Bringing Epilepsy out of the Shadows - Amsterdam

Bringing Epilepsy out of the Shadows was the title of a Press Conference held by the ILAE / IBE /WHO Global Campaign against Epilepsy. The objective of the campaign is to bring epilepsy "Out of the Shadows" by improving the diagnosis, treatment, prevention and social acceptability of the disorder worldwide.

The press conference, which was held on Wednesday the 13th of February 2002 in the Van Gogh Museum, Amsterdam in Holland, while explaining the work of the campaign, also provide the opportunity to show how people can overcome the difficulties presented by the condition and so can achieve success in their chosen field. The press conference, therefore, included a panel of five young people all of whom had epilepsy and had overcome the difficulties this can present.

Carina Muhl diagnosed at the age of 17 lives in the Netherlands and studied to become a primary school teacher. She currently works as an education assistant at a museum in Rotterdam.

Felicity September from South Africa, when diagnosed she was introduced to SANEL (South African Epilepsy League) where she now works.

Carol D'Souza, diagnosed at the age of 11 is now a psychologist working in India, she has also written a book entitled "Conquering Epilepsy".

Andreas Habberstad, from Norway, worked with two of Norway’s largest insurance companies and is now employed by the Norwegian Epilepsy Association as a consultant.

Gary Mc Dermott represented Ireland at the press conference. Gary, 24, has worked with his brother in a wood finishing company. Having completed Brainwave's Pre-employment Training Programme "Training For Success" Gary is now attending a welding course run by FAS.

The press conference was held at Van Gogh Museum, Amsterdam in Holland The venue was chosen because Van Gogh had epilepsy. His seizures began, or at least were first recognised at the age of 35. They were psychomotor seizures, often followed by confusional states or a kind of absence, and were often preceded by a terrifying aura. In 1889 Van Gogh was admitted to a mental hospital, the doctor told Van Gogh's brother that he thought it advisable to keep him under observation, that his chances of recovery were quite slim, as he believed the attacks were caused by a form of epilepsy. He added, "If this is the case we must expect the worst".

Had Van Gogh only lived today, how different the situation could have been as the five speakers on the panel approved.

Irish Times Education Show Ireland 2002

The "Education Show Ireland" Exhibition, in association with The Irish Times, is the country's major annual showcase for the educational resources area.
There were 179 exhibition stands in the RDS main hall providing schools and teachers with information on the latest teaching aids, computer technology for the classroom and school resources from protective rubber paving to adjustable furniture, storage and display systems.

Brainwave was delighted to be part of this prestigious event and was represented as part of the SPECTRUM group. SPECTRUM is an umbrella organisation, which includes the Dyslexia Association of Ireland, Asperger Syndrome Association of Ireland (ASPIRE), H.A.D.D. (Hyper Activity Deficit Disorder), the Dyslexia Help Line (Limerick), and the Association of Gifted Children all of whom had representation on the SPECTRUM exhibition stand.

SPECTRUM's aims are:

1. To raise awareness of hidden disabilities and/or special educational needs
2. To lobby for services for young people with hidden disabilities and/or special educational needs
3. To provide general information on hidden disabilities and special educational needs
4. To encourage research into hidden disabilities and special educational needs
5. To form a united front of organisations within the sector to offer mutual support and to increase total strength

The exhibition also includes a Seminar/Workshop Programme consisting of presentations, which run throughout the three days. SPECTRUM dominated the final day - Saturday April 13th - and provided presentations throughout the day. Paul Sharkey, Brainwave's Training & Communications Manager gave a presentation on Epilepsy Awareness.

During the course of the exhibition Brainwave distributed over 300 handouts - "A Teachers Guide to Epilepsy". It is hoped that those who received them will now have a better understanding of the condition and will therefore provide a better service for any children with epilepsy they might have in their classroom.

Brainwave will continue its relationship with SPECTRUM and readers will be kept informed of future events and developments.

**National Sentinel Audit**

The National Sentinel Audit investigating the instance of SUDEP (Sudden Unexplained Death from Epilepsy) was launched in Government Buildings, Westminster, London as part of Epilepsy Week. The Audit was commissioned by Epilepsy Bereaved.
Brainwave the Irish Epilepsy Association's Call for Action

On Monday May 20th, the findings of the national Sentinel Audit of Epilepsy Deaths (UK) will be formally announced at Westminster. Epilepsy Bereaved conducted this audit over the course of the past two years under the auspices of the Joint Epilepsy Council (JEC) of which Brainwave is a member. The work was financed by the British Department of Health.

The JEC and all its members are dedicating National Epilepsy Week 2002 May 19th. - 25th. to the theme of SUDEP (sudden unexpected death in epilepsy). It is Brainwave's hope that the publicity from the findings will stimulate research into discovering the cause of SUDEP so that many lives can be saved. We also believe that by making many more people aware of the situation that some risks can be minimised for those who may be vulnerable.

Each year 60 - 70 people with epilepsy die in the Republic of Ireland from epilepsy deaths, while 28 - 30 die in Northern Ireland. It is also known that people having seizures are at a much higher risk from SUDEP. For this reason it is essential that everyone involved in epilepsy is working towards a no seizures, no side effects situation at all times. It is therefore imperative that all those involved in the diagnosis and treatment of people with epilepsy are aware of the implications of SUDEP. Being aware it is hoped that the lifestyle implications of living with epilepsy and the minimising of risk factors will be seen as a priority in the treatment of epilepsy and that Brainwave, the Irish Epilepsy Association should be a natural referral point for all who have been diagnosed with epilepsy.

Brainwave is therefore holding a press briefing - "A Call for Action" - in the Shelbourne Hotel on Tuesday May 21st at 4.00pm. The evening will consist of three brief presentations:
The National Sentinel Audit - Mike Glynn CEO Brainwave, the Irish Epilepsy Association.
SUDEP - Dr. Yvonne Langan
Brainwave's National Services - Ms. Ava Battles, Director of Services, Brainwave, the Irish Epilepsy Association

This press briefing will highlight the implications of the National Sentinel Audit for people with epilepsy living in Ireland and will mark a formal call on the Minister of Health and Children to enter into consultation with Brainwave, the Irish Epilepsy Association, to ensure that the findings of the audit are acted upon to the benefit of all those living with epilepsy their family and carers.

Community Epilepsy Specialist Nurse at Beaumont

At long last the good news that Sinead Murphy has become the first ever Specialist Nurse to work in the community with people with epilepsy in Ireland.
Sinead will report to Dr. Norman Delanty, Consultant Neurologist and Epileptologist at Beaumont Hospital. Sinead can be contacted through Brainwave's Head Office Helpline Tel: 01-4557413 on Wednesday's from 9.30am - 1.00pm.
Brainwave is delighted to announce that a new improved version of www.epilepsy.ie will be online by the end of July 2002.

The new site while still containing all the information will be more streamlined, offering a word search facility, which should enable people to locate the information they require much faster.

**Employment and Epilepsy**

Brainwave is pleased to announce the addition of its Employers Information Pack to the ever-growing list of publications. The pack consists of 5 information leaflets covering different aspects of epilepsy & employment related issues.

Brainwave would especially like to thank ELECTRICAID for their contribution to the production of this important publication. ELECTRICAID, the ESB Social Justice Fund is funded by contributions from ESB and its staff. We also thank Mr. Brian Geraghty (Broomfield Management Services) for his contribution.

Brainwave's Epilepsy and Employment - a Guide to Epilepsy in the Workplace will be formally launched later in the year.

**National Conference 2002**

"Epilepsy No Fear"

The day commenced with a presentation from the Community Epilepsy Specialist Nurse (CESN), Sinead Murphy entitled "The Role of the Community Epilepsy Nurse". Sinead explained the Role of the CESN and gave examples of the issues she would discuss with people, she explored the benefits of the service and her future plans.

Following Sinead's presentation, Dr. Norman Delanty, Consultant Neurologist in Beaumont Hospital introduced the Video "Leaving the Shadows". This video on epilepsy was produced by Jim Sherwin with Consultant Neurologist Dr. Norman Delanty and his team in Beaumont Hospital. This video is available from all Brainwave offices Nationwide.

Paul Sharkey, the Communication and Training Manager for Brainwave gave an update of Brainwave's services. He spoke about the employers Information Pack, the new Brainwave website, the Epilepsy Awareness Distance Learning Pack, Membership benefits and the Driving Group.

The key speaker at the Conference was Dr. Pierre Genton.
Dr. Genton is from Marseilles, France. He is one of Europe's most distinguished Neurologists in the field of epilepsy. He was one of the leading speakers at the recent International Bureau for Epilepsy's European "Epilepsy and Society" conference in Lloret de Mar in Spain in June of this year.

Pierre Genton is one of the editors of "Genetics of Focal Epilepsy", published in 1999. He has been involved with the famous Gamma Knife Treatment surgery technique developed at the Timone Hospital in Marseilles and has written and presented extensively on this and many other subjects. Dr Genton studied and lived in Dublin as a young medic.

Dr. Genton's presentation was entitled "Epilepsy: No Fear? He focused on epilepsy and fear(s), looking at both rational and irrational fears. He explored some of the irrational fears held by many people in society, including

- Epilepsy is madness
- TV and sex provoke seizures
- Seizures will make me (my child) mad or mentally deficient
- Anticonvulsants will make me (my child) sick
- Epilepsy is for Life
- Epilepsy prevents people from leading normal lives, from driving
- No coffee, tea, tobacco, booze.
- No pregnancy.

He also explored the rational fears, including

- The possibility of injuries during epileptic attacks
- Sudden death in people with epilepsy
- Poor education of patients.

He discussed the need to maintain a rational approach to fears and stressed how important it is to have adequate diagnosis and treatment. He also emphasised the importance of the individuals "self management" of their epilepsy.

Successful self-management involves developing a full understanding of ones epilepsy, the seizure type, the supports needed in the event of having a seizure, the potential triggers, lifestyle/behaviour implications e.g. effects of alcohol, the interaction of AEDs with other medication and stress management. Understanding ones epilepsy is crucial to the management of the condition and as Dr. Genton expressed it is very important in maintaining a rational view of the fears people face in living with epilepsy. He also stressed the need for more and more people to develop this understanding to ensure positive interaction/relationships and relevant support. He emphasised the role of the voluntary organisations, especially Brainwave, the Irish Epilepsy Association, in providing information and support to people with epilepsy their families and friends, to ensure successful self-management.

Following Dr. Genton's speech there was time for a questions and answers section. There was also the opportunity for members of the audience to record their questions on a sheet and these
questions will be answered (by letter) by the National Information Officer.

The final activity of the day was the Members only Workshops. Brainwave Community Resource Workers facilitated the workshops. Running in parallel to the Workshops was a showing of the Epilepsy and Parenting Video.

The day finished with presentations from each Workshop.

Another very successful component to the day was the Conference Stands. There were stands from Training for Success, The EyiE Project, the Citizens Information Centre, Call Care, Glaxo-Smith Klime and a Brainwave Information Stand.

We would like to thank the organising Committee of the National Conference for all their hard work leading up to the Conference and on the day.

**Leaving The Shadows**

Leaving The Shadows is a new video about epilepsy produced by Jim Sherwin with the assistance of Dr. Norman Delanty, Consultant Neurologist, and his team in Beaumont Hospital. Despite its short running time of only 20 minutes the video provides a very comprehensive study of epilepsy covering a wide range of topics. Brainwave welcomes this new video and would like to congratulate all involved in its production.

Leaving The Shadows is available from Brainwave Head Office. Price 15.00 euro (10.00 euro to Brainwave Members) plus post & packaging.

**MILANO Fashion Show**

On October 8th Emma Glover of Milano’s Restaurant, Clarion Quay, Dublin, organised a fabulous evening of fun and glamour.

Fashions modelled on the evening were from Rococo/Chica in The Westbury Mall, The Design Centre in the Powerscourt Townhouse Centre, Jackpot of Clarendon Street, Carl Scarpa of Grafton Street, Tulle of South Great Georges Street, Karen Millen of Clerys, Autograph at Marks & Spencer, Glynis Robins in Dalkey and Wits End of Ranelagh.

The Fashion Show was a great success and the proceeds were donated to Brainwave. Emma and some of her friends also ran a half marathon in aid of Brainwave.

Well done, Emma and Milano and many thanks.

**Rose Week**

Our annual fundraising event Rose Week took place this year from the 10th to the 16th of October.

We are so grateful for all who helped us in any way. Your support makes such a difference.
The new roses brought a most welcome response. We are looking at ways to make this event even more successful and welcome any suggestions.

If you would like to get involved or if you have any ideas you feel might help this or any campaign, please let us know.

It is with your support that Brainwave will continue to grow.

**Brainwave Annual General Meeting**

Brainwave's Annual General Meeting for year ending 2001 was held on Saturday November 9th. Following a suggestion from one of our members, Brainwave held the AGM outside Dublin.

The venue was The Tipperary Institute, Thurles.

Following the meeting there was a screening of the new epilepsy video leaving The Shadows after which, Dr. Kirker, Epileptologist, facilitated a very interesting question & answer session.

Congratulations and thanks to all who made the event so successful.

**Brainwave’s Midland Office Launched**

Mike Glynn Brainwave CEO, Ava Battles Brainwave Director of Services, Brian Cowen Minister of Foreign Affairs, Margaret Bassett Brainwave CRO and Pat Gaugan CEO Midland Health Board at the launch of Brainwave's new regional office. Brainwave's new office was officially launched by Mr. Brian Cowen Minister of Foreign Affairs, Mr. Pat Gaugan CEO Midland Health Board and Mr. Mike Glynn CEO Brainwave on Monday 11th November.

Brainwave's new Community Resource Officer, Margaret Bassett is looking forward to providing a service for people with epilepsy in the Midland Health Board Region.

Ava Battles Brainwave Director of Services, Pat Gaugan CEO Midland Health Board, Breda-Crehan Roche Director of Services for People With Disabilities Midland Health Board at the launch of the new Brainwave Office