Hayes’ Hotel, Thurles was the centre of activity for the Mid-West Region on the 5th February last. Dr Sean Murphy, Consultant Neurologist, gave a very enlightening and informative talk to a packed house of 150 people. Anna Kelly, Community Resource Officer, reported a very positive feedback in the weeks following the meeting. Comments to the effect of “specific responses to questions”, “decisive and common sense answers”, “real explanations on medications”, and “ability to relate as an equal” were phrases used to compliment Dr Murphy’s talk. The night was sponsored by Michael Smith, Minister for Defence, in response to a need that emerged at an informal meeting which he had attended in November. At the end of the evening Mr Smith reported that Dr Murphy had given of his services without charge.

The core voluntary group is in the process of organising the next evening in Cashel – to be held in May.
The Global Campaign against Epilepsy (GCE) was launched into its second phase by the Director General of the World Health Organisation, Doctor Bro Harlem Brundtland on Monday 12th February in Switzerland.

The campaign was originally launched in Dublin at the 22nd International Epilepsy Congress and with a press conference in Geneva in 1997. As in 1997, there was again an Irish element to this phase of the GCE launch. The Brainwave 'Doctor's Pack', which was one of the Irish chapter's contributions to the GCE in 2000, was included as part of the documentation for the Geneva ceremony.

The event was attended by representatives of IBE chapters from 24 countries around the World, almost half the membership of the Bureau. Also taking part were many representatives of the International League against Epilepsy (ILAE), delegates from other Neurological associations including Audrey Craven, on behalf of the European Neurological Associations.

Audrey is Chair of the Irish Migraine Association, which she founded and was recently elected Chairperson of the Irish Neurological Association, a group in which Brainwave is very heavily involved.

John Bowis, a UK MEP and former British health minister also took part.

John was a speaker at the GCE launch in Dublin and he is due to present the European White Paper on epilepsy to the European Parliament on the 22nd March 2001.

In addition to Doctor Brundtland, many of WHO's most senior figures were in attendance including Dr. David Yach, an Executive Director of WHO, Dr. B. Saraceno another WHO director who chaired the morning session and Dr. Leonid Prilipko who has been coordinating the GCE within the WHO and has been in constant communication with both IBE and ILAE.

Doctor Brundtland in her presentation referred to the continuing scandal of at least 75% of people with epilepsy still not receiving any treatment for their epilepsy. This, she said, represented at least 30 million people and possibly as many as 38 million around the World. Dr. Brundtland and other WHO speakers made the point that the GCE was being campaigned for within the WHO as part of its 'Mental Health and Brain Disorders' division.

Dr. Yach made the point that stigma was at all times being raised as one of the key difficulties for people with epilepsy but sometimes these working in the epilepsy field seem to want to stigmatise mental health problems in their anxiety to distance epilepsy from them. In fact, he said there are huge areas of common ground amongst all conditions related to disorders of the brain.

John Bowis, Hanneke de Boer and Dr. Ted Reynolds, the founder of the Global Campaign, all spoke of the progress that the GCE was making. This has started to come together with four regional declarations being made in the year 2000. These follow on from the European Declaration on Epilepsy in late 1998. Significantly, three of the declarations last year were in developing regions.

These were the African Declaration against Epilepsy on the 6th May, the Latin American Declaration on the 9th September and the Asian and Oceanic Declaration against Epilepsy on the 13th November. The North American declaration was made on the 1st December.

Ms. Carla D'Souza a young woman with epilepsy from India spoke about the situation in India for those with epilepsy including the draconian marriage laws which forbade people with epilepsy from marrying up to recently. She said that it was still possible for women who developed epilepsy to be divorced by their husbands on the basis of their condition.

Details of new GCE projects in China, Argentina, Senegal, and Zimbabwe were also announced at the launch. You can find out all the facts about these and other GCE initiatives and see the World Health Organisation's revised fact sheets on epilepsy at: http://www.who.int/mental_health/Topic_Epilepsy/Epilepsy1.htm
Colonel Jim Dowdall joined the Irish Epilepsy Association in its early days because of his child’s epilepsy. He has chaired the Association through some years of excellent growth but has also seen Brainwave through some difficult times. Jim is a retired Army officer and also continues to serve on the very important Finance sub committee.

Mrs. Tessa Dagge has been involved with Brainwave for well over 20 years. Tessa became involved in the Irish epilepsy movement when her son, who has epilepsy, was very young. She is Vice Chair of the Association and Chairs the key Finance sub-committee. Tessa and her husband Arthur have both worked for the Horseshow Ball for many years and she has also been involved with most of Brainwave’s major fundraising campaigns.

Professor Joe McMenamin has been Brainwave’s Treasurer for a number of years. Joe is Consultant Paediatric Neurologist at Our Lady’s Hospital for Sick Children in Crumlin. Dr. McMenamin has been very successful in increasing his Department at Crumlin and has been joined by Dr. David Webb in recent times and hopes to add another nurse to his staff in the near future. Joe is, of course, the author along with Mary O’Connor Bird of Brainwave’s highly successful video and book; ‘Epilepsy: A Parent’s Guide’. The book was reprinted in 1997 in time for the 22nd International Epilepsy Congress in Dublin.

Dr. John Kirker is Brainwave’s President and has been attached to Beaumont Hospital for many years. He is an Epileptologist and a Consultant Clinical Neurophysiologist and is internationally recognised as a leading authority on epilepsy and driving. Dr. Kirker is Chair of the International Bureau for Epilepsy’s ‘Driving License Commission’ and he has been very active in Brainwave’s own Driving and Epilepsy group. John Kirker was Chairperson of the 22nd International Epilepsy Congress in Dublin and was instrumental in ensuring that the conference was of the highest scientific quality.

Mrs. Eilish and Mr. Vincent McNally have both been involved with Brainwave since their daughter was diagnosed with epilepsy when she was very young. Both Eilish and Vincent have been keen fundraisers for the Association and have supported the organisation in all of its activities. They have a special interest in Brainwave’s training schemes and they attended the inaugural graduation of Training for Success in Sligo last year.

Major General Vincent Savino is a retired Army officer who has an interest in epilepsy through a family member. General Savino is Co-Chair of Brainwave’s Roseweek board that has responsibility for the annual campaign each October that is run jointly with the Irish Society for Autism. Vincent has also been active on the Horseshow Ball.

Mark Dowdall, who is in his thirties, was elected to Brainwave’s Executive Committee last year (1999) for the first time. However, he has been involved with the Association for several years on fundraising projects such as Roseweek and the Horseshow Ball. Mark was persuaded by the Executive Committee to take on the role of Secretary in succession to Mrs Mainin Lindsay. Since joining, Mark has also been co-opted to the Finance Committee and has been involved in fundraising initiatives and in Brainwave’s plans for a website. Mark works in the field of IT in the banking world and brings much needed business skills to the Association.

Mrs. Mainin Lindsay A car accident in 1966 caused serious brain damage and the development of epilepsy in one of Mrs. Lindsay’s daughters. So began her lifetime commitment to the cause of epilepsy and her lengthy involvement as Secretary. Mrs. Mainin Lindsay, has been involved with Brainwave since its very beginning and was until recently its Honorary Secretary. She became involved because two of her own children have epilepsy and helped to found the Irish Epilepsy Association in order to provide information and support to other parents and people with epilepsy. Mainin has been active in providing support and information herself to everybody in Wicklow from her home in Greystones. In addition, she has always involved herself in all of Brainwave’s fundraising campaigns.

Dr. Norman Delany graduated from University College Cork in 1988 and has recently returned to Ireland as Consultant Neurologist and Epileptologist at Beaumont Hospital and runs the Epilepsy Service there. Dr. Delany spent a number of years in the United States at Cornell Medical Centre in New York and more recently at the University of Pennsylvania. Norman was the keynote speaker at Brainwave’s recent National Conference and he was also instrumental in organising the recent GP’s day in Beaumont with Dr. Deirdre McMackin.

Ms. Audrey Muddiman has been active in Brainwave for several years and was elected to the Executive at the last AGM. Audrey has worked as a Journalist and has been a frequent contributor to Epilepsy News. Her most recent article was about her successful epilepsy surgery and her return to driving as a result. Audrey has also been the subject of many newspaper interviews concerning her attitude to being a person with epilepsy. She has also been very active in the Driving and Epilepsy area and has always lobbied her local and national politicians in the cause of epilepsy.

Ms. Margaret McCahill Despite only being elected to the Executive Committee at the last AGM, Margaret McCahill has been actively involved with Brainwave for several years. Working as a pharmacist, Margaret first contacted Brainwave after she lost her driving licence, which prompted her to join and become Chair of Brainwave’s Group on Driving and Epilepsy in 1998. The change in driving legislation at the end of last year is without a doubt, the result of persistent lobbying of politicians by the Driving and Epilepsy Group, who saw the need to bring Irish driving regulations in line with other EU countries. Margaret has also been a contributor to the Epilepsy News, Brainwave’s newsletter and has also been a speaker at a recent Brainwave support group meeting in the North East.
Ms. Claire Dowdall  Trained as a nurse, Claire Dowdall has both a personal and professional interest in epilepsy. While currently acting as team leader in a clinical research organisation, Claire also has experience working in areas such as Spinal Injuries, Cardiology, High Blood Pressure and Health Education. Her involvement with Brainwave dates back to 1989 and since joining, Claire has been actively involved in fundraising, awareness days, Horse Show Balls and the annual Brainwave conferences. More recently, Claire has been involved in the Irish Epilepsy Nurses group since its inception in 1998.

Senator Joe Doyle  Senator Doyle is probably Ireland’s best known person with epilepsy. He has been a wonderful advocate for people with epilepsy in the Dail, the Senate, in Dublin Corporation and Eastern Regional Health Boards. He was a key speaker at the launch of the Global Campaign against Epilepsy during the Dublin International Epilepsy Congress. During his years as Lord Mayor of Dublin, Senator Doyle hosted many functions for Brainwave at the Mansion House, presented “Planning my Future” graduates with their certificates and made official appearances at Brainwave’s National Epilepsy Awareness Day and the Horse Show Ball.

Doctor Bryan Sweeney  Dr. Sweeney is a native of Kildare. He qualified for his MB, BCh and BAO at University College Dublin in 1986. Dr. Sweeney did his internship/SHO at St. Vincent’s and Mater Hospitals in Dublin. After this, Dr. Sweeney trained in the field of Neurology at Cork University Hospitals and moved to England to join Middlesex Hospital and St. Mary’s Hospital. Dr. Sweeney then joined the National Hospital for Neurology and Neurosurgery, Queen’s Square, London. He moved back to Ireland and was appointed Consultant Neurologist at Cork University and Limerick Regional Hospitals in June 1996. In June 1999, Dr. Brian Sweeney was accepted as Fellow of the Royal College of Physicians.

Doctor David Webb  Dr. Webb is a Consultant Paediatric Neurologist at our Lady’s Hospital for Sick Children in Crumlin. Dr. Webb worked abroad for a number of years before returning to Ireland. He worked in Belfast for some time before moving back to work in Dublin. Dr. Webb has a special interest in setting up Medical Satellite clinics for Neurology and Epilepsy such as that at Tallaght Hospital.

Doctor Mary King  Dr. King is Senior Clinical Consultant Paediatric Neurologist at the National Children’s Hospital in Temple Street, Dublin. Dr. King has been a key supporter of Brainwave and in particular it’s projects such as the Doctor’s Pack, the launch of which she recently attended.

Doctor Bryan Lynch  Dr. Lynch is Consultant Paediatric Neurologist at the National Children’s Hospital, Temple Street. Dr. Lynch worked for a number of years in the United States before returning to take up his post at Temple Street. He was a keynote speaker at Brainwave’s National Epilepsy Awareness day in 1998 and had worked closely with epilepsy patient support groups while he was in America. Dr. Lynch was one of the speakers at the recent launch of the new epilepsy drug, Trilipix. Dr. Lynch also wrote a book called “a Guide to Diagnosis, Investigation and Treatment of Epilepsy”, aimed at professionals to mark the occasion.

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My name is John Sullivan. I am a disabled actor and filmmaker. I developed epilepsy as a result of a brain tumour while touring Germany with White Horse Theatre just over two years ago.

While recuperating, I heard about Lights, Disability, Action!, an EU Horizon funded TV and Film Production Course specifically for disabled people. During the course we made a number of short films including “Leading Us Not”. Inspired by my own career as a professional actor, and utilising my personal experiences with epilepsy, I was able to press my tongue against my own cheek and write a story about disability. This evolved into and LDA! Film produced by disabled people that illustrates cinematically our ability to laugh at ourselves. Through ironic humour, we can deconstruct some of the misconceptions about disability that able-bodied people harbour, and therefore make the issues more approachable.

To date, “Lead Us Not” has been screened at two international film festivals - Second London Disability Film Festival, UK and Superfest XX, International Media Festival on Disabilities, Berkeley, California. I have just returned from a month in the US, where I attended Superfest XX. I was also awarded a residential scholarship to the National Theatre Workshop of the Handicapped, Belfast, Maine.

Superfest began in 1970 as a small film showcase and has grown into an international media event. These films and videotapes have offered a forum for the examination of ideas, myths, fears and attitudes about people with disabilities. Superfest has also provided expression for the emerging culture of disability by exhibiting works by and/or about media makers and artists with disabilities. In 1982 Superfest became a primary project of the Corporation on Disabilities and Telecommunication (CDT), a non-profit organisation which works to improve the representation and participation of individuals with disabilities in all aspects of the media. For more information about CDT or Superfest, email: cdtinfo@aol.com

The National Theatre Workshop of the Handicapped (NTWH) founded in 1997 by Brother Rick Curry, S.J., is a training, production and advocacy organisation serving people with disabilities, who are often excluded from existing theatre programmes for a number of reasons. NTWH offers professional instruction in acting, oral interpretation, music, movement and dance, playwriting, theatre management and technical theatre, as well as courses in fine arts. NTWH challenges the practices of using able-bodied actors in disabled roles and its goal is to prepare artists with disabilities to qualify for and obtain work in the performing community. I had a fantastic time in America and am now in the process of setting up, Lights, Disability, Action! As a production company. For more info, contact (01) 8470160 or email lightsdia@eircom.net
Folic Acid for Women with Epilepsy

For some time it has been known that folic acid helps to prevent neural tube defects such as spina bifida. Folic acid is most effective when taken before pregnancy for at least 3 months and continued up to at least the twelfth week of pregnancy. There is now widespread agreement that all women of childbearing age should take folic acid daily if there is a possibility of becoming pregnant.

The risk of having a baby with a neural tube defect is greater for women with epilepsy who are on anti-epileptic medication. For this reason many clinicians advise that women with epilepsy on medication should take a higher dose of folic acid than that recommended for other women. This higher dose may be up to 5mgs per day.

Many doctors are now beginning to advise younger women and teenage girls to take folic acid daily even where there is not a current risk of pregnancy. Some doctors may even recommend that folic acid be continued after the twelfth week of pregnancy but this will need to be discussed with each individual woman during her pregnancy.

If you are of childbearing age:
- Discuss with your doctor whether folic acid should be taken and at what dosage. This may be relevant even if you are not sexually active.
- Be aware that some anti-epileptic drugs may reduce the effectiveness of some oral contraceptives. Discuss with your doctor whether your medication can have this effect and whether you might need a different kind of oral contraceptive.
- Don’t be tempted to reduce or stop your medication – if you have concerns talk to your doctor.

If you are pregnant:
- Don’t reduce or stop medication – the risk of seizures is a potential risk to the foetus.
- Discuss all medication concerns with your doctor.
- If you are not already on folic acid then talk to your doctor about starting it now.
- Ensure you have regular consultations and monitoring with all clinicians involved in your care, GP, Consultant Neurologist – if you attend one and your gynaecologist.

Health Check

The British Epilepsy Association has launched a new educational CD-ROM “Discovering Epilepsy” that aims to inform 9-16 year olds, their peers and families about epilepsy.

The CD-ROM, which costs STG 10 takes the form of an adventure computer game that encourages players to explore a number of rooms each room containing easy to understand information about epilepsy.

One in 130 people in the UK suffers from the condition and the new CD-ROM aims to dispel myths and misconceptions that still exist.

You can find out more about this new CD-ROM by visiting BEA’s website at www.epilepsy.org.uk where you can order a copy online.

Key-planning group within Brainwave

During the last two/three years Brainwave has established the key elements of a strategic plan. The process was detailed and started in 1998 with a management strengths, weaknesses, opportunities and threats analysis. Other steps, over time included Finance Executive/Committee discussions, Staff SWOT analysis, Members Strategic planning workshops.

A decision was made in late 1999 to involve the National Social Services Board now “Comhairle” in the process. Comhairle have a programme of support to the Voluntary and Community Sector called “The Mentoring Programme”. Comhairle has agreed to appoint Dr Sean Gannon as mentor to Brainwave. Dr. Sean Gannon is the director of the Careers Advice Office at Trinity College Dublin. Dr. Gannon has been a scientist and a Management Consultant.

Brainwave management has had a number of meetings with Dr Gannon and a key-planning group within Brainwave has been formed, this will include:

Mark Dowdall,
Finance Committee Member.

Mike Glynn CEO.

Anna Kelly,
Community Resource Officer for the Mid Western Health Board area

Margaret McCahill,
Executive Committee Member.

Marion Wilkinson,
Director of Services.
The Joint Epilepsy Council of the UK and Ireland has established three new working groups. Two groups report their activities in this edition of the newsletter they are the awareness and health groups. In the next edition of this newsletter a report will be given from education action group.

**JEC Awareness Action Group**
The JEC awareness action group (AAG) has had two meetings since it was formed, the last of which was held at Brainwave in Dublin at the end of October. The members of the group are Eileen Gascoigne (National Society for Epilepsy) Sharon Hudson (British Epilepsy Association) Jennifer Preston (Epilepsy Bereaved) Jane Sykes (Fund for Epilepsy) Sarah Hovington (Mersey Region Epilepsy Association) Peter Rogan (Parkhaven Trust) Alesia Raddice (Enlighteen, action for epilepsy, Edinburgh) and Mike Glynn of Brainwave who chairs the group.
The following mission statement of the Group was agreed:

**Promoting good understanding and accurate knowledge of epilepsy so that everyone is well informed about the condition and its impact on people living with epilepsy.**

It was recognised that awareness raising is a wide brief and that it would be necessary to target specific groups for maximum impact. One of the key target groups for immediate action was that of Employers. With this in mind the awareness action group (AAG) has included the following items in its action plan:
- The dates for National Epilepsy Week 2001 have been set for the week 20th to 26th May 2001 inclusive.
- The AAG has set the topic for National Epilepsy Week 2001 as Employment.
- The AAG will initiate an initiative aimed at dealing with Employers concerns with employing people with epilepsy.
- A JEC AAG website which will signpost the members of JEC who can provide information and support for employers in their areas, will be set up.
- JEC’s annual conference for 2001 will be organised by the AAG.

**Joint Epilepsy Council Health Objectives and Plan**
The health action groups’ working document sets out the kind of national health services that the JEC wishes to see for everyone living with epilepsy in Britain and Ireland. It falls into two parts: firstly, what we want to achieve over the next 10 years and secondly, what action we are going to take over the next 12 months to get us nearer to our objectives. The JEC Health Action Group believes that the top three things that would make the Health Services better for people with epilepsy are:
- Access to an epilepsy specialist for everyone within 4 weeks of his or her first seizure.
- Local protocols in place to ensure proper integration between primary and secondary care and between health & social services (and education and employment services too)
- Accurate and easily understood information and advice about epilepsy.

Work has been undertaken in each of the participating epilepsy organisations.

In Ireland Brainwave has met with the Minister for Health and the opposition spokesperson to discuss services for people with epilepsy in Ireland. See last edition of the Epilepsy Newsletter. A further meeting is planned.
The Epilepsy team in Beaumont Hospital under Dr. Norman Delany is planning to invite GPs, obstetricians and neurologists to participate in a unique prospective register of pregnancies in women with epilepsy to track their babies’ births.

The first initiative of this kind in Ireland, Beaumont will be working in conjunction with the Epilepsy Pregnancy Registry in the UK, which operates out of Queen’s University, Belfast, led by Dr Jim Morrow.

Information on these patients, and the use of new and old anti-convulsant medication during pregnancy, is scattered and retrospective, as historically adverse foetal outcome was more likely to be reported than a normal birth.

Under the new scheme, doctors will be asked to report pregnancies among women with epilepsy at the time of diagnosis, with the patient’s consent, to the Epilepsy team. The women will then be contacted three months after the expected date of delivery to determine the pregnancy outcome.

It is also hoped to have a free phone number so that patients can phone up the team and register themselves.

Dr Norman Delany, Consultant Neurologist, Beaumont Hospital, detailed the Centre’s plans to a recent meeting in Dublin of the Neurology Club facilitated by Pharmacia & Upjohn.

He also elaborated on issue pertaining to pregnancy in women with epilepsy, particularly the overriding importance of taking a high dose of folic acid at least three months before conception: “The reason for this being of particular concern in women with epilepsy is that we know from historical studies the incidence of spina bifida is higher in women taking sodium valproate, carbamazepine and perhaps other anti-convulsants probably in the order of two or three-fold higher than the general population. There are also theoretical concerns that many anti-convulsants may have anti-folate effects. So it is particularly important in women with epilepsy to take a higher dose of folic acid if there is even a chance that they may become pregnant.”

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The November sun shone down on us that morning
Eason’s filled her arms with happy people, waiting in anticipation
What chatter and laughter filled the air
Philip arrived with all his glory
Eleven ten we left for Blanchardstown

I sat beside the window in a dream
All around the bus the spirit of excitement could be felt
McDonald’s was the first place we ventured
I got talking to two ladies, one I came to know as Carmel
Her friend worked in James’s Hospital for forty-five years
She will be retiring soon, and had worked very hard all her life
We parted, and I had a wander around the centre for a while
Watching the children waiting to see Santa with their parents and friends
I too wanted to see Santa, a big kid at heart

To get to know people and their lives is important
The need to listen and to understand is a gift in itself
We went to see a film, to tell the truth it’s so long since I have seen one
Carmel and her friend and I went for a ramble
We had a good chat and a laugh
It took me out of myself and I had begun to think about writing this
My heart was thinking madly, ready, a great opportunity for me
But frightening at the same time

People and their lives are what is important
We have a lot to offer each other
Someone had worked to put this day together
What a marvel their lives are
Love and understanding brought his day together
This is what the human race is all about
For this I thank God, for bringing these people into my life
People who are willing to give time to the needs of others
Such were the thoughts of my day in Blanchardstown

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NOTICE

Wife of person with complex-partial epilepsy would like to make contact with others in a similar position for friendship and support - preferably in the Dublin area.

Please write in the first instance to:
“Like Minds”
C/O Brainwave
249 Crumlin Road, Dublin 12.

Letters may also be faxed to
Fax No: 01-455 7013

Nuala Ryan
Therese McDonnell from Knockbridge, Dundalk in Co Louth died recently after a brave struggle. She had been an extraordinary part of Brainwave as part of the staff, as a member, and as a volunteer. Everyone has their own stories of Therese, all of them good. I have chosen a few to celebrate her contribution to Brainwave and to the people of Dundalk who have epilepsy and with whom Therese had shared her time and care.

I first met Therese in 1996 when she joined the “Training for Success” project. Her outlook, personal philosophy and approach to life and to her epilepsy were a source of great strength to all involved in the project in Dundalk.

In the early days of the project, all-round support for people with epilepsy was not in the remit of the project. Therese knew that if we were to assist people in getting work we must offer people individual support. Straight away she started to meet people on the project who might want to talk about their personal experience of epilepsy. Therese always professional about things, rang Cathy O’Donoghue and me to make sure this was OK, and we agreed to talk about the issues coming up. Therese’s personal warmth and empathy struck everyone who met her, in fact when Cathy went on maternity leave Therese willingly and capably stepped in to the breach. In her role as Community Resource Officer, Therese took a group of young people with epilepsy from Dundalk to a training workshop in Cork. At this workshop we were using Forum Theater as a training tool. I bet there are people reading this who can still remember Therese acting as a child hiding under the table. Acting could well have been an alternative career choice, as she portrayed the child with sensitivity and humour.

In 1998 Therese travelled to Germany on behalf of Brainwave to talk about living and working with epilepsy to an audience of over 300 people from France, Germany, Switzerland, Finland, the UK and Ireland. Again Therese used humour, sensitivity and real life to tell her story. A good time was had on this trip talking about life plans and the future. Therese spoke about work, her love of being a Montessori teacher and her painful reassessment of that career. She had so many interests – her family, her work with Macra na Feirme – and yet she remembered important things (although she would disagree with this). In 1999 Therese rang from the motor taxation office to let Brainwave know at first hand about the change in driving licence regulations.

There are so many other stories that could be told, all of them reflecting Therese McDonnell’s selfless energy when it came to others with epilepsy.

Brainwave as an organisation will miss Therese but the people who make up that organisation will miss a true friend.
ACUTE METABOLIC SEIZURES

Norman Delany (Department of Clinical Neurological Sciences, Royal College of Surgeons in Ireland, and Division of Neurology, Beaumont Hospital, Dublin, Ireland).

Metabolic disturbance can provoke seizures in patients with or without epilepsy. Such acute symptomatic seizures are commonly encountered in hospital practice. Encephalopathy and reversible focal neurological signs may accompany these seizures. They often occur in patients with other factors which may lower the seizure threshold, such as organ failure, hypoxic–ischaemic encephalopathy and proconvulsant medication use (e.g., high-dose intravenous antibiotics, theophylline, pethidine, chemotherapeutic agents). Metabolic abnormalities, which may lead to seizures, include hyperglycaemia, hyponatraemia, hypocalcaemia and hypomagnesaemia. These derangements are common in patients with diabetes mellitus and other endocrinopathies, patients using diuretics and those in the postoperative period. Risk of seizure is related to the absolute value of the metabolic parameter and its rate of change, probably in addition to uncharacterised genetic factors. Prompt recognition of the metabolic abnormality is vital as approprioted therapy will usually correct the underlying encephalopathy and prevent further seizures. It is important to explain to patients and their families that seizures due purely to metabolic disturbance do not constitute epilepsy and do not need treatment with long-term anticonvulsants if the underlying abnormality can be controlled.

An Application of Cognitive Behaviour Therapy to Non-Epileptic Seizures

Deirdre A McMackin, Richard Booth, Norman Delany, Beaumont Hosp, Dublin, Ireland; St Patrick’s Hosp, Dublin, Ireland.

RATIONALE: Non-epileptic seizures (NES) represent a considerable treatment challenge for neurology clinics. One area of difficulty is that there is no uniform psychological theory for the treatment of these seizures. While trauma has been recognised as important ES this may be overemphasised as a causal explanation. Cognitive behaviour therapy (CBT) is an established psychotherapy and has led to treatments for disorders such as social phobia, panic and depression. The fundamental tenet of CBT is that belief systems and cognitions are critical in determining moods and behaviour. METHODS: This study assessed belief systems in five patients with established non-epileptic seizures (four women, one man, mean age =27) using a standard cognitive behaviour approach. RESULTS: this revealed a common set of beliefs in this pilot group. Their early life experiences had led them to believe that emotional expression was prohibited and in the event of increased stressors in their lives or a trauma they developed somatic symptoms in the form of non-epileptic seizures. The diagnosis of these behavioural events as epileptic led to further powerful belief systems, which acted as factors creating further somatisation. CONCLUSIONS: While based on a small number of patients, this theory provides a promising approach to the understanding of NES.

Brainwave, The Irish Epilepsy Association supported this project.
Vagus Nerve Stimulation (VNS) Update

S
ome difficulties still exist in relation to funding for VNS surgical operation, according to Professor Jack Phillips of Beaumont who made reference to the matter when he presented his paper on "at the GP's Study Day on Epilepsy recently".

Dr. Norman Delany, Professor Phillips and other prominent specialists had made representations on the matter to the Department of Health in the summer and things have now improved. However, some Health Boards continue to put obstacles in the way of many people who have been approved for the VNS by appropriate Medical personnel. This initially leads to major stress for the people involved and makes a bad situation worse by increasing their seizures and adding more delays to the process. Good news though for some of those who are covered by Voluntary Health Service (VHI) as a number of people have now been able to have their Vagal Nerve Stimulator inserted under their VHI cover.

A word of warning though, as each individual may need to check out the situation with the VHI. The level of cover may depend on the plan you are in, how long you have been covered and other factors. The situation with Bupa seem unclear but, to date Brainwave is unaware of any Vagal Nerve Stimulators inserted having been covered by Bupa. However, we welcome all information on VNS experiences from any members, so please let us know your story.

DUBLIN SUDEP MEETING

Many of those who attended the 'Living with Loss' Seminar last September requested that Brainwave hold a further meeting in Dublin for families who have lost a member to SUDEP (sudden unexplained death in epilepsy) and other epilepsy related deaths.

Some of those who attended the Dublin meeting with Brainwave staff

The 'Living with Loss' Seminar was jointly organised by Brainwave and BEA (The British Epilepsy Association), Northern Ireland, in Dundalk and families from all parts of Ireland were represented at the meeting. At the time it was felt by many people that Dundalk was difficult for some people to get to.

Brainwave held a follow up meeting in their Head Office at Crumlin Road on Saturday, 28th April 2001.

The event was primarily aimed at allowing those who attended to talk to others who have gone through a similar epilepsy bereavement. Six Brainwave staff were in attendance on the day. All people from families who have lost a loved one in this way were invited. Light refreshments were provided, as many people had to travel long distances to be able to attend.
Over 50 Years Experience in the Management of Epilepsy

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THE IRISH EPILEPSY ASSOCIATION
In the words of distinguished Indian Neurologist, Dr Rajendra Kale, “the history of epilepsy can be summarised as 4,000 years of ignorance, superstition and stigma”. Dr Kale spent several years working in Ireland and his often borrowed observation, was used once again in Brussels on March 22nd.

Eradication of Stigma, Discrimination in the Workplace, and Inadequate Research Funding were cited by experts in epilepsy as three key focus areas requiring improvement across Europe at the launch of a White Paper on Epilepsy.

Mr Bowis MEP, who hosted the launch meeting, and who is a long time campaigner for improved epilepsy care, stated: “This initiative is long overdue and provides us with the opportunity to focus our minds on what can and needs to be achieved for those with epilepsy. I cannot stress enough the urgency of action. Everyone, regardless of position in society, can affect the change outlined in this White Paper.”

Mr Bowis went on to say: “The stigma associated with epilepsy is often harder to live with than the condition itself, impacting on many aspects of life, for example, employment. For years epilepsy has been ignored, and I believe this European White Paper on Epilepsy has come at the perfect time. Epilepsy remains notoriously underfunded and misunderstood. This is not a call for action, but a call ‘to’ action. Everyone, whether or not they are currently involved in the epilepsy agenda should pick up the banner and support this campaign”.

Almost 200 people from 27 different European countries attended the launch, including representatives from IBE and ILAE chapters in Europe, and several MEP. Irish MEPs Mary Banotti and Patricia McKenna attended the launch with Brian Crowley and John Cushnahan also lending support.

The White Paper has been constructed in a way that recognises the proposals of EU Health Commissioner David Byrne of May 16th in his strategic approach to public health, but seeks to ensure that people with epilepsy receive equitable treatment under the three key areas of Commissioner Byrne’s framework, i.e. Information, Rapid Response Mechanism and Health Determinants.

In late 1998, the European Declaration on Epilepsy was agreed in Heidelberg setting out the agreed basic requirements for people with epilepsy in Europe. The then Lord Mayor of Dublin, Senator Joe Doyle was a key participant in Heidelberg. “It is not seizures but the fear of the seizure which can be the greatest problem for the person with epilepsy” according to Senator Doyle, who continued, “and these types of problems must be addressed for all people with epilepsy in Europe”.

For further information contact Brainwave, 249 Crumlin Road, Dublin 12. Tel: 01 455 7500, Fax: 01 455 7013
Featured in previous editions of Epilepsy News, 'Like Minds' is an extension of Brainwave's Social Activities programme, aiming to put people with epilepsy in touch. The response from all parts of the country has been very encouraging, and those of you who have already returned the mini-questionnaire should have received your first letter from the secretary.

We would like to welcome more of you on board. The value of 'Like Minds' lies in attracting all sorts of people from as wide an area as possible, together with all their different interests, experiences, hopes and ambitions. You may be able to offer help or support to someone who would value your contribution to their quality of life, or you yourself may welcome a listening ear. Perhaps you have successfully faced a challenge or overcome an obstacle, and would like to share the experience. If you would like to take part in 'Like Minds', please complete the mini-questionnaire and send it to:

Phillip Jackson, LIKE MINDS, Brainwave, 249 Crumlin Road, Dublin 12

Please be aware that no information will be exchanged without your express permission, and that while we do our utmost to facilitate contact between respondents, all responsibility rests with the individuals concerned, and not with Brainwave.

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<td>Address</td>
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<td>Tel.</td>
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<td>Age Group u18-25, 25-35, 35-50, 50+</td>
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<td>Are you in Education yes/no (if yes, please give brief details)</td>
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<td>In Employment yes/no (if yes, please give details)</td>
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<td>Interests &amp; Hobbies</td>
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<td>How would you describe your epilepsy?</td>
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**Epilepsy & Youth in Europe**

**www.eyie.org**

The E.Y.I.E. website, launched in May 2000, is a place where young people from 14 countries, speaking 11 languages have come together to contribute information about epilepsy and youth. There are pages in English and a series of pages from each country in that countries' language. There is also a chat room, where people meet every Tuesday (6.00pm Irish time) to discuss various issues. So if you have Epilepsy and would like to:

- Chat with people like yourself
- Contribute to the site
- make new friends
- discuss a problem

**THEN WHY NOT JOIN THE CHAT SESSION ON TUESDAY'S @ 6.00PM**

*We would love to meet you there!*
Funderland Trip

Aidan McCarthy & Liz McCormack
"All the Fun of the Fair"

Tatiana Horgan & Liz McCormack
"Let's have a cup of Tea"

Tony Jacob, Aidan McCarthy, Philip Jackson, Ina O'Byrne, Dudley Joynt

Maria Jinks with Philip Jackson (Brainwave)
"You need a cup of Tea"

Janssen-Cilag are proud to support the Irish Epilepsy Association
Funderland Trip

We’re with you for ..... life

Novartis

Beech House, Beech Hill Campus, Clonskeagh, Dublin 4.
Tel: (01) 2501255  Fax: (01) 2601263