



Caritas Malta
Epilepsy Association

Malta, L-Epilessija u t-Tfal - Flimkien Naslu

New Dolmen Hotel, Malta
22nd February 2003

organised by Caritas Malta Epilepsy Association



L'Università ta' Malta



International Bureau
of Epilepsy

Welcome - Merhba

Many advances have been made in the last few years on the causation, characteristics and medical treatment of epilepsy in children. This is allowing children with this disorder to be functioning and integrated members of the community. Yet, social and educational exclusion still exists due to stigma and discrimination. As a result, this year, the Caritas Malta Epilepsy Association has decided to focus its national conference on various aspects of childhood epilepsy: educational and interdisciplinary aspects, medical and psychological perspectives, and lobbying of policy makers.

This Conference is our contribution to activities being organised by the Malta National Commission for Persons with a Disability (KNPD) for the *European Year for Persons with Disabilities 2003*. It will consist of a number of talks by guest foreign and local speakers, as well as interactive workshops. It will also form part of the ongoing WHO/ILAE/IBE global campaign (called *Epilepsy Out Of The Shadows*) and EUCARE (European White Paper on Epilepsy) both of which aim to increase social awareness and education on epilepsy.

May we take this opportunity to thank all our collaborators and sponsors in particular, the University of Malta, UNESCO Maltese National Commission, National Commission for Persons with Disability, Caritas Malta, Air Malta, Maltacom, British Council, EUCARE, Vivian Healthcare, UCB, Janseen Cilag, ProHealth and Pharmacia, without whom this conference would not have been possible.

The Organising Committee

Connie Baker, Godwin Cachia, Anna Debattista, Mario Dimech, Janet Mifsud, Frank Portelli, Louis Vella, and Sharon Agius



Programme

0845-0915	Registration and welcome coffee.
0915-0920	Welcome speech. Dr. Janet Mifsud, Adviser to Caritas Malta Epilepsy Association; Secretary, Epilepsy Society of Malta
0920-0930	Opening Address H.E. Prof. Guido de Marco. President of Malta.
0930-0935	Opening Speech . Mons. Dun Victor Grech, Director, Caritas Malta
0935-1000	Keynote Address. From Government to Global Campaign. Mr. John Bowis M.E.P.
1000-1010	Education, children and epilepsy. The Hon. Dr. Louis Galea. Minister of Education.
1010-1020	The Educational needs of students with epilepsy. The Hon. Mr. Evarist Bartolo. M.P.
1020-1100	Coffee Break
1100-1115	A Personal Experience. Mr. Mario Dimech. Chairperson, Caritas Malta Epilepsy Association
1115-1135	The impact of childhood epilepsy on learning : highlighting the medical perspective. Dr. Doriette Soler, Paediatrician
1135-1205	Inclusive education for children with epilepsy Dr. Paul Bartolo, Psychologist
1205-1225	Epilepsy in children: interdisciplinary aspects. Dr. John Chaplin, Lund University, Sweden
1225-1400	Lunch Break
1400-1530	Parallel Workshops A. Lobbying for children with epilepsy Mr. John Bowis, Dr Janet Mifsud B. Medical considerations for children with epilepsy Dr Doriette Soler, Mr Mario Dimech C. Psychological aspects in children with epilepsy. Dr John Chaplin, Dr Paul Bartolo
1530-1600	Reports from workshops
1600	Conclusions : The way forward. Mr. Alfred Bezzina KNPD



Mr John Bowis MEP

From Government to Global Campaign

John Bowis, MEP and former British MP and Health Minister, will recount his personal journey learning about and then doing something about epilepsy. He will record his experience of epilepsy and the stigma attached to it; he will go on to describe how in Government he was able to learn more and do more to put it on the national health agenda; he will show how that proved timely when the WHO asked him to help the launch of the global campaign, 'Out of the Shadows'; then he will explain the campaign - with each WHO region planning to put epilepsy higher on all national agendas, with the coming together in Europe of all the key players to agree the Heidelberg Declaration and then on to the launch of the European White Paper. Finally he will highlight how this can be used locally, nationally and internationally.

John Bowis has been Member of the European Parliament for London since 1999. He is Conservative Spokesman on the Environment, Public Health and Consumer Protection. He is also a member of the Development Committee and the Joint Parliamentary Assembly with the ACP (Africa, Caribbean & Pacific). He is Vice President of the Delegation for Central Asia. He was Member of Parliament for Battersea from 1987 to 1997. From 1993-6 he was Health Minister and 1996-7 Transport Minister. From 1997, he was International Policy Adviser to the World Health Organisation and has travelled extensively to speak on health issues. He is a Trustee of the National Aids Trust, the Epilepsy Research Foundation, a Board Member of the European Men's Health Forum, the Institute of Psychiatry, SANE and the International Institute for Special Needs Offenders; and Vice Patron of the Fund for Epilepsy, Action for Epilepsy, Parkinson's Disease Society. He is member of the working committee for the White Paper on Epilepsy set up by EUCARE, the aim of which is to develop an informed debate and lobbying concerning issues that surround epilepsy.

Dr Louis Galea MP
Education Epilepsy and Children



Dr Galea was appointed Minister for Education and Culture in 1998, responsible for Education, Science and Technology Policy, Libraries and Archives, Heritage, the Arts, Culture, Theatres, Public Broadcasting, Youth and Sport. Dr. Galea was first elected to the House of Representatives in 1976.



Mr Evarist Bartolo MP
Malta, l-Epilessija u t-Tfal

L-akbar xkiel hija l-injoranza taghna. Mill-injoranza jigu l-pregudizzji kontra persuni bl-epilessija. Mill-injoranza tigi n-nuqqas ta' hila ta' kif noholqu ambjent li jghin fl-izvilupp tat-tfal. Genituri, kapijiet, għalliema, tfal, ufficjali edukattivi, dawk li jfasslu l-politika edukattiva jridu jkunu nfurmati sew u b'mod aggornat dwar l-epilessija. Irridu nifthu l-iskejjel u l-klassijiet għat-tfal kollha, naccettaw u niccelebraw id-diversita` tagħhom. Nibnu strutturi ta' appogg madwar l-iskejjel fejn nahdmu lkoll flimkien: edukaturi, nies mill-qasam mediku, mill-harsien socjali u għaqdiet non-governattivi u genituri għall-gid tat-tfal kollha tagħna. Skejjel li jinkludu lil kulhadd huma skejjel għall-gid tat-tfal kollha.

Mr Bartolo is the opposition spokesman for Education and National Culture. He lectures in communications at the University of Malta and in these last few years has also worked in the communication media of the MLP. He has contested three general elections and was Minister of Education between 1996-1998.



Mario Dimech
Esperjenza Personali

L-epilessija hi dizabilita li ilha teffettwa lill-persuna humana għall-eluf ta'snin. Hi dizabilita li tigri fi zmien li iz-zghazgh jkunu għadhom qed jistudjaw u jizviluppaw it-talenti tagħhom. It-tfal tal-lum huma l-generazzjoni ta' għada u għalhekk għandhom dritt għal edukazzjoni tajba u shiha, u jitthallew jizviluppaw it-talenti tagħhom. Mill-esperjenza personali tiegħi, Mario ha juri kif it-tfal għandhom jigu mghallma, kemm jista jkun mic-cokon, x'inhil-epilessiji speċjalment jekk fil-klassi jkollhom lil xi hadd li għandu din il-kundizzjoni.

Din is-sena hi "s-Sena Ewropeja tad-Dizabilita". Qed isir hafna xogħol, minn diversi għaqdiet, biex titnehha l-istigma li hawn fuq id-dizabilita. Hawnhekk ta' min isemmi l-avvanz li sar bill-ligi lokali "Oppurtunitajiet Indaqgħall-Persuni b'Dizabilita" li giet introdotta biex tigi kkontrollata d-diskriminazzjoni u tnaqqas l-istigma. Din il-ligi hi ta' għajjnuna kbira f'dik li hi diskriminazzjoni fuq persuni b'dizabilita speċjalment fil-qasam tax-xogħol, izda anki fl-iskejjel.

Mario has had epilepsy since he was a child. He finished secondary school education and he is employed as a clerical officer in a private enterpriser. He is married and has two children. He joined the Malta Caritas 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 experience with epilepsy and has represented the Association abroad in international conferences in Greece and Madrid.

Dr Doriette Soler

The impact of childhood epilepsy on learning: the medical perspective



Most children with epilepsy function quite satisfactory with proper anticonvulsant medication. However, as a group they tend to run a greater risk for developing learning problems. A local prevalence study has shown that while 82 % of children with epilepsy were attending mainstream schools, 53 % of these were reviewed by educational psychological services because of learning difficulties. In addition 18 % of the local childhood population with epilepsy attend special schools. The relationship between learning ability and epilepsy is a complex one. Factors such as any underlying brain lesions, epilepsy characteristics, attention disorders, subclinical epileptic activity, drug side effects, cognitive functioning and secondary psychosocial problems can alter the child's learning potential. Studies have reported a range of learning difficulties in children with epilepsy. These include difficulties in learning to read and write, alterations in memory processing, speed of information processing and change in sustained and focused attention. For educators these findings imply that in order to provide the appropriate remediation one must have proper understanding and recognition of the various factors that can potentially contribute to the child's classroom difficulties. It is only with the appropriate interventions and a positive approach to this problem that one will overcome the risk of pursuing a downhill course of frustration, failure and diminishing self-esteem for all concerned.

Dr. Doriette Soler graduated MD from the University of Malta in 1985; obtained Membership from the Royal College of Physicians, London in 1989 and Master's in Public Health in 2000. She is a member of the Maltese Paediatric Association, Malta Epilepsy Society, Association for Research in Infant and Child Development, British Neurology Association and European Epilepsy academy, EUREPA. Following her specialization in Paediatrics, she furthered her studies in paediatric neurology overseas. She has published widely on various aspects of child health with a specific interest in neurological conditions in childhood. She presently co-ordinates the School Health Service and runs a paediatric neurology clinic within the paediatric department. She is also a lecturer in the Department of Clinical Pharmacology at the University of Malta.



Dr Paul Bartolo

Inclusive education for children with Epilepsy

Inclusive education aims at removing the barriers to learning and participation for all children. This applies particularly to children and young people with epilepsy: while their difficulties arise within their brain, it is recognised that a major factor in the impact epilepsy can have upon a young person is the reaction of others, be it family, peers, teachers or other professionals. This paper sets out the right for inclusion of persons with epilepsy in regular education. It highlights the importance of the contribution all carers as well as professionals can make towards understanding the student's needs, and the relevance of appropriate knowledge about different types of epilepsy and their impact on the student's learning in the context of other different individual characteristics that affect their learning and participation. It calls for effective communication among all carers, educators and other professionals to deal with the anxieties of parents and educators, to counter the tendency for over reaction and overprotection and to focus on how to respond effectively to the child's holistic potential and individual educational and development needs.

Dr Paul A. Bartolo M.A., M.Ed.(Tor.), M.Sc.(Manc.), Ph.D.(Lond.) is a lecturer in the Department of Psychology, where he coordinates the M.Ed programme in Inclusion and Individual Educational Needs and the PGCE, and educational psychology and special needs input for the B.Ed course. He is the psychologist for the Eden Foundation STEP programme for children with autism and co-ordinator of the National Curriculum Focus Group on Inclusive Education. He has published several articles on disability and inclusion.

Dr John Chaplin

Epilepsy in Children: Interdisciplinary Aspects



Research conducted over the past two years by our centre demonstrates the quality of life issues facing young people as they grow up with epilepsy. Issues facing children with epilepsy change as they get older and understand more about the consequences of having epilepsy. The younger child is more family centred and issues related to acceptance and understanding within the family are paramount whereas as the child grows older more social and school related issues begin to be important. This presentation will examine these issues which are often of an interdisciplinary nature. Where help or advice is required a co-operation between professional and lay organisations may be the best approach. As an example of this approach we will look at the work of the IBE Employment commission on the issues facing young people with epilepsy in Europe today and findings from our survey on transition from school to work.

Dr John Chaplin is a chartered health and occupational psychologist in the UK and Sweden. He has extensive research background in quality of life issues particularly as related to people with epilepsy. He has published widely on employment problems for people with epilepsy and has conducted extensive research in several major companies in the UK. He has been the Chair of the Employment Commission of the International Bureau for Epilepsy since 1996 and is responsible for the founding of the International Employers' Forum on Epilepsy. He is currently a project leader on EU FP5 project concerning the measurement of quality of life in children with chronic diseases. Dr Chaplin also works closely with the medical community and is the Chair of a working group studying the WHO Classification of Impairment of Handicap as related to epilepsy. He is also the leader of a European youth organisation dedicated to skill development, equality and cultural diversity. The Epilepsy and Youth in Europe (EYiE) project was started in 1997 and now includes 26 countries, with regular courses for young people to learn about new technology and develop communication skills. In 2001 he received the award of Ambassador for Epilepsy in recognition of this contribution to international activities advancing the cause of epilepsy.



Dr Janet Mifsud

Dr Janet Mifsud obtained her PhD from Queen's University of Belfast, N. Ireland. Her doctoral research focused on properties of chiral antiepileptic drugs used in absence seizures and has published extensively in the area of the therapeutic management of epilepsy. She has helped to found both the League and Bureau chapters for Malta in 1996. In this respect she has helped both associations to lobby with several health policy makers. She presently co-ordinates the curriculum for undergraduate curriculum in pharmacology for students at the University of Malta and supervises students undertaking masters and doctoral projects in neuropharmacology and pharmacokinetics. Her present research considers various aspects of the incidence and treatment of epilepsy in Malta in specific populations and the newer antiepileptic drugs, and it has now expanded to the genetic implications, especially within a small population setting such as Malta. Dr Janet Mifsud was recently appointed secretary of the European Epilepsy Academy.

Mr Alfred Bezzina

Some notes

Parallel Workshops

A. Lobbying for children with epilepsy

Mr. John Bowis, Dr Janet Mifsud

B. Medical considerations for children with epilepsy

Dr Doriette Soler, Mr Mario Dimech

C. Psychological aspects in children with epilepsy.

Dr John Chaplin, Dr Paul Bartolo

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Caritas Malta Epilepsy Association

Epilepsy is the most common chronic neurological condition worldwide. It is estimated that there are more than 3000 people suffering from epilepsy in the Maltese islands, since the incidence worldwide is 1%. The Caritas Malta Epilepsy Association was set up by voluntary workers in 1996 and now lists 215 local members, of which 166 have epilepsy. In 2001, they were accepted as members of the International Bureau against Epilepsy (IBE).

The Caritas Malta Epilepsy Association is for persons with Epilepsy and their families. 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. Our sister organization, the Epilepsy Society of Malta which is for health care professionals working in the field, is a member of the International League Against Epilepsy (ILAE).

It organises monthly meeting in order for members to share their problems and experiences in full confidentiality, and it also liaises with policy makers and health officials on the various needs and problems met by people with epilepsy. It has also published several information leaflets in Maltese. It may be contacted at Caritas Malta 5, Lion Street Floriana on 21233933; Mr Godwin Cachia or 21370381 godcac@global.net.mt or Dr Janet Mifsud 23402845 janet.mifsud@um.edu.mt

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