



**Caritas Malta Epilepsy Association
- Ten years of work
The Social Impact of Epilepsy**

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- Għaxar Snin ta' Ħidma
L-Impatt Soċjali tal-Epilessija**

Caritas Malta Epilepsy Association - Ten Years of Work The Social Impact of Epilepsy

One percent of the global population has epilepsy, and in Malta there are over 2,900 persons who have this condition. Epilepsy is a hidden disability and many people may not be aware that a person has epilepsy. This will only be evident if they are explicitly informed by that person or his family or if that person has a seizure in their presence. This may have a negative effect on the person's social life. Our organization's main aim and objective is to help these people lead a better quality of life. In order to do this we participated in a Global Campaign Against Epilepsy. This campaign is being organised by the World Health Organisation, International League Against Epilepsy and International Bureau of Epilepsy. The main aim of this campaign is to increase awareness about epilepsy, in order that people may be better informed and the associated stigma eventually hopefully eradicated.

The Caritas Malta Epilepsy Association is organising the third National Conference on Epilepsy, with the focus being on the social impact of the condition. The date for the conference, 18th February 2006, was chosen specifically since it is reputed that St Valentine had epilepsy.

This year it will be our 10th Year Anniversary. **HE Dr E Fenech Adami**, the President of Malta, and **Mgr Victor Grech**, Director of Caritas Malta, shall preside the opening of the event, while the keynote speech *Novel Developments in Epilepsy* shall be delivered by **Prof JW Sander**, Professor of Neurology and Clinical Epilepsy, Institute of Neurology, University College, London. **Dr Ray Galea**, St Luke's Hospital, Malta will discuss *Epilepsy and Women*, while **Ms Maire Tansey**, Course Facilitator, Institute of Technology, Sligo, Ireland will analyse *Social Aspects of Growing up with Epilepsy*. The workshops in the afternoon will allow further interaction and will focus on various aspects of the presentations.

This conference will further enhance our networking experience, and provide you with an opportunity to obtain the new epilepsy identity cards, epilepsy diaries and DVDs in Maltese that have been so kindly supported by our various sponsors. We trust that you will benefit from this conference and return to your organisations and places of work with new insights into the condition. Without your support CMEA cannot deliver its campaign.

Thanking you once again.

CMEA Organising Committee

Programme

- 09.00** **Opening Speeches**
- HE Dr E Fenech Adami, President of Malta
- Mgr Victor Grech, Director, Caritas Malta
- 09.15** **Ten years of activities of CMEA**
 Mr Mario Dimech, President CMEA
- 09.45** **Emerging Drug Treatments for Epilepsy**
 Prof JW Sander,
 Institute of Neurology, University College, London
- 10.30** **Coffee break**
- 10.45** **Epilepsy and women**
 Dr Ray Galea,
 St Luke's Hospital, Malta
- 11.30** **Social Aspects of Growing up with Epilepsy**
 Ms Maire Tansey,
 Course Facilitator, Institute of Technology, Sligo, Ireland
- 12.15** **Questions**
- 12.45** **Lunch**
- 14.00** **Workshops**
- A What is new in epilepsy..... Prof JW Sander
- B Women and Epilepsy..... Dr Ray Galea
- C Social Aspects..... Ms Maire Tansey
- 15.30** **Report from workshops**
- 16.15** **Evaluation / Closure**

Ten Years of Activities of CMEA

Mr Mario Dimech

President CMEA

Ten years ago Maltese persons with epilepsy, felt the need to organise a support group in order for them to be able to share their problems with other people dealing with the same condition.

As time went by the mission of the Caritas Malta Epilepsy Support Group developed into a more widespread one. It was felt that the main objective was to create more awareness about epilepsy, and to be more effective in its work, the group status was changed to that of an association (CMEA) and it became affiliated with the International Bureau of Epilepsy (IBE). This membership has expanded our knowledge about epilepsy and it has put the Association in a better position to help persons with epilepsy and their families, as well as to educate the general public about this condition. CMEA also functions as a pressure group to put forward the plight of epilepsy patients.

Mario has had epilepsy since childhood. He completed secondary school education and he is employed as a clerical officer in a private enterprise. He is married and has two children. He joined the Caritas Malta Epilepsy Association, a few months after it was formed in 1996, and is now its President. He has spoken several times on the media about his own personal experiences with epilepsy and has represented the Association abroad, in international conferences in Greece and Madrid.

Emerging Drug Treatments for Epilepsy

Prof J W Sander MD MRCP PhD

NSE Professor of Neurology and Clinical Epilepsy, University College London

New antiepileptic drugs (AEDs) are necessary for patients with chronic epilepsy and for improving upon established AEDs as first line therapy. Over the last 2 decades, 11 new AEDs have appeared (Progabide, Vigabatrin, Zonisamide, Oxcarbazepine, Lamotrigine, Gabapentin, Felbamate, Topiramate, Tiagabine, Levetiracetam and Pregabalin). Despite the excitement that has accompanied the launch of each new AED, these new drugs have not changed the prognosis of epilepsy dramatically, because few people with chronic epilepsy have become seizure free and in this sense the new antiepileptic treatments have not lived up to expectations.

Most people with chronic epilepsy still rely on the development of novel treatments as their only hope for seizure control. This is a heterogeneous group and it is unlikely that a drug that is efficacious for all patients will ever be found. Another important reason for the continued quest for new AEDs is the need for safer alternatives, as none of the antiepileptic drugs currently available are free from adverse effects. At present there are several potential antiepileptic compounds undergoing clinical testing. In this presentation, potential new antiepileptic drugs are reviewed. The way new drugs are developed, the role of the regulators and timeframes of drug developments will be discussed. In addition, potentially new targets for the development of effective antiepileptic drugs will be highlighted. The development of nationally targeted drugs, antiepileptogenic therapy and the local delivery of effective medication are the real promises for the future of drug treatment of epilepsy.

Ley Sander is the NSE Professor of Neurology and Clinical Epilepsy at the Institute of Neurology of University College London. He is Honorary Consultant Neurologist at the National Hospital for Neurology and Neurosurgery in London, and at the National Society for Epilepsy in Buckinghamshire and he is Head of the WHO Collaborative Centre for Research and Training in Neurosciences, London UK and Director of the Clinical Trials Unit at the National Society for Epilepsy - Chalfont Centre. Ley Sander qualified in the University of Parana in Brazil and after his initial medical training in Brazil, he moved to the United Kingdom where he completed his neurological training. He obtained his PhD at the Faculty of Medicine of the University of London. He served as a member of the Management Committee of the International League Against Epilepsy and is a member of numerous organisations and professional societies including the Royal Society of Medicine, The American Academy of Neurology, The American Epilepsy Society and the British Medical Association. He has published extensively on various aspects of epilepsy but particularly on drug issues, patient care and on the epidemiology of epilepsy. He is a frequent speaker at International Conferences, and is a member of the Editorial Board of several specialist journals. The International League Against Epilepsy and the International Bureau for Epilepsy made him an Ambassador for Epilepsy in 1993.

Epilepsy and Women

Dr Raymond Galea MD, FRCOG, Acc Spec O&G (Leuv)
St Luke's Hospital, Malta

More than 90 % of women with epilepsy will have normal healthy infants. However, they are at greater risk of complication of pregnancy labour and adverse pregnancy outcomes than women without epilepsy.

Women with epilepsy have fewer children than women in general, with a fertility rate 25-33% lower than average. While personal choice and/or social pressure may play some role in this disparity, research has indicated that women with epilepsy have higher incidence of menstrual irregularities, polycystic ovarian disease and reproductive endocrine disorders. Any of these may reduce fertility.

Major malformations are defined as defects of medical, surgical or cosmetic importance. This type of anomaly which will seriously affect a child's life, occurs in 2 - 3 % of all live born children. For women with epilepsy on one seizure medication, the incidence is estimated to be 4 - 8 % and possibly greater for women with epilepsy taking more than one drug. Types of major malformations occurring most often in children of women with epilepsy are orofacial clefts, cardiac abnormalities and neural tube defects. Pre conceptual counselling and co-ordination of care among all members of the health care team is key to treating women with epilepsy of childbearing age.

Dr Galea is a consultant gynaecologist at the Department of Obstetrics and Gynaecology St. Luke's Hospital Medical School and lecturer, Faculty of Medicine and Surgery, University of Malta. He is presently researching the effects of antiepileptic drugs in women of child bearing age in Malta in conjunction with the Department of Clinical Pharmacology and Therapeutics and Department of Medicine.

Social Aspects of Growing up with Epilepsy

Ms Maire Tansey

Course Facilitator, Institute of Technology, Sligo, Ireland

Few medical conditions have attracted so much attention and generated so much controversy as epilepsy. It is a common condition that affects millions of people, yet no other disorder can claim to be as misunderstood. In Ireland epilepsy has been a subject that was rarely talked about, and has carried a considerable social stigma.

The reasons for this are understandable. To observers, seizures can be frightening, confusing and even violent occurrences. The misconceptions of epilepsy, have led to stigmatisation for the individuals with the condition. Stigma is often a daily companion and can negatively affect an individual's quality of life.

In 1998, the Irish Epilepsy association entered into a partnership with the Institute of Technology in Sligo to address the social and educational needs of young people with epilepsy. The programme is the only one of its kind in Europe and is continuing to succeed in directing young people in further education and employment.

Ms Tansey is Course Facilitator/Computer Applications Lecturer with Training For Success, Brainwave's (Irish Epilepsy Association) Pre-employment Training Programme for people with epilepsy run in partnership with the Institute of Technology, Sligo. Training For Success was first established in 1998 to address the needs of young adults with epilepsy in accessing meaningful employment. Marie has the responsibilities for the design, delivery and assessment of the computer module for this programme as well as support for students including personal development training, action planning and goal setting, crisis management and conflict resolution, liaison with parents, employers, FAS, health care workers, statutory and voluntary agencies to ensure the successful progression of individual training and education plans for the students. She was previously Trainer & Internal Verifier, Victoria House Training College, Northfield Birmingham and personal assistant, at the Irish Welfare and Information Centre, Birmingham.



This conference has been accredited 8Credit Points by EUREPA, European Epilepsy Academy

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