National Conference 2010 reviewed

In this issue:

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European Epilepsy Report launched
Waterford support group celebrates 21 years
Brainwave announces new call for epilepsy research
European Epilepsy Day

Dr John Lynch, recently appointed consultant neurologist at University College Hospital Galway speaking at Brainwave’s national conference in October
Note from the Editor

Charities, including Brainwave, have not been immune to what has been a very difficult year for the whole country.

Nevertheless, 2010 has been a productive year for Brainwave with the launch and distribution of our Nurses Information Pack; the appointment of a new Brainwave-funded CESN in Sligo (see page 3); the launch of another call for epilepsy research (page 5) and success in the battle against generic substitution in epilepsy, all while maintaining our services to people with epilepsy and their families.

Next year will see work begin on the development of a new strategic plan for Brainwave, beginning with a meeting for members in January to feed into the process. Meanwhile, the first ever European Epilepsy Day will take place on February 14th, providing a great opportunity for both Brainwave and people with epilepsy to raise awareness.

However, additional HSE funding cuts are inevitable and fundraising to maintain services will again be a major challenge. Earlier this year we asked for your support and you responded brilliantly, through the recent national raffle and in many other ways.

In this issue we highlight some of the tremendous recent fundraising achievements, without which we simply would not be able to continue our work. As Christmas approaches, we would like to thank all our members who continue to support our work in spite of the times. We hope you will continue the good work into 2011.

Merry Christmas to all our members and supporters, from everyone at Brainwave!

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Epilepsy: Planning for the future

In 2011, Brainwave will begin work developing a new 5-year Strategic plan for the charity to come into effect from the beginning of 2012, at the end of the current 2007-2011 plan.

Brainwave’s members, Board of Directors and staff will all have an input in determining the direction Brainwave will take over the next five years in representing the needs of people with epilepsy in Ireland. All Brainwave members are invited to attend a meeting in January to begin work on developing the new plan.

The day will also include a presentation by Dr. Colin Doherty, the HSE’s new Clinical Lead in Epilepsy outlining his plans to address the issues for patients with epilepsy in Ireland.

Prescription Charges

Since October 1st 2010, medical card holders are subject to a 50 cent charge per item dispensed from pharmacies up to a maximum of €10 per month per individual or per family.

The HSE will refund payments over €10 per month on a quarterly basis but if all family members use the same pharmacy, this will help to prevent payments over the €10 maximum arising in the first place.

Families may obtain a Family Certificate to give to the pharmacist to show all members of the family covered by the scheme and to ensure the charges do not amount to over €10 per month. To obtain the certificate, visit www.medicalcard.ie or call 1890 252 919. Alternatively you may enquire at your Local Health Office.

The charges do not apply to the Long Term Illness Scheme, the Drugs Payment Scheme or private prescriptions.

For further information see www.medicalcard.ie or www.hse.ie or call 1890 252 919.

See our website www.epilepsy.ie for information on the impact of Budget 2011.
Brainwave is delighted to announce that a new Brainwave Community Epilepsy Specialist Nurse (CESN) has been appointed in the North West this October. Eithne Cawley, CNM2, will report to consultant neurologist Dr Kevin Murphy and work with his team at Sligo General Hospital. This is a HSE West and Brainwave joint initiative and Brainwave has agreed to fund the new position for the first 18 months. The new position has come about as a result of lobbying by Brainwave to have a CESN appointed outside of Dublin. The first CESN was appointed in 2002 by Brainwave and Beaumont Hospital and a second position was created in 2003 by Brainwave and AMNCH Tallaght. Until now, all attempts by Brainwave at getting posts in place outside of Dublin have failed, even with Brainwave funding offered, largely as a result of HSE cutbacks.

As part of Eithne’s role, she will operate an epilepsy helpline from the Sligo Brainwave office each Friday morning from 9am to 1pm. The helpline began on 19th November and can be accessed at 071 91 41858. This new service will be in addition to the helpline service provided from Head Office by Sinead Murphy, Community Epilepsy Specialist Nurse (Monday, 9.30am - 1pm) and Denise Cunningham, Clinical Nurse Specialist in Epilepsy Services (Wednesday, 9.30am-1pm).

Eithne commenced her General Nurse training at Beaumont Hospital in 1993, graduated in 1996 and has worked within the area of neurology for several years, including in the role of migraine specialist nurse. For the last number of years she has worked as a Diabetes Nurse Advisor both in primary & secondary care in the North West.

We would like to take this opportunity to welcome Eithne to her new roles with Sligo General Hospital and Brainwave.

The role & importance of the Community Epilepsy Specialist Nurse

CESNs play a pivotal role in the treatment and care of people with epilepsy. Studies have noted that epilepsy specialist nurses:

• Are cost effective
• Can reduce the length of stay in hospital for people with epilepsy
• Deliver a perceived higher quality of care and increase patient satisfaction.
• Reduce time spent on travel by patients
• Reduce waiting times
• Lead to better continuity of care

CESNs work in close collaboration with the neurologists and their teams in the assessment and management of epilepsy. They provide essential information, support and advice to people with epilepsy and their families, helping to significantly reduce the impact of condition. Their role is particularly critical in helping patients to understand the risks associated with epilepsy and cope with emergencies.

Accessibility is one of the key advantages of the role. The three CESNs now provide telephone advice for people with epilepsy during office hours and operate an epilepsy advice line with Brainwave one morning each per week. By attending epilepsy clinics, they act as a direct interface between the hospital and community based services.

They also participate in outreach activities including educational presentations for both people with epilepsy and health professionals; workshops and conferences and act as an invaluable resource and support for Brainwave’s service staff around the country.

Importantly, in an environment where consultants are at a premium, CESNs also free up neurologists to concentrate on more complex cases by dealing with many practical problems on a day to day basis.

In Ireland, the lack of epilepsy and neurology personnel at all levels has been well documented and even recent additions will not lift us from the foot of the European league table. In the UK, where epilepsy services are also lowly ranked in a European context, there are currently around 250 epilepsy specialist nurses. With three CESNs currently in position here in Ireland, it is clear that more specialist nurses are still needed.

In 2008, Brainwave presented on this issue to the Joint Oireachtas Committee on Health and Children, advocating the creation of 8 further CESN posts, two for each of the four HSE Regions.

Brainwave will continue to push the message that in these difficult times of funding cuts, the appointment of further specialist nursing positions would provide both a short-term solution to the horrific waiting lists and a vital long-term support to neurologists and other health professionals, ultimately saving resources in the longer term.
Brainwave’s annual conference for 2010, entitled “Epilepsy & The Family” took place on Saturday October 2nd in the Ashling Hotel, Dublin.

As usual, people came from far and wide for an interesting line up of speaker presentations, interactive sessions and workshops.

Dr John Lynch, recently appointed to the post of Consultant Neurologist at University College Hospital, Galway delivered the keynote address, giving a comprehensive overview of epilepsy, its effects on the individual and the family, epilepsy treatments and genetic aspects of the condition.

Dr Gianpiero Cavalleri, Biomedical Research Lecturer in Epilepsy Genetics and Pharmacogenetics at the Royal College of Surgeons spoke about developments in the growing field of epilepsy genetics, particularly his own work aimed at using genetic models to predict how well people with epilepsy will respond to a particular treatment.

Dr Teresa Burke, Senior Lecturer in Neuropsychology at UCD outlined her work looking at cognitive function in individuals with temporal lobe epilepsy and their unaffected siblings.

The conference also featured a lively Questions and Answers session with Dr. Norman Delanty, Consultant Neurologist at Beaumont; Cora Flynn, cAdvanced Nurse Practitioner in Epilepsy at Beaumont & Grainne Griffin and Maria Keegan, Epilepsy Clinical Nurse Specialists, Our Lady's Hospital, Crumlin.

Afternoon breakout sessions were also held on stress management, lifestyle issues and benefits & entitlements while there was plenty of demand as usual for the one-to-one sessions with epilepsy specialist nurses.

Watch conference presentations online
If you missed the conference, please note that videos from the day are now available to view online. You can watch the following sessions free of charge on vimeo.com simply by typing in the appropriate URL:

- Dr John Lynch - www.vimeo.com/16237814
- Dr Gianpiero Cavalleri - www.vimeo.com/16250665
- Dr Teresa Burke - www.vimeo.com/16254925
- Questions & Answers - www.vimeo.com/16265598
Epilepsy Research Funding Available

As part of our ongoing commitment to supporting Irish research, Brainwave - The Irish Epilepsy Association invites applications for epilepsy focused research projects of up to a three-year duration to a maximum of €50,000 p.a. commencing in October 2011.

We particularly welcome applications on the following issues:
♦ Psychosocial aspects of epilepsy
♦ Causes or prevention of/ Potential cures for Sudden Unexpected Death in Epilepsy
♦ Epilepsy in the Intellectual disability population
♦ Role of the Epilepsy Specialist Nurse and effects on patient quality of life

For more information on the application process, see the Research section on our website www.epilepsy.ie or contact:
Peter Murphy
pmurphy.brainwave@epilepsy.ie
01 4557500

Closing date:
January 14th 2011

Brainwave - The Irish Epilepsy Association is the national organisation committed to working for, and to meeting the needs of everyone with epilepsy in Ireland and their families and carers. Brainwave is the only Irish charity which has consistently provided funds for epilepsy research over a period of many years.

www.epilepsy.ie    CHY No: 6170

Brainwave is a member of the Medical Research Charities Group (MRCG). The highest ranked proposals following peer review will be submitted for joint funding under the HRB/MRCG Joint Funding Scheme.
Seizing my second chance:

Erika Dillon is a native of Cornwall, married to an Irishman and living in Australia. On a trip to Ireland this summer to visit family and friends, Erika told Brainwave about her experiences with epilepsy, having surgery and her hopes for the future. We met Erika on the first anniversary of her epilepsy surgery.

What did you know about epilepsy at the time?
I’d heard of epilepsy, but it was totally alien to me. My family were equally shocked. My mum said things like “We’ve never had that before, where did you get it?” and “It’s not from my side anyway”. To this day, I have no idea why I developed epilepsy, but in retrospect I remember some things that happened when I was younger that may well have been complex partial seizures as well, for instance one day I had this feeling of getting smaller and smaller and I couldn’t complete my sentences properly. This lasted for about an hour but I never did anything about it and it never happened again. When I was a child I remember my vision would be affected. I would see something spreading like a cloak across my field of vision and I would get scared, but I never told anyone about it. I also used to complain about strange smells and déjà vu regularly.

How did you react to your diagnosis?
I spent the first few years just coping with medications, going from one to another trying to find something that helped. I had to learn to deal with the seizures and also the horrible effects of the medication like rashes, tiredness and inability to function. I was little more than a zombie for a long time and I’ve lost a lot of memories from that period. Seizures were occurring more often than I realised, often during sleep, and the area of the brain they were occurring in meant my memory was badly affected. We came to Ireland for my friend Helen’s wedding but I have no recollection of the trip.

Did epilepsy get in the way of personal relationships?
My diagnosis was terrifying for Dave but he’s been a rock from day one, never complaining. His only frustration was my stubborn streak which made me keep going doing things and not looking after myself properly.

What about work and hobbies?
I trained as a photographer and I have a real passion for photography but for years following my diagnosis, I was unable to follow my dream. I just couldn’t pick my camera up. Since my operation, I’ve discovered a new lease of life, have gotten my energy back in bundles and have resumed where I left off with the camera. When I picked it up for the first time, two months after my operation, I immediately burst into tears, realising for the first time how epilepsy had stolen my life.

At what point did epilepsy surgery become an option?
The seizures began to worsen and new aggressive symptoms began to occur during them. After one incident when a seizure caused me to shout and scream at a passer-by on the street, my doctor told me he couldn’t allow me to fly back to the UK in case something similar would happen on-board. Incidents like this made me realise that there was no other option but to go for surgery, provided that I would qualify. I went for a sleep study and reduced my medications. I had multiple seizures during the study and the doctors decided I was a suitable candidate for surgery. I was told that there was a possibility the operation wouldn’t work. The odds of my seizures stopping completely were low.

Erika’s brain scan after her successful epilepsy surgery last year

Brainwave: Thank you Erika for sharing your story. When did you first develop epilepsy?
Erika: My first memory of epilepsy is six years ago, when I was in my early thirties being in the bathroom at home in the middle of the night. There was a woman banging at the door telling me to come out immediately or I would be sectioned! I had no idea what had happened but my tongue was a bit sore. Eventually, my husband Dave got me out. The woman at the door turned out to be an ambulance driver. You’d think you could expect better from the emergency services! I’d woken Dave up by kicking him.

So what happened after your first seizure?
I spent five days in the hospital where they did various tests and diagnosed me with epilepsy. I was given medication and told to come back in a week. There were no more tonic-clonic seizures and I thought that meant I didn’t have epilepsy any more. However, I started to have these “zoning out” moments which I didn’t know about but which other people would notice. I was then diagnosed with complex partial seizures.

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What about work and hobbies?
I trained as a photographer and I have a real passion for photography but for years following my diagnosis, I was unable to follow my dream. I just couldn’t pick my camera up. Since my operation, I’ve discovered a new lease of life, have gotten my energy back in bundles and have resumed where I left off with the camera. When I picked it up for the first time, two months after my operation, I immediately burst into tears, realising for the first time how epilepsy had stolen my life.

Was taking control of your epilepsy difficult?
To be honest, I was a bit frustrated with my GP and even my neurologist. They were both very nice to me but I wasn’t getting anywhere with medication and it often felt like I was just going in to them for a chat. They would write a prescription and tell me to come back in six months. They couldn’t tell me why I had epilepsy or give me any assurances about getting it under control. They were doing their best of course, but that didn’t mean I felt less frustrated.

At what point did epilepsy surgery become an option?
The seizures began to worsen and new aggressive symptoms began to occur during them. After one incident when a seizure caused me to shout and scream at a passer-by on the street, my doctor told me he couldn’t allow me to fly back to the UK in case something similar would happen on-board. Incidents like this made me realise that there was no other option but to go for surgery, provided that I would qualify. I went for a sleep study and reduced my medications. I had multiple seizures during the study and the doctors decided I was a suitable candidate for surgery. I was told that there was a possibility the operation wouldn’t work. The odds of my seizures stopping completely were low.

Erika’s brain scan after her successful epilepsy surgery last year
A view from ‘down under’

Erika (left) with her friend Helen Hickey from Co. Meath at the Hill Of Tara this summer

However, I had decided that life couldn’t carry on as it had been so there was no doubt in my mind that I had to have the surgery. It was scary in the 6-month build up and to be honest, I felt like backing out sometimes but Dave was always there to reassure me and convince me to go ahead.

So how did the surgery go when you finally got to go in?

Dave works on gas drilling rigs and was away at the time so I was very grateful to Helen when she decided to give up her holidays to fly from Ireland to be with me. Since we first met in 2002, we’ve been great friends. The surgery was postponed twice (once on the table) but at least I had Helen with me to keep me calm and occupied. It also meant we were able to do all the touristic things together in Sydney while we waited for it to be rescheduled. After the surgery, I was out of hospital within 48 hours and immediately noticed a difference in myself. My medication had been reduced a few weeks before surgery and when I came out, I didn’t feel muddled anymore and I was energetic and cheerful again. I was out walking and shopping within a few more days and haven’t looked back.

Have there been any negative effects?

I haven’t had a seizure in a year. Apart from the 32 shiny staples in my head and the fact that I can now officially call myself an “airhead”, the biggest problem I have had since the operation is the change in my sleeping pattern. My short term memory is still not 100%, especially around numbers and time but it is improving. The doctors warned me about headaches, depression and losing peripheral vision but thankfully none of these issues ever materialised. It’s been almost an entirely positive experience. I’ve even developed an obsession with eating apples!

How has life improved for you in the past 12 months?

I want to get up in the mornings as early as possible and just get on with doing things. I’m back going to music gigs again after years of not being up to it. I feel like I have a life again rather than just an existence and people notice it as well. I’ve considered learning to drive for the first time, but I think I have too much energy for sitting in a car when I could be walking or cycling!

Have you had to adjust to being seizure-free?

One of the big things I’ve had to adjust to since the surgery is remembering that when I feel down or tired or irritable, that doesn’t necessarily mean that I’m going to have a seizure. It’s been hard to let go of that worry but it’s a year on now, and I think it is time to move on. Given how fortunate I’ve been, it would be shameful if I didn’t. People don’t always get a second chance.

What would you say to people considering or waiting for surgery in Ireland?

I think it is important to consider how your life is now, and compare that to where your life could be with successful surgery. If you are at the point where surgery is being considered, then your life is probably seriously affected by epilepsy and you are likely to be unhappy. So you must decide to either carry on that way, or to give yourself a chance of a better life through surgery. I know my story has been very positive and there is another side to epilepsy surgery as well. In my opinion, the risk is one worth taking but it is a decision every individual must make for themselves based on their own situation.

What are your hopes for the future?

I’ve decided since my surgery then that I want to do more for epilepsy. We need to shout it from the rooftops! Epilepsy is not understood, researched or spoken about enough. I also want to get my photography career back on track and I’m currently working on a series of photographs documenting different stages of my recovery.

How do you think the public views epilepsy at the moment?

A lot of people still think of a person with epilepsy as someone shaking on the floor, frothing at the mouth. They don’t see the effects it has – in my case the tiredness, the worry, the effect on relationships, memory problems and work. I remember writing in my diary a few days after the surgery how I feel it is just not right that a disease which takes so much from people’s lives is so silent and so hidden. Is it any wonder that some people don’t admit to having epilepsy in case it affects their job or how other people view them?

How can this change?

People with epilepsy need to do what they can to change perceptions. If you’ve come through the other side and feel up to it, I think you shouldn’t be ashamed to come forward and talk about it. I also don’t think there is enough information out there. For me, it was so hard to get information and very few people to ask. Doctors can’t be a reservoir of information for everyone but no-one ever pointed me to patient organisations or to online support forums. Doctors should always put people in touch with patient organisations or support groups.

Thank you for your time Erika. Enjoy your stay in Ireland and all the best for the future.

If you would like to have your own story featured in Epilepsy News, please get in touch with Peter at 01 455 7500 or email info@epilepsy.ie for further information.
In September, Brainwave’s Waterford Support Group celebrated its 21st birthday and to mark the occasion, members of the group past and present were invited to a reception at City Hall by Lord Mayor, Cllr Mary Roche.

Waterford has been a hub of activity since the foundation of the Brainwave Support Group in 1989 by a small group of committed volunteers many of whom remain involved to this day and whose commitment to the cause of epilepsy is as strong as ever. In this issue, we are delighted to be able to look back at the history and achievements of this unique group.

Led with endless enthusiasm for many years by Theresa O’Brien, the group has done tremendous work not only in supporting people with epilepsy and raising awareness but also in raising funds for epilepsy services.

Epilepsy can be an isolating condition, and perhaps one of the greatest achievements of the Waterford group is how it has brought people together and helped form so many friendships over the years. In an era when more and more people are maintaining “virtual” friendships, the group in Waterford goes from strength to strength bringing people together.

On behalf of everyone involved with Brainwave, I would like to thank and congratulate the Waterford support group on their first 21 years of outstanding work for the cause of epilepsy and wish them continued success for the next 21.

Mike Glynn, Brainwave CEO

The Waterford Support Group – A history of achievement

By Joseph ‘Jody’ Phelan
Waterford Support Group

In the late 1980’s, epilepsy was not something that people spoke much about. Paddy and Theresa O’Brien approached Sr. Regina of the Mercy Sisters in Waterford with some concerns for their daughter Catriona who had epilepsy and who was about to start school.

After doing some checking, Sr. Regina was surprised to find that Catriona was not the only child in the school with epilepsy, and she decided to hold an epilepsy information night for parents and teachers.

The meeting was a success and soon people from beyond the school wanted to know more. To meet the demand, Paddy and Sr. Regina decided to set about organising a support group, which came together in 1989. Early in 1990, the first of many fundraising events took place with a door to door collection.

Public meetings were initially held in the Mercy Convent and proved to be very popular. People were able to attend and get the information and support they needed. All of a sudden, the myth that “epilepsy only affects my child, nobody knows what I’m going through” was gone.

Before long, the support group was holding meetings in the O’Brien’s home and Theresa really started to get involved. Making tea and coffee and providing biscuits was only the beginning!

As the need for information grew, the group decided to set about fundraising for a small office or meeting room where people could drop in for a chat or to get information and support.

My wife Miriam had already been involved for some time before I became involved in the early 90’s. Brainwave decided to organise Balloon Week nationwide to awaken the general public’s awareness of epilepsy. People were still afraid to say the word “epilepsy” for fear it might hurt them. It was taboo.

I approached the Scout movement in Waterford for their help with Balloon Week. They were delighted to get involved and continued to support us for the next few years during Rose Week. With their help, we raised enough money to lease an office on the Quays and get some equipment. The office was opened by President Mary Robinson on 17th September 1991.

On behalf of everyone involved with Brainwave, I would like to thank and congratulate the Waterford support group on their first 21 years of outstanding work for the cause of epilepsy and wish them continued success for the next 21.

Mike Glynn, Brainwave CEO

Just some of the members of the Waterford Brainwave support group and volunteer fundraisers who recently attended a reception with Waterford Lord Mayor Cllr Mary Roche at City Hall. Members were presented with certificates of appreciation by the Lord Mayor.

www.epilepsy.ie
Paddy and Theresa finally got back their home. It was great to have a place of our own but the fact that it was upstairs over a shop was not ideal.

A more suitable premises was found in Poleberry. It had parking outside and we were at ground level. With some funding from head office and our own fundraising it started to come together. The office was only manned for a couple of days and evenings a week, all by volunteers. In later years, Brainwave recruited paid staff and in the south east, we have had three part time CRO’s - Maura Kenny, Deirdre Commins (RIP) and Annette Russell.

Sometime later the house was flooded and we were without a home again. Paddy and Theresa opened the door to their home again and the support group continued.

The Celtic Tiger had driven up the cost of everything and the generosity of local companies was not as evident as in less plentiful times so it was decided not to refit the house in Poleberry. Thankfully the City Fathers came to our aid with the use of a house on the Upper Yellow Road. Later we used the committee room in the Roanmore Sports and Social Centre and since 2005, we have been holding a monthly support meeting in the Cheshire Home on John’s Hill. As we move into our 22nd year we are looking to start a support group in Dungarvan.

Over the course of our 21 years, we have seen the development and growth of fundraising committees in Waterford city, Tramore, Portlaw and Dunmore East. Thank you to everyone in these locations who give or who have given their time for the cause.

Unfortunately, it is not possible to include every detail here or to mention everybody that has given their time and support. However, I would like to thank all the businesses and the wider Waterford community without whose support we could not look forward to the future.

During all that time, the biggest constant within our Group has been Paddy and Theresa O’Brien. Unfortunately we lost Paddy in 2007 but his wife Theresa and daughter Catriona (our unofficial founder) keep his ideal and spirit alive through the workload that Theresa in particular continues to do.

Without the commitment of the O’Brien family, I believe that the Waterford Support Group would have ceased to exist. It was their hunger for information to share with the people of Waterford that created more understanding in our community about epilepsy. Many of the people that were with us on the first fundraising events are still with us today and I believe that is what keeps the Group going. To me they are more than a group - they are like family.

### Brainwave Membership Form

**Membership Category**

- [ ] 1 Year renewal membership subscription @ €12.70
- [ ] 1 Year New membership subscription @ €12.70
- [ ] * 2 Year special membership subscription (New member only)

* 2 year subscription entitles a new member to a free epi-alert identity bracelet or safety pillow.

Please tick relevant box:

- [ ] I am a person with epilepsy
- [ ] I have a child with epilepsy
- [ ] Other _________________________________________________________________________________

Name of person with epilepsy: (Mr./Mrs./Miss./Ms) ________________________________________________________________________________________________________

Address: _________________________________________________________________________________________________________________________________________

Date of Birth of person with epilepsy: ____________________________ Email: ________________________________________________________________________________

Telephone: ______________________________________________________ Mobile: __________________________________________________________________________

Parents/Guardians of child with epilepsy: please enter your name as correspondence will be sent to you instead of child __________________________________________________________________________________________________________________________________________________

I want to help continue the work of Brainwave and I would also like to make a donation

- [ ] €7.30
- [ ] €20.00
- [ ] €50.00
- [ ] €100.00
- [ ] My own amount € ________________________________________________________________________________

- [ ] Tick here if you would like to receive our regular e-mail newsletter. Clearly write your e-mail address in the space above.

- [ ] Tick here if you would like to find out more about volunteering & fundraising for Brainwave

My Cheque/Postal Order/ Bank Draft for TOTAL PAYMENT € __________ is enclosed.

Cheques should be made out to Brainwave The Irish Epilepsy Association and returned with this form to: Brainwave, Irish Epilepsy Association, 249 Crumlin Road, Dublin 12.

You can also join or renew your membership:

- [ ] At www.epilepsy.ie
- [ ] By credit card or laser – call 01 4557500
- [ ] Standing Order – call 01 4557500 for a standing order form

Thank you for your support
Fostering Epilepsy Care in Europe report launched

WHO and international epilepsy organisations expose unacceptable state of epilepsy care across Europe

The 12th European Conference on Epilepsy & Society, held in August in Porto, Portugal witnessed the launch of an important new report into epilepsy in Europe. The Fostering Epilepsy Care in Europe report by The World Health Organization (WHO) and the two international epilepsy organisations, the International Bureau for Epilepsy (IBE) and the International League Against Epilepsy (ILAE) concludes that many aspects of epilepsy care are seriously under-resourced across the continent.

The report has been developed as part of the IBE/ILAE/WHO Global Campaign Against Epilepsy (GCAE). It addresses the current challenges faced in epilepsy care and offers recommendations to tackle them in order to improve care and understanding of epilepsy and reduce stigmatisation.

Key recommendations for action highlighted in the report include:
- Improve access to care for people with epilepsy
- Raise the profile of epilepsy within Europe and work for changes in budgeting and policy-making relating to people with epilepsy
- Develop and implement effective health policy and educational initiatives to reduce the stigma of epilepsy
- Promote and reinforce epilepsy research in the region, including the economic aspects and the more effective use of limited resources
- Make epilepsy surgery, which is potentially curative, more widely available

Speaking at the launch of the report, Dr Matt Muijen, WHO’s Regional Advisor for Mental Health and Brain Disorders said the recommendations in the report will help countries to develop activities to combat stigma and reduce the treatment gap for people with epilepsy in Europe. He said the report is an important instrument for dialogue with governments, healthcare providers, non-governmental organisations and academic institutions.

Hanneke de Boer, Co-ordinator of the GCAE explained that epilepsy affects more than six million people in Europe. It is the clearest example of a neurological disorder for which effective, cost-efficient treatment is available. She said that up to 70% of people with epilepsy could be seizure-free, yet as many as 40% of people across Europe may still be untreated. She described the existing gaps in epilepsy care and the level of stigmatisation faced by people with epilepsy as unacceptable.

IBE President and Brainwave CEO Mike Glynn explained how mortality rates among people with epilepsy are two to three times higher than in the general population. An estimated 40% of all epilepsy-related deaths are as a result of Sudden Unexpected Death in Epilepsy (SUDEP), yet the mechanism behind SUDEP remains unknown and awareness of risk factors is very low. He called for an increased international focus on research into this and other aspects of epilepsy.

The report is available to download from www.globalcampaignagainstepilepsy.org.
Successful research depends on people volunteering their time to take part. Here, one Brainwave member explains why she got involved in one of the three Brainwave studies currently underway.

Why volunteer?
By Deirdre-Anne Wynne Robinson, Brainwave member

I believe that the more research we, as people with epilepsy, take part in the more we help ourselves and others with epilepsy. Hopefully soon someone will find a cure, not just more management techniques. Some day it will happen. That’s why I took part in this study.

Seizures confiscate my control. They leave me helpless. I can’t tell when I’ll have them or how bad they’ll be. I may be able to hide them in company or a seizure may be so bad that I’ll have to be whisked away in an ambulance because my life may be in danger. That’s an extreme but realistic scenario in my life. Taking part in research gives me the satisfaction of knowing that I’m fighting back. I’m deciding what to do. I’m controlling the choices I can make. Most of my seizures are easy and little trouble. Taking part in research is easy and little trouble too. In fact it’s fun!

I really want it to get concrete results and find answers. I love reading everything I can about epilepsy. I enjoy asking my doctor questions – and love when he has a good answer. Sometimes the answer has to be that there’s no research on that yet. That’s disappointing. If I’m asking the question, then thousands of others must want the information too.

Right now I have one beautiful child. Before I had her, I had to change my medications to find the safest one for me and my baby. She’s been diagnosed with dyspraxia. I want to know if the medication I was on during pregnancy had any effect, but there’s not enough research. There’s a correlation between dyspraxia and epilepsy, but is there a direct link? It will take more research to establish or disprove one. It’ll help if I can.

The study I’m taking part in is led by Dr Teresa Burke and funded by Brainwave and the Health Research Board. It is looking at the way people with epilepsy think, versus how their siblings without epilepsy think. It is a fascinating idea. My family have always said I live in my own world. I’ve always been a very ‘black and white’ person, seeing very little of the shades of grey in the world. Things are either right or wrong!

I’m looking forward to seeing the results of the study. I want to know if epilepsy has an impact on how I think. Impacts such as not driving, taking medication, getting enough sleep – so missing out on the late nights parties are obvious to people. Others don’t see the less obvious things such as family planning, the side effects of medication and sometimes the fear of being alone when a big seizure may be coming.

Research is so important. It only takes a small number to take part, compared to the huge number of people whose lives are affected by it. The research takes a short time to complete relative to the time it lasts. Look at Thomas Edison and the impact he had! Research is always worth it. I’m proud to do my bit to help.

Volunteering for epilepsy research

Study investigating cognitive function in people with temporal lobe epilepsy (TLE). Principal Investigator: Dr Teresa Burke, UCD

By comparing cognitive function in people with TLE to their unaffected siblings, this research aims to find out more about risk factors that make people more likely to develop the condition.

If you are aged 18-60 and you have TLE, you have a same-sex sibling who would be willing to participate in this study and you have no history of any other neurological illnesses in your family, you would be the perfect volunteer.

Taking part would involve two appointments for you and your sibling. The first is a neuropsychological assessment involving tasks such as memory exercises and solving different types of problems. The second appointment is for an MRI scan.

For further information, contact Helena Maher at 085 1438487/01 8092983 or helena.maher@ucdconnect.ie

Study investigating possible cause of Sudden Unexpected Death in Epilepsy (SUDEP). Principal Investigator: Dr Yvonne Langan, St James’s Hospital

The baroreflex is one way our body maintains a suitable blood pressure. The researchers are looking at whether the baroreflex functions as well as it should in people with epilepsy. If it doesn’t, there may be evidence that it plays a role in SUDEP.

The researchers are looking for people aged 18 to 50 who have had a seizure in the last 5 years. Ideally, participants will provide a friend or family member to take part who does not have epilepsy, but this is not essential.

Taking part is simple and non-invasive, involving one or two visits to St. James’s lasting approximately an hour. People with certain medical conditions may not be eligible to take part. Please note that taking part does not put you at any increased risk of SUDEP.

For further information, contact Aoife Laffan at aoiela@emusic.ie or 086 8492076 Mon-Fri, 10am-12.30pm.

Study to identify genes involved in difficult-to-treat epilepsy
Principal Investigator: Dr Gianpiero Cavalleri, RCSI

This study is looking at identifying particular genes involved in difficult to treat epilepsy.

The researchers want to recruit people whose epilepsy is either very well controlled or those who continue to experience seizures despite ongoing treatment. Participation only involves providing a blood sample.

If you are under the care of Beaumont Hospital (Dr. Delanty) or St. James’s Hospital (Dr. Doherty) and are interested in getting involved please contact Dr. Cavalleri at 01 8093825 or gcavalleri@rcsi.ie.
Fundraising

Mega Raffle raises €23,000

A huge thank you to all our members and supporters who helped make such a success of the Mega Raffle promoted in the last issue of Epilepsy News.

We were delighted with the huge response received – over 7,000 tickets were returned for the draw and almost €23,000 was raised! Unfortunately, due to the costs involved, we were not able to acknowledge or thank all our sellers individually, but we are very appreciative of all the effort put in by everyone to raise so much. We plan to do another evem bigger raffle in 2011!

The draw took place at the National Conference when Brainwave’s Patron, 2FM DJ Rick O’Shea pulled the winning tickets from the drum. Congratulations to all the winners:

1st Prize: €1,500 cash
Winner: Val Langstone, Ballymun, Dublin 9.

2nd Prize: VIP day trip to Paddy Power Gold Cup @ Cheltenham (Courtesy of Paddy Power)
Winner: Roisin Hannigan, Letterkenny, Co Donegal.

3rd Prize: John Rocha Necklet & Bracelet set (Courtesy of John Rocha)
Winner: John Philips, Newcastlewest, Co Limerick.

4th Prize: Two-night break for 2 at Renvyle House Hotel, Connemara (Courtesy of Renvyle House)
Winner: S Doyle, Drumcondra, Dublin 7.

5th Prize: Return trip for car & 2 passengers to Liverpool (Courtesy of Norfolk Line)
Winner: Josephine Walsh, Clonmel, Co Tipperary.

Seller’s Prize: €200 cash
Winner: Seller of first prize ticket, M Langstone.

Over €3,500 raised in memory of Leon

Brainwave would like to thank Colum Carter of Rhode, Co Offaly and a group of running enthusiasts who took part in the Great Ireland Run in the Phoenix Park, Dublin in April, raising an amazing €3,568.

The money was raised in memory of Colum’s late brother Leon (pictured), a member of Brainwave who passed away in June 2009. “Leon was about to start raising money for Brainwave, but never got a chance as he passed away suddenly”, says Colum, who decided to take on the mantle in honour of Leon.

As well as Colum, the group of runners included Amanda Egan, Derek Kearney, Finbar Killally, Jason Hand, Liam Morley, David Keenan. The effort was ably supported by an extended group of fundraisers including Pat, Liam, Ray and Ian Carter, Frank Kennedy, Carmel Kelly, Tom Fawcett, Shane Rushe, Zsuzsanna Kovacs, Chris Furey, Lil Carter and Bernie Carter. Our thanks to one and all.

Cork Ladies Mini Marathon

The ladies in Cork turned out once again to support Brainwave in the 2010 Cork Mini Marathon in September, ably assisted this year by a few gentlemen in disguise.

The numbers were also boosted by a large group from Kerry led by CRO Kathryn Foley. A sincere thank you to everyone who participated in the marathon and to their many sponsors. Thanks also to everyone who gave their time to help with the refreshments afterwards at Bishopstown GAA club.

Maire & Patricia, Beaumont Hospital

Thanks to Maire White, Clinical Nurse Specialist in Epilepsy and Patricia Ennis, Epilepsy Monitoring Unit at Beaumont hospital who recently organised a book sale at the hospital and raised a fantastic €1,160.
**Fundraising**

**Philip Courtney Memorial Tournament**

Pictured at the presentation are from left to right: Bernie Courtney, Brendan McShane, sponsor; Brian Woods, organiser; Brendan McCabe, sponsor and Peter Murphy, Brainwave.

The Philip Courtney memorial GAA tournament is held every August bank holiday at Blackhill GFC in Castleblaney, Co Monaghan. Philip was a former chairman of Blackhill football club who died suddenly in 2004. Since then, his wife Bernie, family and friends have come together to organise an annual football tournament, which has so far raised €30,000 for various charities.

This year, Brainwave was very grateful to have been chosen as the beneficiary charity for the tournament, which raised a fantastic €4,408.

Bernie would like to thank everybody who took part, who helped out and who donated to the fundraising. Brainwave would like to thank Bernie, the Murphy family and all the organisers, sponsors and supporters for all their hard work in raising such a fantastic amount.

**Nom-Con convention**

Thank you to Nathan Smithson and the organisers of Nom-con 2010, an anime convention which took place in Dublin in August for raising almost €2,000 for Brainwave through an auction and a bucket collection at the event.

**Louth family raise over €7,000 for Brainwave**

Warmest of thanks to Larry and Deirdre Mulrey from Dundalk and all their family and friends, who this year embarked on a major fundraising and awareness campaign to mark the 10th anniversary of the death of their son Larry Jr from SUDEP.

Larry Snr took part in a local 10k run in May while other friends and family members took part in the women’s mini-marathon and the Belfast marathon. €1,500 was also raised by organising a world cup prediction competition.

The fundraising culminated in a live music fundraiser to remember Larry Jr at the Lisdoo Arms on September 25th when family members presented Brainwave’s Ina Murphy with the funds they had raised. Brainwave would like to thank Larry Snr, Deirdre, Seamus Bailey, Tina Garreth and everybody else who contributed to this fantastic campaign.

**Brainteaser Quiz Night**

The 2nd Brainwave Brainteaser table quiz was held in D-Two in Dublin on October 21st and over €2,400 was raised. Our thanks again to quizmaster Rick O’Shea, all the businesses and individuals who sponsored prizes and of course everyone who came out on the evening. If you would like to organise a quiz night in your area, please get in touch. Brainwave can supply questions, scoresheets, promotional posters and lots more to help get your quiz up and running.

**Barrack Hill Ball Roll raises €5,550**

The fourth annual Barrack Hill Ball run in Cobh took place on Bank Holiday Monday 2nd August and Brainwave was one of the two charities to benefit this year. Over 6,000 numbered balls were sold for €2 and at 4pm they were all released from the top of Barrack Hill, with the owner of the first ball to reach the bottom declared the winner. Over 700 people attended including former World Athletics Champion Sonia O’Sullivan and her daughter Sophie. A fantastic total of €5,550 was raised for Brainwave! Our sincerest thanks to the organisers, Cllr Paddy Histon & Jim Sheeley for their ongoing support and to everyone who supported the event this year.

Tina Garreth, Larry Mulrey Snr, Ina Murphy (Brainwave) and Deirdre Mulrey present their fundraising proceeds

Members of the winning team with quizmaster Rick O’Shea and Brainwave’s Peter Murphy

Brainteaser Quiz Night

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Cork hurling legend Willie John Daly releases the balls at the top of Barrack Hill. Photo courtesy of John Hennessy Photography & The Evening Echo.

Cllr Paddy Histon (3rd from left) presents the proceeds of the Ball run to Brainwave’s Catherine Healy (l), Bernard Hughes and Frances Ambrose (r)
Fundraising

Fundraising Drive remembers Daire

Thank you to Vanessa O’Sullivan from Co Kerry for organising a charity drive around the Ring of Kerry in June for Brainwave. The event was held in memory of Vanessa’s cousin, Daire Foley from Tralee who died as a result of epilepsy at just nine years of age in 2006. The drive was launched at The Gleneagle Hotel by Deputy John O’Donoghue and featured almost 60 cars. Collections took place at various points on the drive and an amazing €2,123 was raised. Our thanks to Vanessa and to everyone who took part for their fantastic efforts.

Danielle & Mark’s Cycle

Congrats to Danielle Behan and Mark Harman who undertook the considerable task of cycling all the way from Dublin to Shannon to raise funds for Brainwave this September, raising a fantastic €860. “Brainwave has shown great support to me so it’s nice to give something back. It was tough, but worth it!” says Danielle.

Reunion raises €650

Our thanks to Mary Gorman from Co Laois and her colleagues who decided to donate €650, the proceeds of their recent telephonists reunion to Brainwave.

Moycullen Brownie & Guides

Thank you to the Moycullen Brownie and Guides in Galway who raised an outstanding €675 for our work. Pictured below are S Regan, G Egan, Evelyn Monson-Kirby (Brainwave), Sharon Griffin, Marie Turk and Erin Bohan.

All our Athletes

Thanks to all the athletes who pushed the limits to raise money for Brainwave this year, taking part in marathons at home and abroad. Pictured here are just three of many supporters - Michelle Whelton (Edinburgh marathon, right); Barry Doherty with Ita and Tara O’Leary (Cork, below right) and Lesley Browne (Dublin, below).

Rose Week

Thank you to everyone who contributed to the success of this year’s Rose Week in October. Pictured are just some of the volunteers who took part. Above are Mary Murphy, Sarah Murphy and Helen Lyons. Below is Shane Sinnott from Wexford. If you would like to volunteer for the upcoming St Valentine’s Roses campaign, we would be delighted to hear from you (see also back page).

www.epilepsy.ie
Regional News

Upcoming Events

Cork

Support Group
Tuesday 14th December 2010
Cork Office, 35 Washington St., 2.30 p.m.

Parents Support Group
February 2011
Bishopstown GAA Club
Date & Time to be confirmed.
For further information, contact Niamh at 021 4274774

North Cork Outreach Service
Mitchelstown, Mid-February 2011
One-to-one appointments, strictly confidential. For details or to make an appointment please contact Mary at 021 4274774

Kerry

Parents support group
Friday February 4th 2011
Brainwave Office, Killarney, 10.30am
For further Information contact Kathryn at 064 6630301

Midlands

(Co’s Offaly, Laois, Westmeath & Longford)

Parents Support Group Meeting
Thursday 3rd February 2011
OCIL, Clonminch Rd, Tullamore, 7.00pm

Parents and Carers Seminar
Monday, 14th February 2011
OCIL, Clonminch Rd, Tullamore
7.00pm
Speakers: Denise Cunningham, Clinical Nurse Specialist & Margaret Bassett, CRO. Admission is free but booking is essential. Call Margaret at 057 9346790

Contact Corner

Epilepsy, the senses & space

Claire Nolan is currently in the final year of her degree in architecture and needs your help! Claire writes, “For my thesis I am proposing a medical rehabilitation/treatment centre for people with long term medical conditions. As part of the process I am interviewing people with epilepsy about the relationship between epilepsy, the senses, and space. If you are interested in contributing to this (anonymous) study, please contact me at claire.nolan87@gmail.com.

Myoclonic-Astatic Epilepsy/Doose syndrome

The parents of a young child with Myoclonic-Astatic Epilepsy (MAE) or Doose syndrome are anxious to make contact with other parents in a similar situation, to discuss challenges and coping strategies. Contact Paul at Brainwave for details – 01 4557500.

Nurses Pack launched

Dr Colin Doherty, consultant neurologist and the HSE’s Clinical Lead for epilepsy officially launched Brainwave’s new information pack for nurses in October. Dr Doherty welcomed the new resource as an invaluable reference tool to all nurses caring for individuals with epilepsy. He said that patients with epilepsy will benefit greatly from this sharing of information.

The pack has been distributed by Brainwave staff to almost 20,000 nursing professionals all over the country this summer. It is the fourth pack developed for a specific professional audience over the past four years, aimed at GPs and employers.

Brainwave has also officially launched the online version of the pack. It is now available to download free of charge and to all nurses in Ireland. Nurses can email info@epilepsy.ie for access details.
Help us mark the first ever
European Epilepsy Day
Monday 14th February 2011

BRAINWAVE
THE IRISH EPILEPSY ASSOCIATION

- Watch out for our Seizure-Aware epilepsy awareness campaign in February

- Mark European Epilepsy Day and St Valentine’s day by taking part in our Valentine’s Roses fundraising campaign. Did you know that St. Valentine is the patron saint of epilepsy?

- Celebrate European Epilepsy Day by organising an awareness event or fundraiser in your community

Call us at 01 4557500 or see www.epilepsy.ie for more information on all of the above.