

L-Epilessija – Kif negħlbu l-istigma **Epilepsy - How to overcome stigma**

Saturday 25 February 2012, Dolmen Resort Hotel, Malta

Welcome address

The drive to overcome the stigma associated with epilepsy has been chosen to be the theme of this year's national conference of the Caritas Malta Epilepsy Association. The conference is being held in conjunction with the Department of Clinical Pharmacology and Therapeutics of the University of Malta. The conference, which will convene at the Dolmen Resort Hotel on 25th February, 2012, will highlight the European Parliament's recently approved **Written Declaration on Epilepsy**. The declaration calls on the EU Commission to prioritise epilepsy as a major disease which imposes significant burden across Europe.

There are over 3,000 persons who have been diagnosed with epilepsy in Malta and Gozo. Epilepsy is often a hidden medical condition which requires several varying medical and support services and it can greatly affect a person's social and personal life. This year's national conference will discuss how stigma can be overcome in order to ensure a better quality of life for persons with epilepsy in the community. We are honoured that among the speakers at the national conference will be Commissioner John Dalli, EU Commissioner for Health and Consumer Affairs, Mgr. Victor Grech, Director of Caritas Malta, Prof. Mike Kerr, from the Department of Psychological Medicine & Neurology, University of Cardiff, UK, and Ms Hanneke de Boer, Co-ordinator, WHO/IBE/ILAE Global Campaign against Epilepsy, Sein Epilepsy Centre, Netherlands. We also have several distinguished local speakers including representatives of ETC, Malta Employers Association, KNPD and also interactive workshops.

We are sure that this conference will be of great interest to all the participants and the interactive session will stimulate a great deal of discussion. We would like to thank you for your continuing support and interest.

THE ORGANISING COMMITTEE

*Janet Mifsud, Mario Dimech, Victoria Dimech, Frank Portelli,
Manuel Camilleri, Mandy Vella, Adriana Soler, Caroline Attard.*



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The conference will provide 5 CPD credits for Nurses and Midwives registered with the Department of Health; 2 CPD points for members of the Malta College of Pharmacy Practise and 3 CPDAS points for members of the Malta College of Family Medicine.

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Saturday 25 February 2012, Dolmen Resort Hotel, Malta

- 08.30 **Registration and welcome coffee**
- 09.00 **Chair**
Dr Janet Mifsud, Vice-President (Europe) International Bureau for Epilepsy
- Welcome Remarks**
Mgr Dun Victor Grech, Director, Caritas Malta
Mr Mario Dimech, President, Caritas Malta Epilepsy Association.
- 09.10 **Opening Address**
Commissioner John Dalli, EU Commissioner for Health and Consumer Affairs
- 09.30 **Science versus Society: defeating the stigma of epilepsy**
Prof Mike Kerr, Department of Psychological Medicine & Neurology,
University of Cardiff, UK
- 09.55 **Living with epilepsy- overcoming the stigma.**
Ms Hanneke de Boer, Co-ordinator, WHO/IBE/ILAE Global Campaign against
Epilepsy; Sein Epilepsy Centre, Netherlands.
- 10.20 **Questions**



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10.30 **Coffee break**

11.00 **Interactive session: Il-Każ ta' Steve**

Written by Giovann Attard

Actors: Bernardo Riolo, Daniela Micallef, Giovann Attard

11.30 **Panel round discussion and questions**

Mr Joe Camilleri, Malta National Commission for Persons with Disability (KNPD);

Ms Dorianne Pawney, Employment and Training Co-operation (ETC), Malta;

Mr Joe Farrugia, Malta Employers Association (MEA);

Mr Joe Gerada, Foundation for Human Resources;

Dr Roselyn Borg, Lawyer;

Dr Josanne Aquilina, Consultant Neurologist;

Mr Manuel Camilleri, Caritas Malta Epilepsy Association (CMEA).

12.30 **Lunch**

14.00 **Workshops**

A Stigma and Quality Of Life – Prof Mike Kerr; Ms Victoria Dimech; Mr Joe Gerada,

B Living With Epilepsy: Practical Aspects – Ms Hanneke de Boer;
Mr Mario Dimech; Ms Dorianne Pawney

C How to Reduce Stigma In Employment – Mr Joe Camilleri; Dr Roselyn Borg;
Mr Manuel Camilleri

15.30 **Report from workshops** Dr Janet Mifsud



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Professor Mike Kerr

Professor Kerr's clinical practice is in the epilepsies associated with intellectual disability and in the assessment and treatment of epilepsy and psychiatric disorders. He has been closely associated with initiatives in improving the public health of people with an intellectual disability including developing the Cardiff Health Check, which is used across the UK.

Academically he has published widely on healthcare, epilepsy and intellectual disability and held research grants from many funding bodies. He is chair of the Advisory Board for Wales of Epilepsy Action, a trustee of Epilepsy Research UK and is a medical advisor for the Rett Society and Epilepsy Bereaved. He is a member of the International League Against Epilepsy (ILAE) commission on neuropsychiatric aspects of epilepsy and an editor of the Cochrane collaboration epilepsy group.

Abstract: Science versus Society: can science reduce the stigma of epilepsy?

Despite international and local initiatives stigma remains a significant burden on the lives of people with epilepsy. This presentation will explore how scientific advances can be used to reduce stigma. Examples from other stigmatizing conditions such as mental illness will be described.

The main focus for science to reduce stigma is in three key areas. Firstly, improvements in seizure reduction through advances in neurosurgery and medication. Secondly, evidence production through research to remove ignorance and myth, such as the false belief that there is a link between epilepsy and violence. Lastly through the treatment of comorbidity associated with epilepsy such as depression that adds to the burden of people with epilepsy.



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Hanneke de Boer

Hanneke de Boer has been working in the field of epilepsy since 1966. She was IBE's Secretary General from 1989-1993 and its president from 1997-2001. Since 1999 she has been involved with the ILAE/IBE/WHO Global Campaign Against Epilepsy "Out of the Shadows is a joint initiative of the World Health Organization, the International League Against Epilepsy and the International Bureau for Epilepsy. Ms. De Boer works at a large special centre for Epilepsy (Stichting Epilepsie Instellingen Nederland) originally as a vocational consultant where she was finally charged with the coaching and training of vocational consultants, with the setting up of employment projects for people with epilepsy. During the last 10 years or so she has been involved in the development and maintenance of international contacts for this Epilepsy Centre, (which has been designated by WHO as a WHO Collaborating Centre for Research, Training and Treatment in Epilepsy since 2004). She has presented and published numerous papers on the social aspects of epilepsy, with an emphasis on the employment and employability of people with epilepsy, on the influence of stigma on the lives of the people and the burden of the disorder. Ms. De Boer has received a number of awards for her work.

Abstract: Living with epilepsy: overcoming the stigma

Epilepsy presents a global problem affecting all ages, social classes, groups and countries. Fear, misunderstanding and the resulting social stigma and discrimination surrounding epilepsy often force people with this disorder "into the shadows". The most significant problems people with epilepsy encounter in daily life often are not related to the severity of the condition, but stem from concepts of epilepsy held by the general public. The impact of epilepsy on social functioning, or the ability to participate in a broad range of social activities and interpersonal relationships, can be quite varied. Although some people with epilepsy have few, if any, disruptions in social functioning, others have severe problems that prevent them from engaging in fully productive lives. People with epilepsy have a higher prevalence of social problems than those from the general population. Children and adolescents often suffer from overprotection within the families and at school. In adult life problems are reported concerning obtaining and retaining employment, which is confirmed by research findings. Older people like younger ones suffer a loss of confidence. They may lose their functional independence. All chronic conditions have an impact on the quality of life, however the impact of epilepsy may be greater partly because of the unpredictability of the seizures and partly because of the associated stigma. During this presentation some examples will be given on how to live as full and productive lives as possible, by taking some simple precautions or measures.



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INTERACTIVE SESSION: il-Każ ta' Steve.

XI PUNTI GĦAD-DISKUSSJONI.

1. X'parir tagħtuni li nagħmel?
2. Tagħtuni tort li jien ġibt ruħi b'dan il-mod?
3. Huwa tort tiegħi li jien għandi l-epilessija?
4. Hija diskriminazzjoni li lili ma jimpjegawnix minħabba l-kundizzjoni li għandi?
5. Kif nista' nipprova li din hija diskriminazzjoni?
6. U jekk ngħid il-verita', x'se nagħmel biex insib xogħol li jogħgob lili?
7. X'għandi inqas minn oħrajn, jien li għandi din il-kundizzjoni?

POINTS FOR DISCUSSION.

1. What advice would you give me?
2. Do you blame me that I reacted in this way?
3. Is it my fault that I have epilepsy?
4. Is it discriminatory that no one employs me because of my condition?
5. How can I prove that this is discriminatory?
6. If I tell the truth, what can I do to find a job I like?
7. Why am I being treated differently from others because I have epilepsy?





EUROPEAN PARLIAMENT 0022/2011

Written declaration on epilepsy

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.



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Tribute to Joe Camilleri

Nixtiequ li din il-konferenza niddedikawha b'mod partikolari lil ex Membru tal-kumitat tal-Caritas Malta Epilepsy Association Joe Camilleri, li għadda għall-ħajja aħjar is-sena l-oħra.

Joe kien jaħdem hafna u bil-qalb speċjalment biex jippreparalna xogħol ta' art work u xogħol bil-kompjuter. Għalkemm kien minn Għawdex rari kien ifalli xi laqgħa.

Minkejja li nħossu n-nuqqas tiegħu ninsabu ċerti li għadu jsegwina minn fejn qiegħed.

We would like to dedicate this conference as a special tribute, to an ex Member of the Caritas Malta Epilepsy Association, Joe Camilleri, who passed to a better life last year.

Joe worked extremely hard and with great enthusiasm especially in the preparation of designs and art work and other related work on the computer. Although he lived in Gozo he rarely missed a committee meeting.

Although we miss him so much, we are sure that he is still following our activities from above.

The Organising Committee would like to thank the following Sponsors for their invaluable support.



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