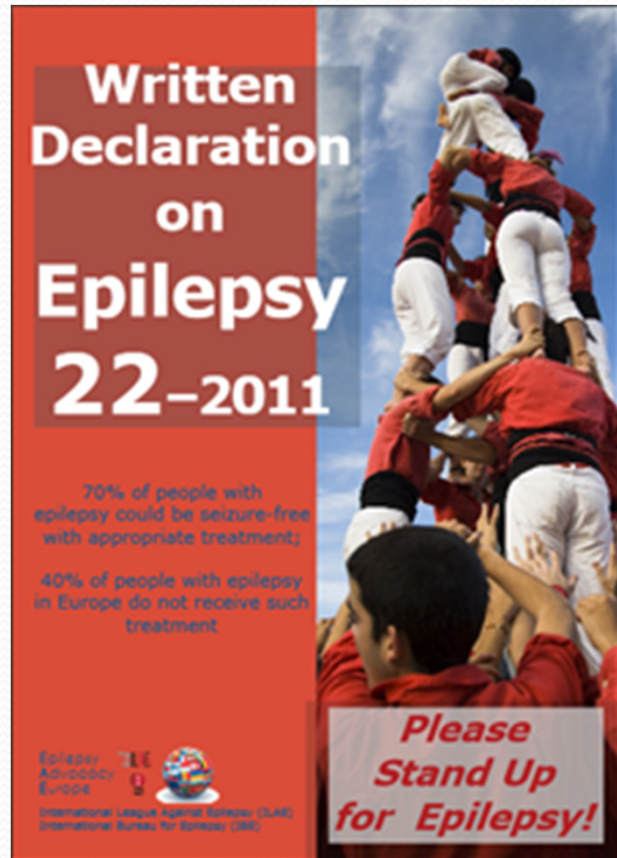


WHAT THE EU CAN DO TO HELP US REDUCE THE BURDEN AND STIGMA OF EPILEPSY?

Presented by Mike Glynn,
Joint Chair of Epilepsy Advocacy Europe
(the IBE / ILAE European Joint Task Force)

EU Written Declaration on Epilepsy



On the 15th September 1 2011 the Written Declaration on Epilepsy was passed.

When the declaration closed for signatures the total number of signatures obtained was 459.



IBE Members & their National MEPS



Eighteen of the 56 MEPS who participated in celebrating European Epilepsy Day

IBE & ILAE Presidents meet EU Commissioners

IBE President Mike Glynn, and President of the ILAE, Nico Moshe held meetings with two key Commissioners - **John Dalli**, then Commissioner for Health & Public Policy and **Máire Geoghegan-Quinn**, Commissioner for Research, Innovation & Science. The focus of these meetings was to highlight the need for research and education education to improve services for people with epilepsy.



Funding a European Prevalence & Costs research project



SAVE THE DATE!

**Workshop on
Prevalence
& Costs
of Epilepsy**

**19th FEBRUARY 2013
14:00 - 15:00
Room: ASP 5E3**

Hosted by Gay Mitchell MEP
Speakers: Dr Christine Linehan (Ireland)
Prof Torbjörn Tomson (Sweden)

An Epilepsy Advocacy Europe Working Group on Prevalence & Costs of Epilepsy in Europe has identified 66 studies on the prevalence of epilepsy in European countries. They present conflicting data, which are likely a consequence of methodological differences and shortcomings.

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 the rational allocation of resources to ensure adequate and cost-effective epilepsy care across Europe.

Stand Up for Epilepsy



Europe-wide Public Awareness Campaign



Epilepsy Ireland experience in legislation since the EU Declaration on Epilepsy was passed ...

- **Epilepsy Monitoring Units** ... *remain unopened*
- **Benzodiazepines Proposals** ... *illegal to possess without authorisation*
- **Generic Substitution of AEDs**



CONVENTION on the RIGHTS of PERSONS with DISABILITIES



EU Support

EU support for the use of appropriate language around Epilepsy

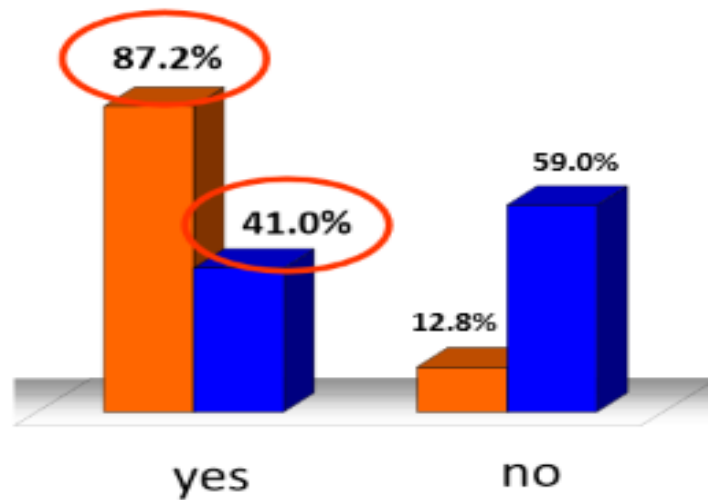


Some words have the power to cut very deeply when used in the wrong way and for all people living with and working in the field of epilepsy the dreaded “**E**” **word** has this impact

LANGUAGE EXPRESSION

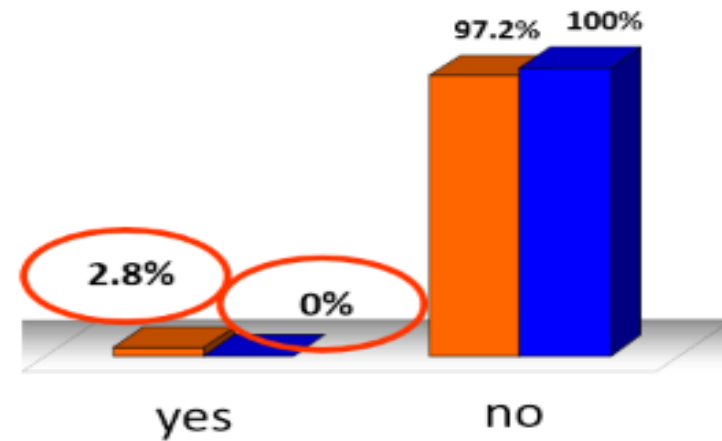


Do you think that epileptics / people with epilepsy are rejected by the society?



$p < 0.001$

Do you have prejudice against epileptics / people with epilepsy?



$p = 0.08$

■ EPILEPTICS ■ PEOPLE WITH EPILEPSY

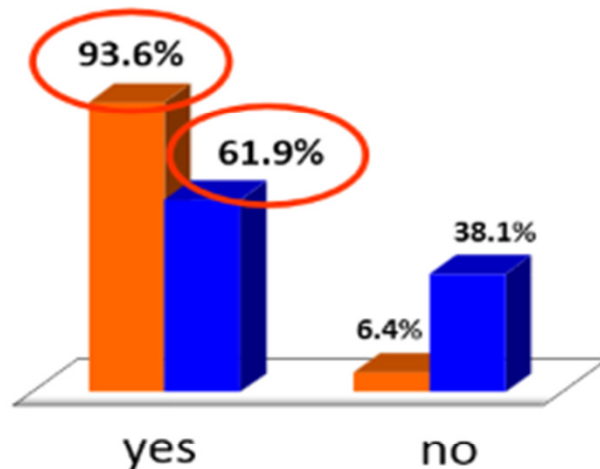
(Fernandes et al., 2009)



LANGUAGE EXPRESSION

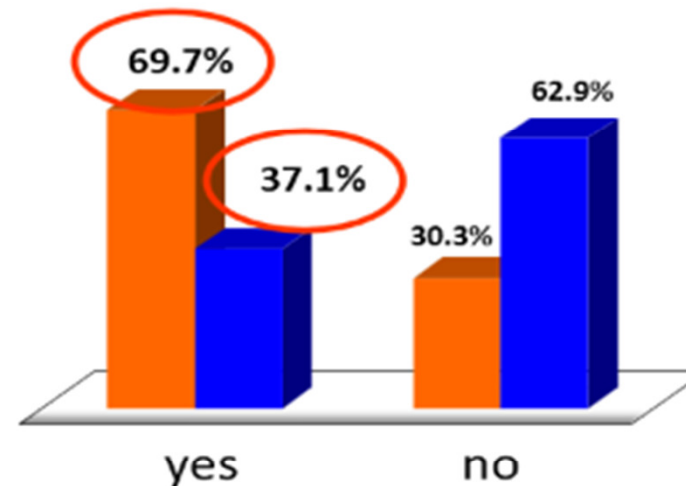


Do you think that epileptics / people with epilepsy have more difficulties to get employed?



$p < 0.001$

Do you think that epileptics / people with epilepsy have more difficulties at school?



$p < 0.001$

 EPILEPTICS  PEOPLE WITH EPILEPSY

(Fernandes et al., 2009)



Epilepsy and Driving

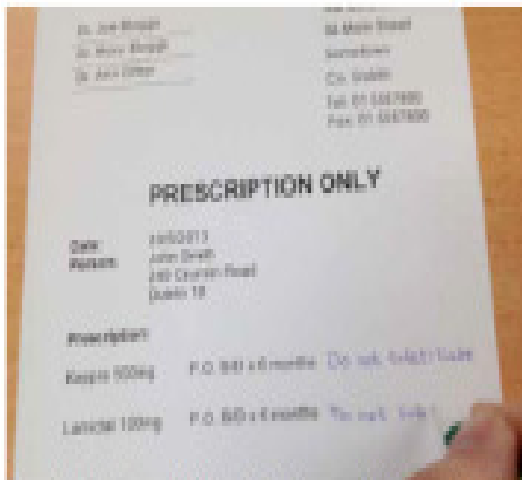
European Directive 2009 /
112 EC on Epilepsy and
Driving to be fully
implemented



Benzodiazepines



People with Epilepsy to be
protected from criminalisation
in the use of Benzodiazepines



Example of two AEDs prescribed using the brand name and with 'do not substitute' hand written by the prescriber

YOUR MEMORY AID

Detach this card and keep it in your wallet for the next time you visit your prescriber. It may help you remember what you need to say.

Dear Prescriber,
 Please write my AED prescription using my regular brand name.
 Please hand write 'do not substitute' beside each AED on my prescription.

www.epilepsy.ie Tel: 01 451 7500

Vision:
 Epilepsy Ireland's vision is to achieve a society where no person's life is limited by epilepsy.

Mission Statement:
 Epilepsy Ireland is committed to working for, and to meeting the needs of everyone with epilepsy in Ireland, their families and carers.

Contact Us:

Head office: 249 Crumlin Road, Dublin 12. Tel: 01-451 7500
 Specialist Nurse Helpline (Mon-6.30 - 1pm) Tel: 01-451 4133

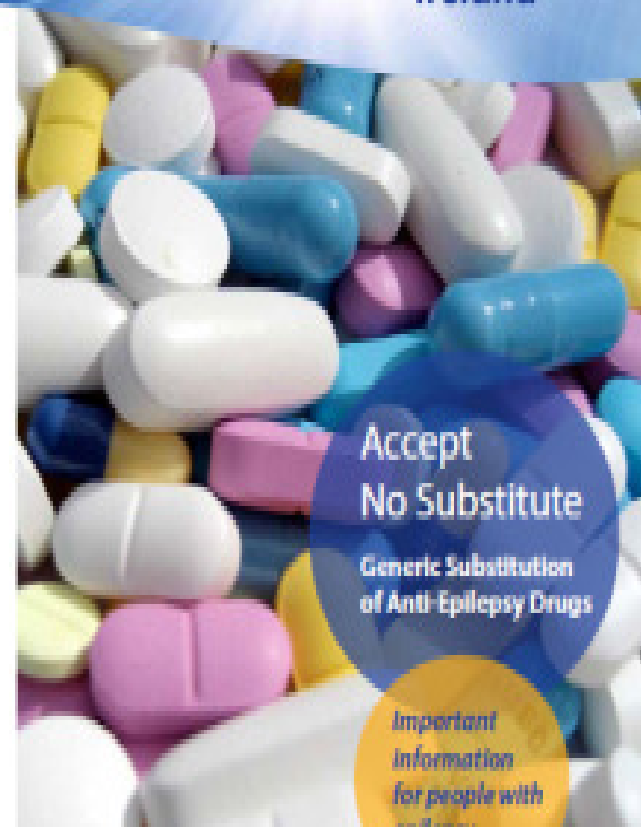
Cork: Tel: 021-4219774
 Dundalk: Tel: 042-9337086
 Galway: Tel: 091-887540
 Kildare: Tel: 045-7389504
 Kilkenny: Tel: 084-9030321
 Letterkenny: Tel: 074-9168725
 Limerick: Tel: 061-915771
 Sligo: Tel: 071-911888
 Tallinn: Tel: 007-9348790

Training for Success
 11-week pre-employment course at the IT Sligo: Tel: 071-9155301

Email: info@epilepsy.ie
 Web: www.epilepsy.ie
 Facebook: www.facebook.com/epilepsyie
 Twitter: @epilepsyireland
 Online support group: support@epilepsy.ie



Brainwave - The Irish Epilepsy Association trading as Epilepsy Ireland is a company

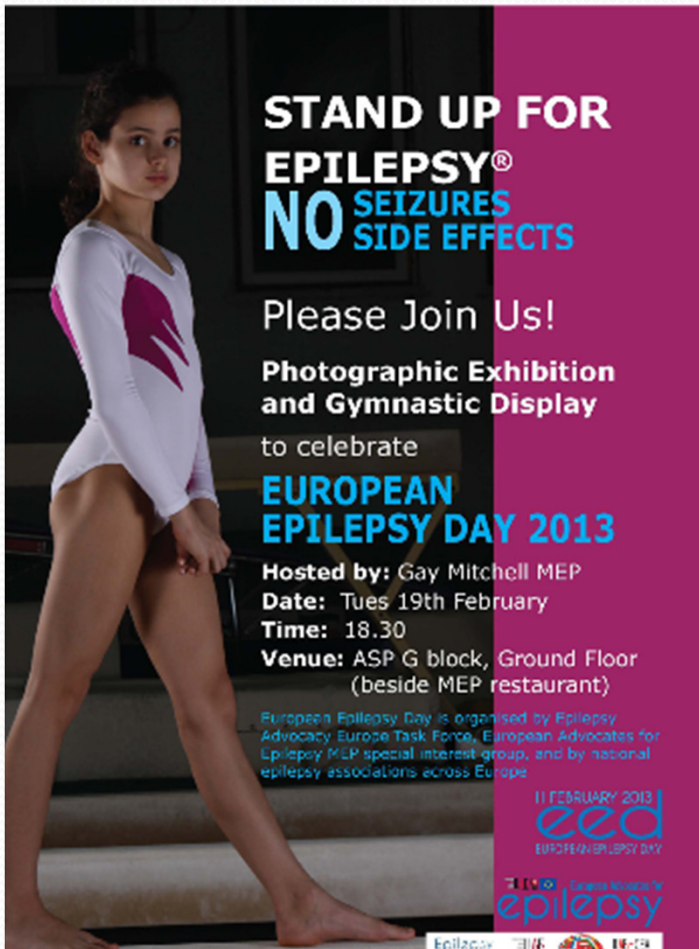


Accept
 No Substitute

Generic Substitution
 of Anti-Epileptic Drugs

Important
 information
 for people with
 epilepsy

Stand Up for Epilepsy!



**STAND UP FOR
EPILEPSY®
NO SEIZURES
SIDE EFFECTS**

Please Join Us!
**Photographic Exhibition
and Gymnastic Display**
to celebrate
**EUROPEAN
EPILEPSY DAY 2013**

Hosted by: Gay Mitchell MEP
Date: Tues 19th February
Time: 18.30
Venue: ASP G block, Ground Floor
(beside MEP restaurant)

European Epilepsy Day is organised by Epilepsy
Advocacy Europe Task Force, European Advocates for
Epilepsy MEP special interest group, and by national
epilepsy associations across Europe

11 FEBRUARY 2013
eed
EUROPEAN EPILEPSY DAY

Organised by
epilepsy

Epilepsy Europe

Veronika is 12 years old

**Her dream is to become a
famous gymnast**

Veronika Mytikóis being prevented from access to her gym and from gymnastic competition by Hungarian authorities on the basis that she has epilepsy. This is despite the fact that her epilepsy is fully controlled and her medical consultant has certified that there is no medical reason why she cannot participate in the sport.

Veronika ...



PHOTOGRAPHED AT EED 2013 IN THE EUROPEAN PARLIAMENT (left-right): Jim Higgins MEP, Francisco José Millán Mon MEP, Filip Kaczmarek MEP, Gay Mitchell MEP, Anna Záborská MEP, Veronika Mitykó, Pat The Cope Gallagher MEP, Sean Kelly MEP, , Kristzina Danczik, Dr. Judit Jerney M.D., President of the Hungarian Epilepsy League (Hungarian Chapter of the International League Against Epilepsy) and Ann Little Executive Director IBE (International Bureau for Epilepsy)

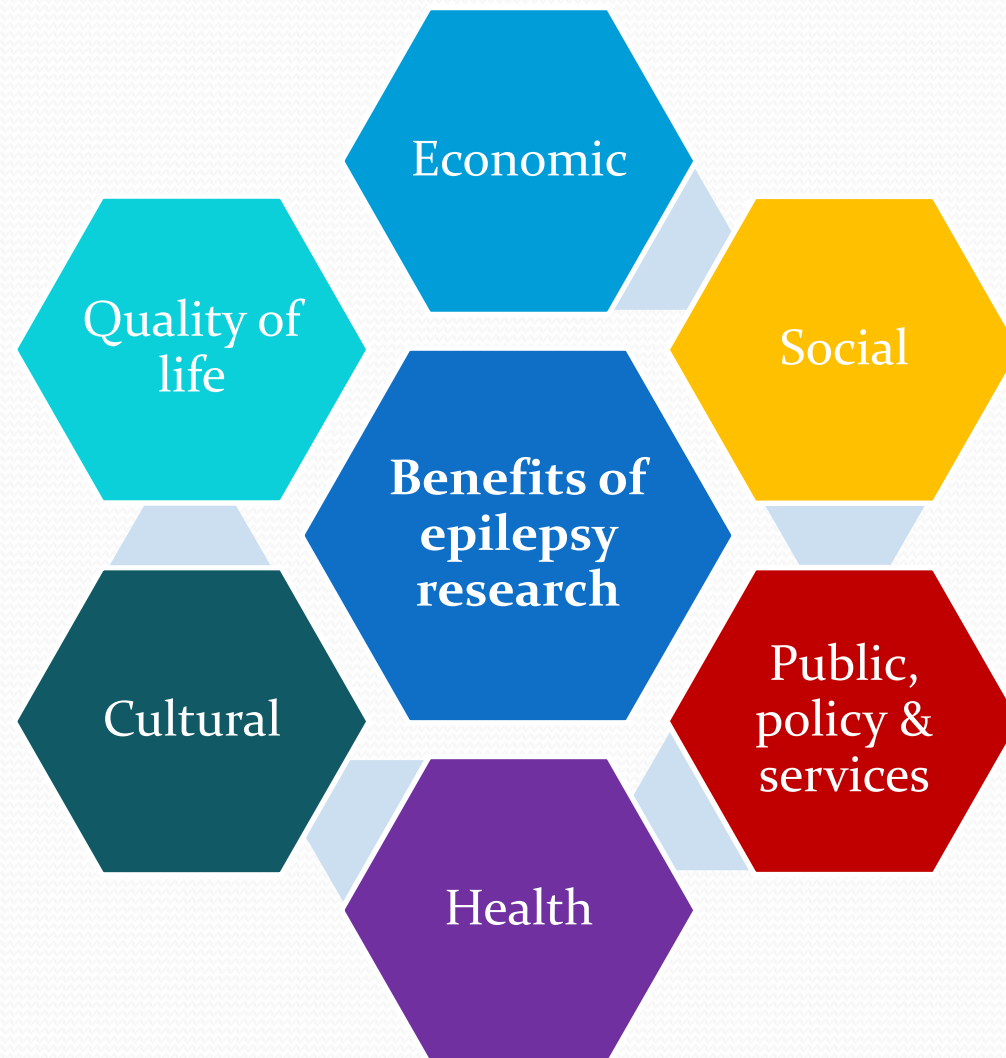


Dr. Judit Jerney & Veronika



Veronika giving a wonderful performance

Increase Epilepsy Research



Showcasing Epilepsy Research Projects



Act Local Think Global!

DATE FOR YOUR CONGRESS DIARY!

Date: Sunday 23rd June 2013

Time: 17:00 - 18:30

Venue: Palais des Congrès de Montréal

EXCITING WORKSHOP SHOWCASING SUCCESSFUL RESEARCH PROJECTS

IBE's Research Task Force is planning an interactive workshop that will be of interest to all those who have ever considered undertaking research. The event will act as a catalyst for improving the social condition and quality of life for people with epilepsy.

Showcasing research carried out by IBE members, and others working to support people with epilepsy and their families, this will be the ideal opportunity to discover new methods that could be adopted for use at local level. There will also be ample Question and Answer time for you to pose your questions to the session speakers.

Public Knowledge, Private Grief: A Study of Public Attitudes to Epilepsy in the United Kingdom and Implications for Stigma

*Ann Jacoby, *Joanne Gorry, †Carrol Gamble, and ‡Gus A. Baker

**Department of Primary Care, †Centre for Medical Statistics, and ‡Department of Neurosciences, University of Liverpool, Liverpool, United Kingdom*

Summary: *Purpose:* For many people with epilepsy, the continuing social reality of their condition is as a stigma, thus representing a source of much private grief. To understand fully the nature of epilepsy stigma, it is important to examine attitudes and beliefs of not just the “targets” but also of the “perceivers” of stigma. Perceivers may hold erroneous beliefs and stereotypes that lead them to have negative expectations of people affected by epilepsy. This study examined levels of knowledge and attitudes among perceivers of epilepsy stigma in the U.K.

Methods: A random sample of >1,600 members of the general public was interviewed as part of the bimonthly UK Omnibus Survey. The response rate was 62%. **Results:** One fourth of informants knew someone with epilepsy and one half had witnessed a seizure. One half agreed that people with epilepsy are treated differently by others, and themes of exclusion, restriction, and nonnormality were commonly cited as reasons for this. Epilepsy ranked second in a range of health conditions, in terms of which would cause them greatest concern if informants had to work with someone so affected. Responses to a series of attitude statements indicated that most held highly favorable attitudes; but one fifth agreed with the statement that people with epilepsy have more personality problems than do others. Responses were influenced by informants’ sociodemographic characteristics.

Conclusions: The survey revealed attitudes and knowledge gaps that have the potential for discriminatory behavior. There are implications for how public education campaigns should be implemented, and who should be targeted.

LATE LATE SHOW – April 2013



What the EU can do to reduce Epilepsy Stigma

- Finance and support a Europe-wide JTF epilepsy awareness campaign
- Provide funding for an EU Prevalence & Costs study
- Direct all member states to provide proper, timely epilepsy Mortality statistics
- Use its good offices to support the epilepsy community in pressurising Governments to implement the recommendations of the European Declaration on Epilepsy