Review Article

The European Declaration on Epilepsy: Past, Present and Future

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The day of September 15, 2011 will be remembered in Europe as a historical date for all people engaged in the fight against epilepsy. On that date, the Parliament of the European Union (EU) approved the Written Declaration on Epilepsy, a landmark document which calls for the political establishment to improve the lives of people with epilepsy by promoting public awareness, quality of care and scientific research. The Declaration has resulted already in several positive initiatives in a number of countries, and its impact extends beyond the boundaries

of the EU.

The purpose of this article is to explain the background that motivated the drafting of the Declaration, to describe the processes that led to its approval, and to discuss future developments in the implementation of the plan set out by the Declaration. It is hoped that the activities described in this report will provide an inspiration to further actions in other parts of the world to mobilize stakeholders, address diagnostic and treatment gaps in epilepsy care, and stimulate greater allocation to resources to epilepsy research.

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Background

Epilepsy is the most common chronic serious neurological disorder worldwide. In the European WHO Region, which also includes countries which emerged from the dissolution of the Soviet Union, the number of people with active epilepsy is estimated to be in the order of 6 million, and those who will have had epilepsy at some time in their lives are a staggering 16 million (Report, 2007). The medical and social implications of this burden of disease are impressive.

People with epilepsy are at increased risk of seizure-related morbidity. For example, in a study conducted in 9 European countries which followed up prospectively 951 individuals with epilepsy and 904 matched controls, the cumulative probability of people with epilepsy experiencing an accident after 2 years was almost 60% greater than in controls (27% vs 17%, respectively), a highly significant difference (Beghi et al, 2002). Other factors contributing to a reduced quality of life in epilepsy include comorbid conditions, particularly depression, the adverse effects of antiepileptic medication (Luoni et al, 2011), and social factors such as stigma, prejudice and discrimination (De Boer, 2010). Mortality is also increased in people with epilepsy. In a population-based study from Finland that followed up a group of people with epilepsy for 40 years since childhood, the mortality rate was as high as 24%, three-times the rate expected in the general population, and more than 50% of the

deaths had epilepsy-related causes, particularly sudden unexpected death (SUDEP) (Sillanpaa and Shinnar, 2010). In addition to the human suffering caused by the disease and its complications, there are huge monetary costs associated with epilepsy. In the European region, these costs have been estimated at EUR 20 billion per year (Report, 2007).

In view of the medical, social and economic impact of epilepsy, it is a sobering consideration that epilepsy care has been found to be suboptimal in virtually all regions of the world. Despite the fact that antiepileptic drug treatment can produce seizure control and restore quality of life in up to two thirds of people with epilepsy (Perucca and Tomson, 2011; Perucca, et al, 2011), a large diagnostic and treatment gap still exists in many countries. For example, one study found that in some areas of Azerbaijan, a country which belongs to the WHO European Region, less than 10% of people with epilepsy were receiving treatment (Report, 2007). Likewise, a study in Estonia, a country within the European Union, reported that about 22% of all people with epilepsy did not take antiepileptic medication (Oun et al, 2003). Lack or under-utilization of facilities for epilepsy surgery is also a widely recognized deficiency across many European countries (Report, 2007). In parallel with gaps in medical care, there has been no adequate action to address ignorance, stigma and prejudice. For example, in a

recent study which tested awareness and attitudes of the general public towards epilepsy in Italy, only 29% of those interviewed gave an exact estimate of the prevalence of the disease, 56% thought that epilepsy was a psychological or psychiatric disease, 36% considered it to be some form of insanity, and 4% believed that it is related to possession by an evil spirit (Mecarelli et al, 2010).

If resources dedicated to epilepsy care are grossly inadequate, the same can be said for support to epilepsy research. Indeed, despite the obvious need for research that could ultimately lead to better treatments and hopefully a cure for epilepsy, financial support to epilepsy research has been disproportionately low, particularly in Europe. Out of over EUR 50 billion set out by the European Commission to support research and development over the period 2007-2013 as part of the Framework 7 Programme (European Commission, 2011), funding for epilepsy research was only EUR 30 million for the first 4 years of the program, or less than 0.001% of the indicated budget (European Parliament, 2011a).

Recognizing the need to raise public awareness and to stimulate investment into epilepsy care and research, the International League against Epilepsy (ILAE) and the International Epilepsy Bureau (IBE) jointly embarked on a worldwide campaign to sensitize the political establishment about the medical, social and economic dimension of the disease. In Europe, this advocacy action

was conducted through the newly established Epilepsy Advocacy Europe (EAE) Joint Task Force, co-chaired by Emilio Perucca on behalf of ILAE and Mike Glynn on behalf of IBE. Other EAE members include Asla Pitkanen, Michel Baulac and Christian Elger for ILAE and Hanneke de Boer, Janet Mifsud and Reetta Kalviainen for IBE. The main objective of this Task Force during its first year of existence was the promotion of the Written Declaration of Epilepsy at the EU Parliament.

What is a Written Declaration in the EU system?

A written declaration is an official document of the EU Parliament, which consists in a text of up to 200 words addressing a matter which comes within the EU's jurisdiction. Members of the European Parliament (MEPs) can use such declarations to launch or relaunch a debate on a topic falling within the EU's sphere of activity.

A group of up to five MEPs can submit the text of a written declaration to be signed by their colleagues. The text is printed in all the official languages of the EU, distributed and entered in a register that can be signed by those MEPs who support the declaration. Declarations lapse after three months in the register if they have not been signed by at least half the MEPs. If the declaration is signed by a majority of the MEPs, it becomes an officially approved EU document and it is forwarded to the President of the EU

Parliament, who announces it in a plenary session.

All approved declarations are forwarded to the institutions named in the text, together with the names of the signatories. In the case of the Written Declaration on Epilepsy, these institutions include the EU Commission and the Parliaments of all EU Member States. Typically, declarations, including the Written Declaration on Epilepsy, contain recommendations for specific actions to be taken by the institutions to which they are directed.

How was the Declaration on Epilepsy drafted?

As explained above, declarations can only be submitted by MEPs. Therefore, it was necessary for ILAE and IBE to approach the EU Parliament for support. An opportunity for this came in February 2011, when the EU Parliament accepted to host a joint ILAE-IBE delegation to celebrate the newly established European Epilepsy Day. This event was made possible thanks to the vision and generosity of Mr Gay Mitchell, an Irish MEP who has a family member affected by epilepsy and therefore has first-hand experience of the challenges and difficulties faced by people with epilepsy and their carers. Through admirable commitment, Mr. Mitchell was able to sensitize many fellow MEPs about the need for action against epilepsy and the potential benefits that a Written Declaration on this subject could eventually achieve.

Within a short period, several MEPs with a special interest in epilepsy created the “European Advocates for Epilepsy Working Group”, who had as initial funding members Mr Gay Mitchell (chair), Mr. Nirj Deva, Ms. Marian Harkin, Mr. Peter Skinner, and Ms. Angelika Werthmann. The first action taken by the Working Group was the submission, in April 2011, of the Written Declaration on Epilepsy, which was prepared in collaboration with the EAE Joint Task Force (European Parliament, 2011b). The text of the Declaration is shown in Figure 1.

From submission to approval: the path to success

Submitting a Written Declaration to the EU Parliament does not guarantee success. Indeed, obtaining approval of a declaration is no easy task, because of the large number of supporting signatures required (at least 369, out of a total of 738 MEPs). In fact, it is estimated that only about 5% of the declarations which are presented to the EU Parliament achieve the minimal number of signatures required for approval.

The Written Declaration on Epilepsy was first open for signature at the May 2011 session of the EU Parliament in Strasbourg, and the process had to be completed by the end of the September 2011 session. If the required number of signatures had not been received by that date, the Declaration would have failed.

In the end, it was a most remarkable success story. At the closing date of September 15, 2011, a total of 459 MEPs (90 more than the minimum number required) supported the Declaration with their signature. This is the highest number of signatures ever achieved for any Written Declaration in the current EU term!

This achievement was the result of fantastic team work. Virtually all individual MEPs were approached, provided with material about the significance of epilepsy and its needs, and actively encouraged to sign the Declaration. Many contacts were made directly by the 30 MEPs who are member of the European Advocates for Epilepsy Working Group, and by representatives of the EAE Joint Task Force who travelled to Strasbourg and to Brussels to attend the EU Parliament sessions when the Declaration registers were open. Such impressive achievement, however, would not have been obtained without the great work and commitment of ILAE and IBE chapters and associations, and many individual colleagues throughout Europe. Representatives of national chapters also travelled to Strasbourg and to Brussels to meet MEPs from their country, and personalized letters were sent to MEPs within each country. It was very gratifying to see how many people dedicated their abilities and time to support this effort, and how this initiative brought together chapters and associations from diverse

countries, all united in advocating for a common goal!

How does the Declaration on Epilepsy translates into practical actions?

The Declaration calls for a number of actions to be taken by the EU and its Member States, and it is essential to ensure that those actions are implemented in all relevant areas. At present, the entire epilepsy community in Europe is mobilized towards this goal and many positive developments are indeed taking place.

At EU level, the most important impact of the Declaration is to ensure that adequate funding is allocated by the European Commission to support research in epilepsy. Officials from the Commission have signalled to the community that the recommendations made in the Written Declaration on Epilepsy are being taken into consideration, and epilepsy research has indeed been included in the last call of the 7th EU Framework Programme for Research. It is also expected that epilepsy research will receive attention in the future EU Research Programme (Horizon 2020). The EAE Joint Task Force is actively interacting with EU institutions to ensure that these developments will indeed materialize.

Unlike research, health care in the EU is primarily under the responsibility of the governments on individual Member States. The Written Declaration on Epilepsy has

been forwarded by the President of the EU Parliament to the Health Ministers of all EU countries. The Declaration sends a strong signal to all national governments that the EU Parliament recognises the need for improved health care and expanded services for people with epilepsy. This is proving to be a powerful tool for national associations and advocacy groups in order to obtain greater attention to the needs of epilepsy care from national and regional governments. The EAE Joint Task Force is assisting national chapters and associations in this effort, and already there are indications that a number of governments are setting up initiatives in compliance with the recommendations listed in the Declaration. Interestingly, this is occurring not only in EU Member States, but also in European countries that are not part of the EU.

The future

As a consequence of the Declaration, politicians and institutions in Europe are showing an unprecedented interest in epilepsy. It is essential that momentum is not lost, and that we use this opportunity to advance public awareness, quality of care and research in epilepsy. ILAE and IBE, in partnership with the World Health Organization (WHO) whenever applicable, are actively working towards this goal.

As part of the post-Declaration activities, the EAE Joint Task Force has organized in

May 2013 a European Epilepsy Forum in Dublin which brought together all major stakeholders, including representatives of EU institutions and national governments, clinicians, basic scientists, advocacy groups, and industry representatives in order to catalyze synergic alliances for an action plan against epilepsy. In parallel with this initiative, the Joint Task Force is liaising with EU institutions to advocate for the implementation of a well designed study to reliably assess the prevalence and costs of epilepsy in different regions of Europe. There are surprisingly little data on this topic, and the results of this study could be invaluable for rational allocation of resources both in health care and in research.

Finally, it is rewarding to see that, in parallel with the Written Declaration on Epilepsy in the EU, exciting initiatives are also taking place in other parts of the world. These include the Institute of Medicine (IOM) Report on Epilepsy in the U.S.A (Institute of Medicine, 2012), the PAHO Strategy and Action Plan on Epilepsy (Pan-American Health Organization, 2011) in the Americas, and several demonstration projects organized in a variety of countries in conjunction with the ILAE-IBE-WHO Global Campaign against Epilepsy. To some extent these initiatives complement each other, and communication and collaboration across regions is of critical importance to ensure the best level of synergy. Only by working together we will be able to fulfil our common

goal and vision: a world where no person's life will be limited by epilepsy.

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Figure 1. The European Written Declaration of Epilepsy (European Parliament, 2011b).

Written Declaration on Epilepsy (0022/2011)

The European Parliament,

- having regard to Rule 123 of its Rules of Procedure,
 - A. whereas epilepsy is the most common serious disorder of the brain,
 - B. whereas 6 000 000 people in Europe have epilepsy, with 300 000 new cases diagnosed each year,
 - C. whereas up to 70% of people with epilepsy could be seizure-free with appropriate treatment, while 40% of people with epilepsy in Europe do not receive such treatment,
 - D. whereas 40% of children with epilepsy have difficulties at school,
 - E. whereas people with epilepsy in Europe experience high levels of unemployment,
 - F. whereas people with epilepsy are exposed to stigma and prejudice,
 - G. whereas epilepsy damages health but also disrupts every aspect of life, and can impose physical, psychological and social burdens on individuals and families,

1. Calls on the Commission and Council to:

- encourage research and innovation in the area of prevention and early diagnosis and treatment of epilepsy;
- prioritise epilepsy as a major disease that imposes a significant burden across Europe;
- take initiatives to encourage Member States to ensure equal quality of life, including in education, employment, transport and public healthcare, for people with epilepsy, e.g. by stimulating the exchange of best practice;
- encourage effective health impact assessments on all major EU and national policies.

2. Calls on the Member States to introduce appropriate legislation to protect the rights of all people with epilepsy;

3. Instructs its President to forward this declaration, together with the names of the signatories, to the Commission and the Parliaments of the Member States.