



## Letter to the Editor

### The Written Declaration on Epilepsy: An important achievement for Europe and beyond

On 15th September 2011, the European Written Declaration on Epilepsy was passed by the European Union (EU) Parliament. This was a significant moment for all people who have been fighting over the years for a just recognition of the importance of epilepsy in the European political agenda. The whole process described below included several months of concerted effort by Members of the European Parliament (MEPs) and by Epilepsy Advocacy Europe (EAE), a joint task force of the International League Against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE). ILAE and IBE member associations in Europe and many individuals also contributed greatly to the success of this initiative.

#### 1. What is a European Written Declaration?

A Written Declaration is a text of a maximum of 200 words on a matter falling within the EU's sphere of activities. MEPs can use written declarations to launch or re-launch a debate on a subject that comes within the EU's remit.

A group of up to five MEPs can submit a Written Declaration by presenting a text to be signed by their colleagues. If the Declaration is signed by a majority of the MEPs, it is forwarded to the President, who announces it in plenary session.

The Declaration is then forwarded to the institutions named in the text (in the case of the Written Declaration on Epilepsy, this was the EU Commission and the Governments of EU Member States), together with the names of the signatories. It is also included in the minutes of the EU Parliament sitting at which it is announced.

#### 2. How the Declaration on Epilepsy came about

Following on the success of the first European Epilepsy Day, launched in Strasbourg in February 2011, several MEPs with special interest in epilepsy created the "European Advocates for Epilepsy Working Group" chaired by Mr Gay Mitchell, MEP. The four other MEP founding members were Nirj Deva, Marian Harkin, Peter Skinner, and Angelika Werthmann. The first activity of the Advocates for Epilepsy Working Group was the submission of the Written Declaration on Epilepsy in April 2011, which was done in collaboration with the ILAE/IBE joint task force. The text of the Declaration, which follows the strict template, is as follows:

#### 3. The process

Written Declarations are printed, translated into each EU official language and posted in a register at the European Parliament. The register is public and is kept outside the entrance to the Chambers in Strasbourg and Brussels during plenary

#### Written Declaration on Epilepsy No. 22/2011

##### *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.

sessions. Declarations are also published on the Parliament's website.

The Written Declaration on Epilepsy was ready for signing in time for the May plenary session in Strasbourg. Thereafter MEPs were able to sign it during the plenary sessions in Strasbourg in June, July and September and during the June mini session in Brussels. These sessions, usually lasting 4 days each month, are the only times when the books are open for signatures.

To have the Written Declaration carried requires the signature of a majority of MEPs. With the total number of MEPs being 738, this meant that the Declaration on Epilepsy had to achieve support

from a minimum of 369 MEPs. If the required number of signatures had not been received by the closing date of the Declaration, it would then have lapsed.

#### 4. The plan of action and the outcome

Having the support and advice of Mr. Gay Mitchell, MEP, and the 29 other members of the European Advocates for Epilepsy Group was very important to us in identifying how best to encourage MEPs to sign the Declaration. MEPs were encouraged to sign by committed fellow MEPs and by the ILAE/IBE Joint Task Force, who had representatives present in Strasbourg and Brussels when the Declaration registers were open. Promotional materials – leaflets, posters, and banners – were distributed to MEPs during the plenary sessions, and personal meetings were set up with MEPs or their assistants, during sessions. Additionally, ILAE and IBE member associations in EU countries proved extremely helpful in contacting and enlisting the support of MEPs from their countries, an activity that played a vital part in having the declaration carried.

In the end, it was all very worthwhile. When the Declaration closed on 15th September, the target threshold of 369 signatures was actually surpassed, with a final number of 459 MEPs supporting the Declaration with their signature! This made the Written Declaration on Epilepsy the one with the highest number of signatures in the current EU term, and also the third highest number for a health-related Declaration since records exist!

#### 5. What will a Written Declaration on Epilepsy mean for people with epilepsy and their families?

At national level, the Declaration demonstrates that the EU Parliament recognises the need for improved services for people with epilepsy. The approval of this declaration is thus an important mechanism for those who have epilepsy, their families, their friends and their carers, as well as for individual ILAE and IBE associations, to approach national governments and advocate for improved allocation of resources to epilepsy care. There have already examples of this occurring successfully not only in some EU member states, but also in countries outside the EU.

Epilepsy research is grossly underfunded in the EU. The Written Declaration thus also signals to the European Commission the need to support research on the mechanisms of epilepsy and the development of more effective treatments.

Equally, there is a need for a European-wide awareness programme to address the stigma which affects all aspects of the life of people with epilepsy, including legislation, schooling, employment, and personal relationships. Meetings have already been initiated with the Directorate General on Health and Consumer Affairs (DG Sanco) and the Directorate General on Research within the European Commission, in order to discuss how epilepsy can become a priority in their various EU research and funding programmes.

With epilepsy now recognised as a health priority by the World Health Organization (WHO), the Pan American Health Organization (PAHO) and the US Institute of Medicine (IOM), the

endorsement of the Written Declaration on Epilepsy by the European Parliament has added a further key impetus to this international effort.

ILAE and IBE, supported by the European Advocates for Epilepsy Group in the EU Parliament, are now working towards the creation of a comprehensive European programme to improve epilepsy awareness, care and research. The approval of the Written Declaration was the first essential step in this direction.

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