



L-Universita' ta' Malta



www.caritasmalta.org/epilepsy

National Epilepsy Conference

**L-EPILESSIJA MHIJIEK SEMPLIĊIMENT
AĊCESSJONIJIET**

L-istigma fl-epilessiya tikkawża



**BIEX INTEJBU L-KWALITÀ TAL-ĦAJJA
NEHTIEĠU**



Epilepsy
Advocacy
Europe



Saturday 22 February 2014
Dolmen Resort Hotel, Malta



Dear Colleague

The Caritas Malta Epilepsy Association, in conjunction with the Department of Clinical Pharmacology and Therapeutics, University of Malta, is organizing its national conference on **Saturday 22 February 2014**, Dolmen Resort Hotel, Malta.

The title of this year's conference is:

Epilepsy is more than just seizures
L-Epilessija mhijiex sempliciment aċċessjonijiet

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 in epilepsy causes discrimination, inequality, social exclusion and employment problems. In order to improve quality of life of persons with epilepsy we need employment legislation, access to treatment, education and funding for research.

We are honoured that among the speakers at the national conference will be Prof Phil Smith, Consultant Neurologist, University Hospital of Wales, UK and Ms Christine Bennett, UK Epilepsy Nurse.

We also have several distinguished local speakers and also interactive workshops. We are sure that, as usual, this conference will be of great interest to all the participants.

It will also be an excellent opportunity to network. We wish you all a great conference.

***Janet Mifsud, Victoria Dimech, Mario Dimech, Frank Portelli,
Manuel Camillieri, Caroline Attard, Adriana Soler
Organising Committee***



National Epilepsy Conference

Saturday 22 February 2014

Dolmen Resort Hotel, Malta

Programme

08:30 Registration and welcome coffee

09:00 Chair Prof Roger Ellul-Micallef, Head, Department of Clinical Pharmacology and Therapeutics, University of Malta

09:05 Welcome Remarks

Mgr Carm Farrugia, Director, Caritas Malta

Mr Mario Dimech, President, Caritas Malta Epilepsy Association

09:15 Opening Address

Hon Evarist Bartolo, Minister for Education and Employment

09:30 Epilepsy is more than just seizures

Prof Phil Smith, University Hospital of Wales, Cardiff UK

10:30 Coffee break

11:00 Chair Prof Janet Mifsud, Vice President, International Bureau of Epilepsy

11.05 Epilepsy: the role of the epilepsy nurse

Ms Christine Bennett, Epilepsy Specialist Nurse, UK

11:30 Round table: The local scenario

Chair: Mr David Casa, MEP European Advocacy Epilepsy Group.

Panel: Dr Doriette Soler, Ms Victoria Dimech, Mr Matthew Attard, Mr Frank Portelli

12:30 Lunch

14:00 Workshops

A Addressing medical needs

Prof Phil Smith/Mr Matthew Attard

B How can an epilepsy nurse help?

Ms Christine Bennett/

Ms Caroline Attard

C Addressing children's needs

Dr Doriette Soler/Ms Adriana Soler

15:30 Report from workshops Prof Janet Mifsud

Epilepsy is more than just seizures

Prof Phil Smith
Consultant Neurologist,
University Hospital of Wales, Cardiff, UK



There is far more to epilepsy than just the seizures. The profound effect that epilepsy can have on people's lives goes way beyond the disability borne of the actual seizures. The mismatch between visible disability and perceived disability is never greater than for epilepsy, where, for 99+% of the time, patients are not having seizures and appear to be perfectly well and healthy. Yet the concern that a seizure may occur leads to perceptions of stigma, mood change, avoidance behaviour, lifestyle changes and generally reduced quality of life; furthermore, the restriction on driving privileges and society's restrictions to certain aspects of education and employment further add to these negative perceptions. Despite advances in understanding and effective management of epilepsy, it remains under a shadow of stigma, mostly felt stigma rather than enacted. Even the term "seizure" derives from the inference of devil infestation and so this notion still subliminally pervades modern practice. Epilepsy is different and special, and cannot be simply bracketed together with other chronic neurological conditions.

Epilepsy is a symptom not a disease: yet many people with epilepsy find themselves defined by their condition (and may even define themselves) as being "epileptic", in a way that would appear inappropriate for the symptoms of other conditions, e.g. dementia or pain. Epilepsy has a low public profile, there are almost no celebrities or people in the public eye disclosing their epilepsy, and so few positive role models for people with epilepsy to follow. There are many conditions that resemble epilepsy (most commonly syncope and psychogenic events) and even epilepsy itself comprises many conditions with many and varied aetiologies. The emerging genetic basis of some of the epilepsies tells us that epilepsy will eventually be recognised as many thousands of different conditions. Furthermore, epilepsy management traditionally falls to many different specialties, neurology, psychiatry, paediatrics, general practice, emergency units, and obstetrics. There is no specific test for epilepsy and diagnosis of seizures and the assessment of level of control of seizures depends crucially upon the history. The lack of a specific test means that non-epilepsy conditions are often erroneously treated as epilepsy. Furthermore, with no test available, just taking antiepileptic medication may be enough to imprint the label of epilepsy.

Co-morbidities are very common, especially behavioural changes in children and anxiety and depression in adults; the antiepileptic drugs are often blamed, though not always be at fault. It is crucial for patients that their clinicians should maintain an appreciation of the broader aspects of epilepsy and its effects on lifestyle, and to teach our trainees to think more broadly than counting seizures, adjusting medication and reinforcing driving restrictions.

Professor Phil Smith is Consultant Neurologist at the University Hospital of Wales in Cardiff and previously was Consultant Neurologist in Treliske Hospital in Cornwall. In addition to a busy clinical role, mainly in epilepsy, he is undergraduate Sub-Dean for Assessments for Cardiff Medical School and co-editor of the journal Practical Neurology. He was President of the UK Chapter of the International League Against Epilepsy (2008–11) and co-organised the 2012 European Epilepsy Congress in London. He is President-Elect of the Association of British Neurologists.

Epilepsy: the role of the epilepsy nurse



Ms Christine Bennett
Epilepsy Specialist Nurse, Hull and East Yorkshire Trust, UK

This presentation will give background to the role of the Epilepsy Nurse in the UK and how the role has evolved and changed over the last 20 years.

It will look at the evidence as to what individual nurses undertake as part of their role. There is a strong legal framework to which guides nurse practice in the UK, I will look at this in the context of the Epilepsy Nurse role with regard to nurse prescribing and autonomous practice.

There are challenges in taking Epilepsy Nursing forward in the UK in the next 10 years. Hopefully I can share some of the strengths and strategies that we have used in the UK to strengthen some of your services here in Malta

Christine Bennett (RGN, BSc Hons, RSCN, Independent Nurse Prescriber) has worked as a Children's Epilepsy Nurse for the last 14 years.

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- **GlaxoSmithKline (GSK Malta)**
- **The Alfred Mizzi Foundation**
- **Novartis Malta**
- **Consolidated Biscuits**
- **Dolmen Hotel Resort**



EPILEPSY IS MORE THAN SEIZURES

Stigma in epilepsy causes



TO IMPROVE QUALITY OF LIFE WE NEED

