

Focussing On Change: Improvements in Lifestyle and Healthcare For Persons With Epilepsy

**9th European Conference on Epilepsy and Society,
New Dolmen Hotel
Malta
18th – 20th March 2004.**

Epilepsy is the **most common neurological brain disorder**, affecting over 1% of the population worldwide. Many advances have been made on its causes and several new medicines are now available which control seizures in over 80% of the population. Yet, in many countries, even in Europe, there is still social exclusion and discrimination, due to ignorance and stigma, which adversely affects the employment and education of these persons. These issues must be tackled if these persons are to be socially included and lead more productive lives.

It is estimated that there are more than 3000 people suffering from epilepsy in the Maltese islands, since the incidence worldwide is 1%. ***The Malta Caritas Epilepsy Association*** was set up in 1996 with the aim of helping Maltese persons with epilepsy and their families enjoy an improved quality of life. It aims to promote education and local awareness about epilepsy, especially because of the stigma suffered by people with this condition in society particularly in employment. Our campaign is aimed at improving health care services, treatment and social acceptance of epilepsy, as a serious yet treatable neurological disorder. The Caritas Malta Epilepsy Association now lists 215 local members, of which 166 have epilepsy. In 2001, it was accepted as an affiliated member of the International Bureau against Epilepsy (IBE).

This year, Malta was chosen as the venue, and Caritas Malta Epilepsy Association acted as host, for the 9th Epilepsy and Society Congress, '*Focussing on Change*' organised by the European Committee of the International Bureau of Epilepsy. The principle aim of this congress was to provide an educational, interactive, and discussion forum for people with epilepsy and their families, at which every day issues related to epilepsy, can be explored. Three hundred persons from all over Europe attended this conference of which 100 were Maltese persons with epilepsy and their families. The opening ceremony of the conference was kindly hosted by HE Dr George Hyzler (Acting President of the Republic), in the absence of Prof Guido DeMarco who was abroad, at the Grandmaster's Palace in Valletta. Prime Minister Dr Lawrence Gonzi, Dr Louis Deguara, Minister for Health, Hon Helen Damato, Hon Michael Farrugia, Dr Ray Busuttil DG Health and Prof R. Ellul-Micallef Rector University of Malta also attended the event. The participants were addressed by Mons Dun Victor Grech, Director Caritas Malta, Mr Mario Dimech, President, Caritas Malta Epilepsy Association, Mr Phil Lee, President International Bureau for Epilepsy and Ms Hilary Mounfield, Chair European Committee of International Bureau for Epilepsy.



The aims of the 9th Conference on Epilepsy and Society were to directly enhance the quality of life, educational and employment potential and the independence of persons with epilepsy in Europe, taking account of their expectations and of the greater contributions they could make to society, in terms of persona and social well-being as well as employment (rather than the usual health care and medical treatments). The first day was related to *living with epilepsy – personal experience of change* with emphasis on a parent's experience, teenagers, women and men with epilepsy, employment, education, complementary therapies and SUDEP. The workshops were related to *focussing on change: what are my choices?* On the second day the discussion focussed on *how change can be brought about - delivering improvements in healthcare*: nursing, GPs, surgery, new medicines and a session on the EUCARE action pack.

During this conference, Maltese persons with epilepsy had the opportunity to express and share opinions, experiences and attitudes related to their condition thus assisting them in overcoming their isolated upbringing due to overprotection and social stigma. This experience also helped them to develop their potential, which are mandatory steps if their social integration is to succeed. Through the interactive workshops the hidden potential of these people emerged and the workshop facilitators assisted them in understanding, how, despite their differing cultural and national backgrounds, they have common needs and potential, thus improving their chances of leading a more fulfilling life.

The conference would not have been held without the support of local sponsors whose sponsorship helped to subsidize Maltese participation. These included HE Prof Guido de Marco, President Emeritus of Malta, Community Chest fund, Caritas Malta, University of Malta, HSBC Malta, MFOPD, Vodafone Foundation Malta, Merz Malta (Clinipharma Ltd), Janssen Cilag Malta (AM Mangion Ltd), Sanofi-Synthelabo Malta (AM Mangion Ltd), UCB Malta (Pharmasud), Arrowsmith, Central Bank of Malta, Central Cigarette Company, Mizzi Holdings, Frank Salt, Galepharma, JPM Holdings, KNPD, Metco, Mira Holdings, Mirage Holdings, P Formosa, Pharmacos Ltd, SMS, and Wembley Ice Cream.

Photos enclosed

1. Dr Lawrence Gonzi, Dr George Hyzler, Prof R Ellul-Micallef
2. Dr George Hyzler, Dr Janet Mifsud, Mr Mario Dimech, Mr Phil Lee
3. Conference participants