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EPILEPSY - AN UNKNOWN QUANTITY IN EUROPE

PREVALENCE & COSTS OF EPILEPSY

A Workshop hosted by Gay Mitchell MEP EEP

Date: Tuesday 19 February 2013
Room: ASP 5E3
Time: 14:00 - 15:00
Speakers: Dr Christine Linehan (Ireland)
Prof Torbjörn Tomson (Sweden)

- Across three decades, 76 studies on epilepsy prevalence were completed in 21 countries.
- Nearly half of all studies were undertaken in just three countries.
- Many are regional - national data are rare.
- Large areas of Europe are unrepresented.
- Definitions and estimates vary widely.

So, what needs to be done to find the right answers?

Over the last 30 years, at least 76 studies on the prevalence of epilepsy in European countries have been undertaken. Yet, because they present conflicting data, which are likely a consequence of methodological differences and shortcomings, there are still no accurate data on actual prevalence rates. The prevalence and costs of epilepsy in Europe is a field with major knowledge gaps, which should be addressed urgently.

Obtaining reliable information on this issue is essential for rational allocation of resources to ensure both adequate and cost-effective epilepsy care across Europe. Without this knowledge, national health authorities will struggle to establish the needs of their citizens.

The workshop is one of a series of events happening in the European Parliament on 19th and 20th February, to mark European Epilepsy Day 2013.

European Epilepsy Day aims to highlight that:

- epilepsy still remains a hidden disease due to the **stigma** attached;
- it is **treatable**, yet **40% of** the estimated 6 million people with epilepsy in Europe do not receive appropriate treatment;
- lack of treatment imposes a huge **financial burden** on national health systems;
- **research** and **legislation** remain key issues in improving the quality of life of persons with epilepsy.

Organised by the International Bureau for Epilepsy (IBE) and the International League Against Epilepsy (ILAE).

IBE (founded 1961) is an international umbrella organisation of national patient epilepsy associations.

ILAE (founded 1909) is an international association of healthcare professionals in the area of epilepsy.

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Fact about Epilepsy

- Epilepsy is a collective term for a large group of disorders of the brain that are characterized by seizures.
- A seizure is like an internal electrical storm. It is the consequence of abnormal, excessive discharges of nerve cells.
- Seizures are symptoms of the disorder, they are not the disorder itself, yet it is the seizures and associated stigma, rather than the condition itself, which ruin the lives of people with epilepsy.
- Epilepsy is the most common serious brain disorder and a global problem that recognizes no class distinction or global boundary, affecting all ages, races, social classes, and countries.
- It is estimated that 50 million people have epilepsy, six million of these live in Europe.
- Three hundred thousand (300,000) new cases are diagnosed in Europe each year.
- Forty per cent (40%) of children with epilepsy have difficulty at school; people with epilepsy in Europe experience high levels of unemployment; and people with epilepsy are exposed to stigma and prejudice.
- Based on a UK government report, it has been shown that SUDEP (Sudden Unexpected Death in Epilepsy) is responsible for 33,000 deaths in Europe each year, of which 40% are preventable.
- With appropriate treatment, up to 70% of people with epilepsy become seizure-free. Yet only 40% of people with epilepsy in Europe receive appropriate treatment.

About the International Bureau for Epilepsy (IBE)

WWW.IBE-EPILEPSY.ORG

- **IBE** is an international umbrella organisation of national lay (patient) epilepsy associations, which was founded in Rome in 1961.
- **IBE** exists to improve the social condition and quality of life of people with epilepsy and those who care for them and has a vision of the world where everywhere ignorance and fear about epilepsy are replaced by understanding and care.
- **IBE** works to increase awareness, understanding and knowledge of epilepsy and to increase awareness, understanding and knowledge of how best to meet the needs of people with epilepsy and those who care for them.
- **IBE** currently has a membership of 122 epilepsy associations, based in 92 countries worldwide.

About the International League Against Epilepsy (ILAE)

WWW.ILAE-EPILEPSY.ORG

- **ILAE** was founded in 1909 and is the world's preeminent association of Epileptologists, neurologists and other healthcare professionals working in the field of epilepsy.
- **ILAE** is working towards a world where no persons' life is limited by epilepsy.
- **ILAE's** mission is to ensure that healthcare professionals; people with epilepsy and their care givers; governments and the public, have the educational and research resources that are essential in understanding, diagnosing and treating persons with epilepsy.
- **ILAE**, with a membership policy of one member association (chapter) per country, has 107 chapters.

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