychopharmacologicum, and many others.

In return, patient organisations can bring to the industry the voice of patients, can serve as an honest broker to bring together academic science, healthcare professionals, and the industry to focus attention on patient needs as they are, not as one would wish they were. The patient organisations can, of course, also provide an effective and “spinfree” channel for professionals and industry to speak to patients.

Perhaps most crucially, patient organisations can deliver to policy makers the needs of patients as well as the professionals and industries that try to meet those needs. This requires an understanding that “profit” is not evil. Development of new medicines and treatments is a high risk activity that demands huge investment, and this investment is largely sustained by profits. The cost and time to deliver new treatments could be eased by changes of policy and patients, especially those with slowly progressing, but terminal illness may well prefer better quality of life for a shorter time than poor quality for longer. Do they not deserve that choice?

These are social and ethical issues that should be resolved by governments and accountable policy makers, not by contingency fee lawyers. Management of chronic illness requires not only

medical knowledge, but also the patient knowledge of living with an illness. Patient involvement in the policy making and direction of research is essential. It is for everyone worth considering that while some are scientists, doctors, lawyers, judges, ethicists, or parliamentarians, all will be patients. When they are patients, would they not wish to be heard?

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