

## **EPILEPSY CONFERENCE- PORTO 27TH AUGUST 2010**

### **Speaking Note**

#### **"The Role of the EU in Providing Support for People with Epilepsy- Influencing Policy"**

##### *What is the EU?*

The European Union was created as a reaction to two devastating conflicts that ravaged this continent in the first half of the 20th century. In World War II alone over 60 million Europeans died, many of them innocent civilians. World War I was deemed to be "the war to end all wars" yet after just 20 years Europe was embroiled in a conflict that dwarfed it in scale and brutality. The leaders of Europe needed a practical way to ensure that such a war could never happen again, so it was decided that certain nations, France, Italy, West Germany and the Benelux countries, would pool those resources most needed for the prosecution of war; coal and steel.

Thus the European Coal and Steel Community was born as Europe's first supranational entity and the seeds for the modern EU were sown. The European Union is unique in many ways, not least in the way it evolved and has grown. We in Europe did not have a blank sheet of paper upon which to create a constitution as was the case in the United States. The modern EU is a product not of revolution but of evolution. The Union has been widened but also deepened by a succession of treaties between the Member States that have given it its character. In 1957 the Treaty of Rome established the European Economic Community, the Merger Treaty of 1967 created the European Community, and the Maastricht Treaty the European Union. The Treaty of Amsterdam which I helped negotiate, as Ireland's then Europe Minister, came into force in 1999 and gave the European Parliament a new remit and competency for health promotion, as the report "Epilepsy in W.H.O. European Region" launched yesterday points out.

This process most recently culminated in the signing of the Lisbon Treaty.

What specifically does the Lisbon Treaty do?

- The Lisbon Treaty amends the two current EU Treaties, 55 changes are made to the Treaty on the European Union and 358 are made to the European Community.
- The purpose of the Lisbon Treaty is to enhance "the efficiency and democratic legitimacy of the Union" and to improve its coherence. It is about updating its decision making arrangements to take account of its increased size and give it a stronger voice in global affairs.
- It makes Europe more democratic by giving a greater role to National Parliaments, the European Parliament and its citizens. Article 10 sets out the principles of representative democracy at EU level.
- It sets out the powers given to the EU by its Member States and the limits of those powers. Article 11 enhances the transparency of EU institutions.

How, you may ask, is this relevant to the concerns and needs of those of us living with epilepsy? Well out of the quest for peace that inspired Europe's founding fathers, grew another idea. The pooling of coal and steel created advantages for member states on the world stage, they were able to pool ideas and technologies as well as resources. It soon became clear that the European ideal had moved on from simply defending against war. It became a vehicle to remove barriers, to share ideas and to move collectively toward common standards and best practice. Most of the equality legislation, for example, we now enjoy across Europe had its genesis in this ideal. Soon it was decided that markets should be shared, barriers to movement of workers removed, and borders opened. Closer ties politically and economically were established. Today we are in the position today where citizens, politicians, governments and interest groups can come together to discuss, promote and implement common standards throughout 27 member states across an enormous range of policy areas. This has had, and will continue to have, a great impact on people living with medical conditions and other diseases or disabilities.

However, a 2003 comparative study on epilepsy across Europe found substantial differences between European countries in terms of treatment and recognition of the challenges faced. One striking result was the vast difference in terms of the number of neurologists per million inhabitants, which ranged from 3 to 131. Even within leading countries, considerable discrepancies were observed between, for example, rural and urban areas. Differences in terms of financial support were also evident.

#### *Driving licences*

Driver licensing requirements vary considerably across the Union. Until recently, a number of Member States banned driving for life for anyone who had had a seizure.

#### *Continued Discrimination*

Although advances have clearly been made, it is important to underline the extent and nature of discrimination which people with epilepsy have suffered in virtually every European country.

As recently as 1970, a law existed in the UK forbidding people with epilepsy from marrying. And in Germany and Italy the rate of unemployment among people with epilepsy was as high as 20% at the turn of the millennium.

#### *The situation in selected Member States:*

##### *Germany*

The outlook for the treatment and management of epilepsy in the EU's largest Member State is broadly positive, and facilities are relatively advanced. A professional qualification certified by the International League Against Epilepsy (ILAE) exists, as well as treatment guidelines. In 2005, there were 38 epilepsy outpatient clinics for adults and adolescents. In addition, there are eight specialised centres for epilepsy. However, hospitalisation has generally been viewed as excessive. In many cases, patients are kept in hospital after seizure for monitoring, even when they have a note from their doctor to say this is unnecessary.

The German chapter of the ILEA is also active in the dissemination of public information, though some gaps have been identified.

### *United Kingdom*

In the early 1990s, there were only 300 neurologists practicing in the UK. This was approximately the same number as in Denmark, a country one tenth its size.

However, in more recent years the quality and extent of care for neurological disorders has improved, due to policy lobbying, consumer empowerment and greater overall focus on neurology treatment in the UK.

### *Ireland*

In Ireland, the prevalence of epilepsy is broadly in line with the European average. A recent study shows 9 per 1,000 Irish people aged over five suffer from epilepsy. This means there are 36,844 people aged five and over living with epilepsy in Ireland.

The organisation Brainwave has raised over €500,000 in the last few years for research and is a focal point for epilepsy services and awareness in Ireland.

Epilepsy was also at the root of the first test case of new Irish equality legislation when, in 2001, a woman suffering from epilepsy was awarded damages for unfair dismissal relating to her condition.

It can be seen from this cursory survey that treatment and availability of medical experts varies greatly across the EU.

### *European Action on Epilepsy*

In 1998, the European Declaration on Epilepsy was drafted and adopted. A key outcome was the European White Paper on Epilepsy, published in 2001.

### *The White Paper on Epilepsy:*

This milestone document was drafted by the ILAE's Commission on European Affairs. Though not an official EU policy document, the initiative received cross party support from over 40 MEPs. The paper focused on the importance of multicentre European research in epilepsy at clinical and experimental levels. It underlined the need to intensify such research.

The White Paper also provided a framework for legislation to protect the rights of people with epilepsy from discrimination, and to ensure epilepsy does not disadvantage people in important areas such as driving. In this way, the socio-economic burden on these European citizens could be reduced.

### *The Framework Employment Directive:*

Directive 2000/78/EC provides for equal treatment of workers regardless of disability, and includes an obligation on the part of employers to grant reasonable access and accommodation for all its employees.

An important related issue in terms of epilepsy policy concerns the scope of the definition of disability. Epilepsy is usually classified as an illness and thus cannot be classified as a disability per se. It may, however, be the case that epilepsy causes disability.

The relationship between disability and its causes was dealt with in 2005 by the Court of Justice of the European Union in *Sonia Chacón Navas vs Eurest Colectividades SA*. In its judgment, the court sought to clarify the legal distinction between 'disability' and 'sickness'. In doing so, they referred to the WHO International Classification of Function, Disability and Health, which introduces disability as a fluid concept, avoiding rigid definitions. Disability therefore, is not defined as a prescriptive set of conditions, but rather takes into account the social impact of the condition on the sufferer. Thus, whether epilepsy qualifies as a disability for the purposes of EU law will depend on how the epilepsy impacts on the person's abilities. This is an area where MEPs working with representative organisations could influence the agenda for the better.

#### *The Driving Licence Directive:*

Directive 2009/112/EC entered into force on 29 August 2009, amending the existing directive on driving licences. The Directive's aim is the standardisation of national laws concerning the holding of a driving licence.

Concerning epilepsy, the rules require a one year seizure-free period in order to be eligible for a licence to drive cars and motorcycles.

In those Member States which did not allow people with epilepsy to drive at all, the transposition of this directive into national law radically alters the current position. In response to the directive, Lithuania, Estonia, Latvia and Portugal have all recently introduced legislation amending their laws to allow people with epilepsy to obtain licences after specified seizure-free periods.

In addition, the directive also provides for a ten-year seizure-free period for eligibility to apply for driving licences for buses and lorries. This is a considerable liberalisation over the laws in most Member States, where at present people with epilepsy face complete bans from driving commercial vehicles.

#### *Policy support for research*

FP7 is the short name for the Seventh Framework Programme for Research and Technological Development. This is the EU's main instrument for funding research in Europe and it will run from 2007-2013. Work is underway for the formation of its successor FP8. There is still time to influence this process. The Commissioner charged with overseeing the research portfolio of the European Commissioner is Maire Geoghegan-Quinn the Irish representative at President Barroso's Commission. Ms Geoghegan-Quinn is a former counterpart of mine in the Irish Parliament whom I know well. There is a real opportunity for groups and organisations representing people living with epilepsy to influence the agenda especially related to research.

Under FP7 a number of epilepsy projects receive EU funding. The most recent, the TOBI project, involves projects to develop brain computer interaction technology products for the market. This includes better EEG (Electroencephalography) test systems, which should help improve the detection and characterisation of epilepsy.

Another key project in EU-funded research into epilepsy is the EPICURE project, which began in 2007. With an EU contribution of just under €10 million, the project aims to harness synergies of multiple research groups across Europe, in order to better

understand the genetic factors which play a central role in epileptogenesis (the development of epilepsy). The project has attracted participation from research centres across Europe.

A success story through EU funding for research into epilepsy came in April of this year when the four-year, seven-partner NEUROGLIA project, which received EUR 3 million under the Health Theme of the Seventh Framework Programme made a major breakthrough in the understanding of the chemical and biology roots of focal epilepsy which has opened up new avenues of research and marks a huge step forward in the development of new therapies and drugs to control focal epilepsy.

### *Product standards*

There is little evidence that the specific concerns of people with epilepsy have been taken into account in the development of EU guidelines on product safety standards. While the Commission's 2007 risk assessment guidelines for product standards do cite the triggering of seizures in the category of a "severe" injury, along with, for example, amputation of hand or foot or piercing of the eye, there exists no specific material dealing with flashing lights or other product characteristics that may trigger seizure. Thus, the 2001 Directive on General Product Safety makes no mention of specific product characteristics, referring only generally to a requirement that products be "safe", as determined by the national laws of MS.

A recent Commission initiative to switch to energy-efficient lighting by 2012 was criticised by then MEP John Bowis for failing to take into account the health effects for people with epilepsy, severe migraine or autism.

### *In the European Parliament*

#### *Political Advocacy Group*

A further outcome of the European White Paper on Epilepsy was the formation of the Political Advocacy Group (PAG) for Epilepsy during the fifth legislative term. This group of MEPs was chaired by John Bowis (UK, EPPED).

It provided key support for epilepsy issues at the level of European institutions.

Its initiatives included:

- developing a dialogue with European Parliament and national governments
- putting forward petitions or written declarations on epilepsy
- efforts to raise public awareness on the issue

For example, the PAG called for the development of Europe-wide guidelines on standards for flashing images and regular patterns. The nature of the single market implies that product-standard guidelines of this nature must be coordinated at EU level.

The EU can combat discrimination, promote equality and advance best practice in issues related to epilepsy but this not happen of its own accord. You can and should seek to influence the agenda.

MEPs, Commissioners and Ministers network each other and are networked in turn by the public and representative organisations. Many make the mistake that this done at national level only and through national governments. This is wrong, the Parliament

now jointly decides about 95% of legislation with the Council of Ministers and must agree the budget for 100% of the EU's actions, therefore it is imperative that MEPs are networked on the issues surrounding epilepsy. This takes time but can pay dividends. MEPs are accessible, usually more accessible than national ministers, and are disposed to assist with issues such as epilepsy. MEPs are members of committees and working groups that can bring about significant change. They have access to other decision-makers, including Commissioners, Ministers and senior civil servants.

Health matters are always sensitive and as such health policy has been kept as a national competence. This means that decisions relating directly to health systems are taken at a national level rather than through the European Union. However, it is still very much possible to influence, through the EU matters relating to health policy. It is interesting to note that much of the environmental legislation across Europe was agreed intergovernmentally before the treaties provided environmental competence. There is for example a European Commissioner for Health, John Dalli, whose remit it is to support the effectiveness and efficiency of European healthcare systems, and be responsible for policy on pharmaceuticals and medical products. This gives the Commission an important role in promoting best practice throughout the EU.

Since the beginning of this year I have been working closely within the Commissioner on another health policy to do with vaccine safety. Commissioner Dalli has been very receptive and keen to work through ideas and possible solutions within his competence.

There is more that we can do within the European Parliament. My former colleague John Bowis did great work on this issue as you know, and there are many MEPs prepared to build on his work. For example we could work a Motion for Resolution within the Parliament calling for the promotion of best practice across Member States and the continuation of research funding. A Motion for a Resolution passed through Committee and Parliament creates strong political pressure on the Commission to react with proposals relating to subject of that resolution. The draft motion could be specifically about epilepsy or be broader and encompass a range of health topics. The subject matter could cover a range of things from research to discrimination, awareness raising to availability of services. It would then be incumbent upon the European Commission to address these concerns and where necessary begin a legislative process to tackle shortcoming across the EU within their area of competence.

We could introduce a Written Declaration within the Parliament to raise awareness among policy makers of the issues surrounding epilepsy. This would require the signature of a majority of MEPs but a campaign to secure those signatures would, in itself, heighten the awareness of the issue of epilepsy at EU level. Remember this; the political agenda is always full. Like a conveyor belt when one issue alls off another takes its place. Our objective should be to get our issue onto that conveyor belt.

There are a number of informal ways that issues relating to epilepsy can be discussed and their profile raised. There is an Intergroup on Disability which brings together MEPs from across the political spectrum to discuss topics surrounding disability and illness with view to raising awareness and designing possible initiatives that can impact in a more formal way.

Additionally, I am the founder and Chairman of the European Parliament's Working Group on Human Dignity. This group is designed to promote and protect the dignity of every person regardless of their status, we attempt to raise important issues and monitor the work of all the European Union's institutions to ensure that the fundamental principle of human dignity is respected. Last year I sponsored an exhibition within the European Parliament designed to highlight the difficulties faced by those living with disabilities in the developing world.

Your national and international organisations are to be complimented on the work they have been doing to achieve this.

*(Conclusion)*

The European Union is a place that rewards persistence, patience and pro-activity. Those concerned and involved with issues surrounding and affecting epilepsy need to understand and embrace this so that they can influence the agenda across the 27 member states. The European ideal has evolved far beyond sustaining peace on European soil and into a quest to raise standards of living for 500 million European citizens. The European Union motto is "Unity in Diversity". We are part of that diversity and it is important that we organise to ensure our voice is heard.