The Rose and the Thorn
Obama-inspired book supports Brainwave

National Epilepsy Week 2011
May 16th - 22nd
What do you know about your epilepsy?

In this issue:
Training For Success open day
Parenting & Epilepsy
International award for Irish epilepsy documentary
Irish epilepsy researchers make genetic discovery
Action Plan for Neurological Care
Welcome to the Summer 2011 issue of Epilepsy News. It’s another busy issue as we approach National Epilepsy Week (NEW), which takes place from May 16th – 22nd.

On page 3 you will find details of a new book, by Don Mullan and Brainwave member Audrey Healy which is being launched in NEW to help raise funds and awareness for epilepsy.

Also in this issue we present a four page feature called “What do you know about your epilepsy?” This comes about as a result of recent Irish research showing that many people with epilepsy are not well informed about their condition. While raising public awareness of epilepsy is an important aspect of Brainwave’s work (e.g. the recent Seizure Aware campaign), promoting awareness among people with epilepsy should not be overlooked. If you’re in Dublin, we’ll be hosting an information evening during NEW looking at issues raised in the study in more detail and you are very welcome to attend. See page 12 for more details. You can find details of other NEW events around the country in our Regional News section.

On page 4, we have a report on exciting new Irish research which may lead to a simple genetic test to identify which patients will experience side effects to one of the most common anti-epileptic drugs, carbamazepine.

Don’t forget that you can stay fully up to date with all the news and events by joining us on our ever growing Facebook and Twitter pages.

Best wishes from all at Brainwave!
Irish celebrities write about their highs and lows of the past year in support of Brainwave.

In a new book entitled The Rose and the Thorn, compiled by Don Mullan and Brainwave member Audrey Healy in aid of Brainwave, 50 well known Irish personalities, from Denis O’Brien to John O’Shea, Bryan Dobson to Joe Duffy, Mary O’Rourke to David Norris, all take time out of their busy schedules to reflect on their recent ‘roses’ and ‘thorns’ (their ‘highs’ and their ‘lows’ of the past year).

Contributors speak candidly about the passing of broadcaster Gerry Ryan and that of Michaela Harte, about the birth of much loved grandchildren and the legacy of the current economic climate amongst many other diverse and intriguing subjects.

Most of all, they speak from the heart and this is evident in the unique compilation of contributions included in this book which will be launched this National Epilepsy Week by Morning Ireland presenter Aine Lawlor, Senator David Norris and RTE’s Midland correspondent Ciaran Mullooly.

Amongst the varied selection of contributors are: Bertie Ahern, Claire Byrne, Brian Carthy, Una Claffey, Louis Copeland, Sharon Commins, John Creedon, Myles Dungan, Kieran Goss, Larry Gogan, Mick Hanly, Mike Hanrahan, David Kelly, Sr. Stanislaus Kennedy, Gerald Kean, Justin Kilcullen, Fr. Liam Lawton, Alf McCarty, Charlie McGintigan, Patsy McGarry, Eamon Morrissey, Deirdre Mullan, Mike Murphy, Denis O’Brien, Joseph O’Connor, John O’Shea, Cian O’Connor, Feargal Quinn, Eamon Ryan, Rebecca Storm, Eleanor Shanley and Ted Walsh.

The title of the book is inspired by Barack Obama who in 2009 revealed to journalists about how his family refers to their daily highs and lows as their “roses and thorns”. In 2010, Obama was asked in a TV interview about his recent “roses and thorns”, a clip that was later played on RTE’s Morning Ireland. At the end of the segment, presenter Aine Lawlor commented, ‘Isn’t that a wonderful question!’ Listening was journalist Don Mullan who immediately called his colleague, Audrey Healy, saying I’ve got a good idea for a new book!’ The rest is history!

Our thanks to Don and Audrey for all their work on this fantastic project to raise funds and awareness for epilepsy.

Get your copy today

The Rose and The Thorn is published by A Little Book Company and is available in Easons and all good bookshops for €9.99. You can also buy your copy from the online shop on Brainwave’s website at www.epilepsy.ie.

Competition: What are your Roses and Thorns?

Brainwave is asking our members to write about their own personal “roses and thorns” of the past twelve months. You can enter the competition by submitting a maximum of 400 words by email to info@epilepsy.ie before June 30th. Don’t forget to enter your name, address and daytime contact number. Entries will be judged by authors Audrey Healy and Don Mullan and the winning entries will be published in the next issue of Epilepsy News. The winners will also receive a signed copy of “The Rose & The Thorn”. For more info, contact Peter at 01 4557500.

National Epilepsy Week

What do you know about epilepsy?

Information Evening
Carmelite Centre, Dublin 2
Wednesday May 18th, 7pm

A recent Irish study (see page 9) has found that many people with epilepsy are not particularly well informed about aspects of their condition. This information evening will address all the areas of misunderstanding highlighted in the study. Admission is free and all are welcome.

Find out more and take the questionnaire used in the study at www.epilepsy.ie from May 16th.
A multinational team of scientists including Dr Gianpiero Cavalleri and his team at the RCSI have identified a gene that could indicate if epilepsy patients starting carbamazepine (tegretol) are likely to experience side-effects.

Dr Cavalleri’s work is part-funded by Brainwave’s research programme under the HRB/MRCG Joint Funding Scheme.

Carbamazepine is one of the most commonly prescribed treatments in epilepsy. It has been on the market since the 1970s and works well for many people. However, about 5% of people will react negatively to the drug. Some will develop a rash that will stop if the drug is withdrawn. Other rarer reactions include fever, hepatitis and kidney inflammation.

This study has raised the possibility of a simple genetic test that could predict which patients are likely to experience side-effects, allowing doctors to prescribe the drug with greater confidence and saving many patients the trauma of side-effects.

The researchers examined DNA from epilepsy patients in Ireland, UK, Belgium and the US. They screened over a million variants across the human genome to look for the genetic differences which mean some patients are more prone to the drug’s side-effects than others. They linked the effects with a gene called HLA-A*3101. Combining their findings with a team in Liverpool who were doing similar work, the researchers ascertained that the risk of developing reactions to the drug increases from 5% to 26% for patients with the gene.

Dr. Cavalleri says: “We hope that testing for this gene will soon become available for newly diagnosed epilepsy patients. Genetic testing approaches to diseases and treatments enable clinicians to develop more personalised treatment plans for patients.”

This significant research is published in the leading scientific journal, The New England Journal of Medicine.

As part of the Thinking Ahead campaign (www.thinkingahead.ie), the Neurological Alliance of Ireland has developed a 10-point Action Plan for neurological care outlining the steps that the new Government urgently needs to take to address the neurological crisis.

The Plan was launched by Prof. Orla Hardiman during Brainwave's research programme under the RCSI's Joint Funding Scheme. The Plan is supported by over 30 charities including Brainwave.

In summary, the Plan calls on the Government to:
1. Commit to protecting and improving neurological care
2. Develop and implement a comprehensive plan for neurological care
3. Protect funding to charities that are central to neurological care services
4. Develop acute neurology services to ensure that people can be diagnosed and treated as quickly as possible
5. Ensure that people with sudden onset neurological conditions have access to prompt specialist treatment
6. Ensure access to specialist rehabilitation
7. Develop specialist services in the community to support people with neurological conditions to live as independently as possible
8. Ensure that people with neurological conditions have an effective care plan and access to a key worker or case manager
9. Provide effective support for carers of people with neurological conditions
10. Provide the necessary skilled staff needed for our neurological care services

The full Action Plan can be downloaded from www.thinkingahead.ie.

What you can do:
You can support the Action Plan by:
- Adding your name to the growing list of people already supporting the Action Plan at www.thinkingahead.ie
- Lobbying your local TD to let them know how urgently they need to prioritise neurological care. You can send a personalised email from www.thinkingahead.ie to the TDs in your constituency.

Brain Awareness Week 2011 was one of the most successful to date with over 90 events organised nationwide by NAI member groups including Brainwave. The Week was launched by RTE’s Jimmy Magee focusing on how the number of people in Ireland with neurological conditions is set to increase from 700,000 at present to almost 870,000 by 2021 as our population ages.

A large crowd at the NAI’s Brain Awareness Week conference listens to Dr Barry White, Director of Clinical Care in the HSE.
International Award for RTE documentary

Niamh Maher, the producer of the 2009 RTE documentary "This is Me" has been announced as the winner of the 2010 Excellence in Epilepsy Journalism Award (broadcast section).

The award is a joint initiative of the International Bureau For Epilepsy and the biopharmaceutical company UCB and aims to raise awareness about epilepsy across the globe. It recognises journalists who have excelled in reporting compelling and informed stories that engage the audience on this often misunderstood condition. It is open to entrants from all over the world. A total of 43 entries from 17 countries were submitted.

Niamh Maher's documentary "Not Out", featured Brainwave member and Irish international cricketer Emma Beamish (right) and examines how Emma has learnt to live with her epilepsy through ups and downs since first diagnosed at the age of 14.

The documentary was aired on July 6th 2009 on RTE 1, attracting over 212,000 viewers.

The independent seven-member judging panel consisting of media experts and people with experience of epilepsy offered high praise for the documentary:

"Niamh Maher's observational documentary is a personal, insightful and inspiring piece of journalism," said Robert Cole, Chief Executive of Epilepsy Association of South Australia and the Northern Territory. "The heartfelt reflections on living with epilepsy provide a profound, positive insight into the important supportive role of family and friends. It is also a testament to the fact that epilepsy should not stand in the way of someone's aspirations."

Brainwave would like to congratulate Niamh and thank her and Emma for all they have done to improve epilepsy awareness in Ireland through this outstanding documentary.

The awards also recognise excellence in print journalism (won by Makiko Tatebayashi from Japan) and online journalism (won by Jessica Solodar, USA).

For more info, see the IBE website www.ibe-epilepsy.org

Programme for Government

The Fine Gael / Labour Programme for Government outlines the new government’s plans to address the major challenges faced by Ireland over the coming five years.

The full document runs to over 60 pages but in this article, we describe its main elements as it applies to people with epilepsy.

Health

The programme commits the Government to developing a universal, single-tier health service, with Universal Health Insurance (UHI) guaranteeing access to medical care based on need. UHI will provide guaranteed access to care for all in public and private hospitals on the same basis as the privately-insured have now.

More healthcare is to be delivered in the community. Universal Primary Care will be introduced removing fees for GP care. This will be initially available to claimants of free drugs under the Long-Term Illness scheme (which would include people with epilepsy) and on a phased basis to all others thereafter.

Everyone will be obliged to register with a primary care team when the system is fully implemented. Incentives will be provided to GPs to care more intensively for patients with chronic illnesses in order to reduce waiting lists and pressures on the hospital system.

Measures will be taken to reduce costs in the delivery and administration of the health care system. The HSE will cease to exist over time. Reference pricing and greater use of generics will be introduced to reduce the State’s large drugs bill. The previous government indicated that epilepsy medications would not be subject to generic substitution.

Unfortunately, neurological services or conditions with the exception of Alzheimer’s disease were not specifically addressed in the programme.

Social Welfare & Taxation

The programme includes a commitment to maintain both social welfare rates and the current rates of income tax bands and credits.

Education, Work and training

It is proposed to replace FAS with a new National Employment and Entitlements Service so that all employment and benefit support services will be integrated in a single unit managed by the Department of Social Protection. The programme also includes proposals for implementing the Education for Persons with Special Needs Act 2004.

Equality & Disability

The National Disability Strategy will be published and implemented in partnership with the disability sector.

The Programme aims to ensure that the quality of life of people with disabilities is enhanced and that resources are allocated reach the people who need them. For example, a proportion of public spending will be allocated to a personal budget model so that people with disabilities or their families have flexibility to make choices that best suit their needs.

It also aims to facilitate people with disabilities in achieving a greater level of participation in employment, training and education.
About Her: Film to raise awareness of SUDEP

By Darren Wells

Four years ago my girlfriend Sharon died of undiagnosed epilepsy at her flat and I found the body. I promised her in the chapel of rest that I would do the right thing, with no clue what that was. I firstly thought it was to write a book about our lives together, as a work of fiction. Rather like the character in the upcoming film, I always wanted to write. A few years ago, I finished fourth in a national poetry competition but it wasn’t until Sharon’s death that I found the motivation to write. I was lucky enough to get the book, Life & Soul published. On the face of it, it seems like a depressing story, but there’s lots of humour in it and some colourful characters. I then had coverage in a national magazine about the book and I was approached by writers who were interested in turning the story into a film. I initially worked with Irish writer, Gareth Smith and then with the Director, who is also an experienced film writer. The initial idea was a year and a half ago and we are now in the final stages of finalising that script.

We have been working with a number of companies, as well as with BAFTA award winning director, Nigel Douglas and an amazing producer, Richard Wynn. At the moment, we are lining up an incredible cast, with some amazing announcements in this regard to follow. We are looking to start shooting later this year. I’ve lived in Bournemouth all my life and having a film set here, about people I know and things I was part of is amazing. I think what makes this special is that it all really happened.

The thought of raising awareness of epilepsy, in a non-preachy way is something that’s been vital with every rewrite of the script. I now have a script that people seem to be excited about. I am hoping this film will give the same coverage to epilepsy as say Philadelphia did for HIV and maybe make it a tiny bit ‘trendy’!

A portion of the proceeds of the film will go to selected members of the Joint Epilepsy Council and the International Bureau For Epilepsy.

Please check out the website on www.abouther.org and the facebook page www.facebook.com/aboutherfilm. It would be great if nothing else if people could become fans. This is truly a place where you get something for nothing!

About Her: The Film

Set on the south coast of England, this contemporary film explores the nature of the pursuit of love and loss. Ethan, an everyman in his mid thirties, leads a dull unadventurous life, lonely and unfulfilled. The product of emotionally conservative parents, his time to find “the right one” is slowly ticking away. Then out of the blue, explodes a bundle of energy and free spirit. Victoria lives to live. Unaffected by the need to fit into conventional existence, Victoria works only to earn enough to travel the world. And look after her rabbit.

But she, like Ethan, has a desire to find an opposite – in her case, someone stable that she can build her future upon. This is a story of opposites attracting and making a perfect whole. Love comes quickly and totally.

This relationship threatens the security of the people around Ethan. Adam, his best friend from school, relies on Ethan as his playmate still living out their teenage years of pubs and clubs, whilst Ethan’s parents still see their son as their little boy – Victoria is far too much woman for their sheltered conservative life. They plan to marry, much to the horror of his parents.

Whilst Ethan is on his stag do, Victoria has a seizure and dies. Ethan’s life seems ruined and he must try to rebuild it, this time trying to recapture the excitement Victoria showed him. He knows he cannot go back to his boring life...ever. At first, he tries to live through Victoria’s memory, but this takes him deeper into grief and despair, until he faces suicide. Homeless, he feels there is nothing left for him.

He is dragged back from the edge by Anna. She, like Victoria, is free-spirited. She works at a shelter where she meets Ethan, helping him find a ‘new normal’. She becomes his only support. He, quite simply, feels he is against the world, until she helps him work out what he wants and helps him finally find comfort in his own skin.
Welcome!

Norma Mitchell
New Board Member of Brainwave

We are delighted to welcome Norma Mitchell to the Board of Directors at Brainwave. Norma was diagnosed with epilepsy at the age of 24, while canvassing in her husband’s first General Election campaign.

Married to former Minister for European Affairs and current MEP for Dublin Gay Mitchell, Norma was the organisation leader for his successful four City Council, eight Dáil and two European Parliament campaigns. She continues to manage his busy Dublin office during his absence in Brussels and Strasbourg.

A former Lady Mayoress of Dublin, she has been a youth leader and sports enthusiast and continues to be a community worker and volunteer with a number of organisations.

A mother of four, Norma has been a political activist in her own right and has held officer positions in the Dublin South Central organisation of Fine Gael where she was constituency secretary for many years.

Norma has been associated with Brainwave for many years and attended the European Congresses in Porto in Lisbon in 2010 and Copenhagen in 2006.

Michael McLoughlin
New Finance Committee member

We are also delighted to welcome Michael McLoughlin as a new member of Brainwave’s Finance Committee. Michael is the Chief Executive of Amárach Research – the leading independent market research agency.

Prior to joining Amárach in 2000 he worked in banking and financial services. In the course of his work he has undertaken a range of market research projects on consumer and business attitudes to products, services and the state of current affairs.

He led an important research project into Public awareness of epilepsy for Brainwave in 2005-2006.

He has recently led the expansion of Amárach into the US with the launch of a new monthly research programme on Irish America. He has been interested in politics and current affairs since he was a child, and was the Political Director of Fine Gael (on secondment from Amárach) between October 2008 and October 2010. He has MA and MBA degrees from UCD.

Outside of work Michael is married with two teenage children and a cairn terrier!

Research Funding Scheme

As part of our ongoing commitment to funding epilepsy research in Ireland, Brainwave launched our second call for funding proposals in late 2010. A total of 12 applications for funding were received, covering many different aspects of epilepsy research and showing once again the tremendous appetite and expertise within Ireland for conducting high quality epilepsy research.

Following an extensive peer-review process by dozens of international experts, Brainwave’s Research Board, chaired by Professor David Chadwick from the UK met in March to assess the applications and to make recommendations on which ones could be funded by Brainwave.

Unfortunately, Brainwave does not have the resources needed to fund all of the high quality proposals received, which would amount to an investment of over €1.2 million. However, two leading proposals were selected for submission to the Health Research Board (HRB) to be considered under a scheme of joint funding between the HRB and charities such as Brainwave.

Should the HRB consider these proposals worthy of funding, the total cost of the research will be split between Brainwave and the HRB.

A final decision will be made by HRB later in the summer and we will of course bring you further news then. Brainwave is currently funding three research projects, details of which can be found at epilepsy.ie

Roddy Fitzpatrick

An appreciation upon his retirement

A long standing member of Brainwave’s Finance Committee from 1994 – 2010, Roddy Fitzpatrick came to Brainwave at a time when his financial expertise was greatly needed.

At the age of five, Roddy began his lifelong association with Belvedere College. He later became involved with the Belvedere Benevolent Association and with the Belvedere Boys charity which raised funds for disadvantaged inner-city children.

Mr. Fitzpatrick was Branch Manager in Bank of Ireland, Rathfarnham. It was this financial expertise that he brought to Brainwave where he actively and tirelessly worked to improve the financial standing of the Association. He was appointed Chairman of the Finance Committee in 2000, a position he held until his retirement.

He was known to many Brainwave members through his active participation at the Horse Show Ball and other events, where he was always ready to offer support and encouragement to staff and supporters alike.

Roddy decided to retire from the Finance Committee to act as sole carer for his wife. His dedication to Brainwave and the expertise he brought to the Finance Committee is deeply appreciated, and his commitment to people with epilepsy will long be remembered.

Left: Members of Brainwave’s Research Board which met in March. (l-r) Dr Cathy Madigan, Prof David Henshall, Dr Pat Dicker, Mike Glynn, Dr Gianpiero Cavalleri and Prof David Chadwick (Chairman).
**Parenting with Epilepsy**

**Practical Issues for Mums and Dads with Active Seizures**

**By Geraldine Dunne, National Information Officer**

Becoming a parent can lead to a rollercoaster of emotions from excitement to apprehension. When your seizures are active there are additional issues to consider.

For women with epilepsy with queries regarding pre-conception, pregnancy and birth the Epilepsy and Pregnancy Register can offer specialised advice (Freephone 1800 320 820).

**Planning ahead**

If you cannot legally drive, you need to look at access to current services and those extra appointments at baby clinics etc. If relocating, home accessible transport links will be a priority. The home layout should be reviewed to make it easier to manage with a young baby or small child.

**Babycare**

Wash the baby on a mat on the floor rather than in a bath. Use a feeding chair so that the baby is secure. Reduce the use of stairs by keeping two sets of changing things - one upstairs and one downstairs. Seizure alarms can be used to dial contact persons for assistance.

**Explaining to Young Children**

Young children need age appropriate explanations of a parent’s epilepsy and how to call help for seizures. Even toddlers have been able to dial pre-set numbers to tell Granny that “Daddy fell” or call emergency services. Simple analogies like lights going out will help them understand seizures. Brainwave has leaflets which can support you with explaining epilepsy to your child.

**Supervision**

Parents with epilepsy may worry about their child’s safety if they have a seizure. All the usual toddler proofing precautions are advised with regard to sharp objects, open fires, cords, water, heat sources, sockets, flexes, freestanding objects, stairs, doors, medication and household chemicals. Ideally, it is best have the support of another adult to supervise the child if you have a seizure. However, it is wise to consider risks and ways to counteract them. If you know you will be alone at certain periods, you might designate one downstairs room for this purpose and keep it as free of hazards as possible. Window locks need to be effective and limit the furniture to low height to minimise falls. Ensure the garden is safe and secure and locks on gates are effective.

**Out and about**

A cord attached to the child’s wrist will prevent them straying if you have a seizure. A pram or buggy can be fitted with a “dead mans handle” to prevent it rolling. If you get a warning you may be able to ask for help or phone someone.

**Parental Help Card**

Even young children can use a parental help card. The child can be taught to give this to someone if mum or dad needs help. For safety reasons you may prefer to teach them to give this card to gardai, store security or shop assistants. The card states that the parent has epilepsy, explains seizure management and gives a contact phone number.

**Driving**

School runs and shopping trips can be curtailed if you cannot drive. If you have Disability Allowance or Invalidity Pension you can claim a Free Travel Pass. If you have supportive family or friends, this will be invaluable. It is often hard to ask for support but in a rural area you will need it more. Find out about local transport initiatives in your area. Transport issues may influence future decisions about where to live, work and send your child to school.

**Support**

A good support network of trusted people is key to coping with epilepsy and parenting especially if you can’t drive or need help with childcare. However, some people live distances from their families or have little support. Joining local networks, e.g. parent-toddler groups can help reduce isolation. If ongoing needs emerge regarding seizures and childcare, your Public Health Nurse may offer home support options.

**Tiredness**

Lack of sleep is a trigger for seizures and sleep can be affected by night feeds, teething and when a child is ill. It’s best if a partner can deal with these so you get sleep. Make up for missed sleep when you can. In the early months particularly, call in those offers of help to reduce seizure risk from sleep deprivation.

**Lone parenting**

Parenting alone can be challenging. If this is a difficulty for you talk to your Public Health Nurse and link in with a lone parents group.

**Custody and Access**

Occasionally, a parent’s epilepsy becomes an access or custody issue in the breakdown of a relationship, whereby one parent has cited the other’s poorly controlled epilepsy as a safety concern regarding unsupervised access. Courts must decide in the best interests of children but the few cases we are aware of have been resolved satisfactorily for the parent with epilepsy. Epilepsy need not become a barrier to custody and access. The focus should be on finding ways to support the parent with epilepsy to remain involved in their children’s lives.

For further information, please contact Geraldine Dunne, National Information Officer at 01 4557500.

[www.epilepsy.ie](http://www.epilepsy.ie)
Understanding Epilepsy

National Epilepsy Week Special Feature

Introduction

In the modern world, information is everywhere. Whereas twenty years ago, many people with epilepsy struggled to find the information they needed to better understand their condition, today a Google search of the word Epilepsy returns almost 20 million results.

But does simply having access to such vast quantities of information (existing on many levels of quality and reliability) mean that we are now better informed about epilepsy?

According to a recent study undertaken by the Department of Neurology at St. James’s Hospital and the School of Medicine, Trinity College, many people with epilepsy are NOT well informed about their disorder.

In this special feature to mark National Epilepsy Week 2011, we look at the findings from the study and then try to address some of the information deficits highlighted by it.

The study, “What do people with epilepsy know about their condition? Evaluation of a subspecialty clinic population” was published recently in the medical journal Seizure.

The Importance of knowledge and understanding

Many previous studies have found that a patient’s knowledge and understanding of their chronic disease has an important role to play in establishing good quality outcomes for that patient.

For example, a better informed patient with epilepsy will be more likely to provide relevant information to their doctor to aid in diagnosis. Well informed patients will also attain better compliance with medication, thereby resulting in better seizure control.

Studies undertaken with people with diabetes have found that education and counselling programs have demonstrated significant improvements in long-term control.

However, very little information exists regarding what patients with epilepsy actually know about their disorder. One recent American study concluded that patients with epilepsy are not well-informed about their disorder, irrespective of age, educational background, or number of years with epilepsy.

A UK study found that the majority of those interviewed with epilepsy were generally unaware of their seizure type and indications for their medication.

The St. James’s/Trinity College study aimed to determine, for the first time, the level of knowledge that patients with epilepsy have - not only about their own condition but also about epilepsy in general.

Study Methods

Seventy patients attending the St. James’s epilepsy clinic in Dublin were originally screened to take part in the study from June to September 2007. Of this pool, 52 adult patients were included in the final analysis.

Patients completed three surveys which had been used in the previous US and UK studies mentioned above, each designed to examine various aspects of patient’s knowledge:

1. A personal survey (Epilepsy Knowledge Profile-Personal) where patients were asked to write down their medication regime, the purpose and details of their treatment, and the results of their investigations.

2. Two separate surveys (Epilepsy Knowledge Scale & Epilepsy Patient Knowledge Questionnaire) consisting of true/false and multiple-choice questions regarding treatment, home circumstances, social effects of epilepsy, employment and driving. These surveys served to test the accuracy of patients’ beliefs surrounding the condition in general.

Results

1. The Personal Survey

• Just under 60% of patients knew the correct name for their seizure type.

• Just over half the patients (54%) who had an EEG assessment done actually knew the results of the test, while less than half (45.5%) of the patients who had a brain scan knew the results of the scan.

• While the vast majority of patients (94%) were taking AEDs and able to describe their medication schedule accurately (86.5%), only slightly more than half were aware of what their therapy was actually supposed to do.

2. Knowledge of Epilepsy

The results of the Epilepsy Knowledge scale (True or False questionnaire) are presented in Table 1 overleaf. In total, only 9 of the 19 questions were correctly answered by more than two-thirds of the people involved.

The results of the second questionnaire, the Epilepsy Patient Knowledge Questionnaire found the following:

• The majority (71%) of people correctly defined epilepsy as a disorder caused by abnormal electrical discharges in the brain.

• However, a significant 21% believe epilepsy is either a mental disorder or a contagious disease that causes symptoms such as shaking.

• Only two-thirds were able to list two things that they themselves could do to reduce their chances of actually having a seizure.

• One in ten patients believed it was acceptable to stop taking medication without first consulting a health professional if the patient had side effects or stopped having seizures.

• One-third of patients believed it was standard procedure to place an object in the patient’s mouth to prevent tongue swallowing.

• 40% thought that women should stop taking their seizure medication if they become pregnant.

• 10% thought it was acceptable to drink several units of alcohol daily with a meal.

• Only one-third were aware that patients must be seizure free for a year before being permitted to drive. One in five believed that patients could still drive while having seizures if they had someone else in the car, doubled up on medication, or pulled over when they sensed an aura.

• Only 21% of patients were aware that it is illegal for potential employers to specifically inquire about the diagnosis of epilepsy.
Understanding Epilepsy

What do these results mean?

The main finding is that there are widespread misconceptions about epilepsy, its origin, diagnosis, treatment and prognosis. Patients scored slightly better on questions related to the particulars of their own condition rather than general epilepsy-related facts. The researchers suggest that this is due to “a deficit in information transfer from health professionals rather than general lack of interest of engagement”.

Another key finding is that patients tended to get more questions relating to legal issues and safety wrong compared to questions on medication and social issues. On the positive side, the vast majority of people were able to describe their treatment regimen, which may imply good general compliance.

However, the authors also point out that because the patients involved in the study had access to structured counselling and education through the epilepsy clinic, their knowledge may actually be higher than people who attend general neurology clinics.

The results of this Irish study show both similarities and notable differences when compared to the US and UK studies mentioned above. Compared to the American study, Irish patients scored better on legal issues regarding employment, but worse on legal requirements for driving. In the UK study, patients scored lower on questions related to their personal condition rather than general knowledge of epilepsy, the opposite of what was found in Ireland.

Clearly, this study highlights the fact that there is a need for better education on specific epilepsy-related matters particularly in relation to personal safety, legal and employment issues.

The authors recommend that Epilepsy Nurses should play a critical role in patient education. Brainwave Community Resource Officers, whose role is to support and educate people with epilepsy and their families also play a key role in helping to empower patients to make good decisions about their epilepsy, promote good self-management and alleviate anxiety associated with seizures.

Table 1: Results of the Epilepsy Knowledge Scale used in the recent Irish study.

<table>
<thead>
<tr>
<th>Question</th>
<th>Correct Answer</th>
<th>% of correct replies</th>
</tr>
</thead>
<tbody>
<tr>
<td>People with epilepsy should avoid strenuous work because this can provoke seizures</td>
<td>False</td>
<td>48%</td>
</tr>
<tr>
<td>An EEG can always prove the diagnosis of epilepsy</td>
<td>False</td>
<td>58%</td>
</tr>
<tr>
<td>People with epilepsy are as capable as other people</td>
<td>True</td>
<td>94%</td>
</tr>
<tr>
<td>All people with seizures should avoid working with open machinery</td>
<td>False</td>
<td>19%</td>
</tr>
<tr>
<td>Every seizure destroys a number of nerve cells in the brain</td>
<td>False</td>
<td>38%</td>
</tr>
<tr>
<td>People with seizures should not swim without an accompanying person</td>
<td>True</td>
<td>75%</td>
</tr>
<tr>
<td>All people with epilepsy should avoid flashing or strobing lights (eg. disco lights, TV or computer screens)</td>
<td>False</td>
<td>48%</td>
</tr>
<tr>
<td>In most cases, doctors can control epileptic seizures with medication</td>
<td>True</td>
<td>86%</td>
</tr>
<tr>
<td>If your seizures are controlled for some months, you can reduce the dose of anti-epileptic medication</td>
<td>False</td>
<td>42%</td>
</tr>
<tr>
<td>All people with epilepsy have similar symptoms</td>
<td>False</td>
<td>71%</td>
</tr>
<tr>
<td>If a patient expects a seizure, he/she should take an additional dose of anti-epileptic medication</td>
<td>False</td>
<td>75%</td>
</tr>
<tr>
<td>On job applications, a patient should always disclose his/her epilepsy condition</td>
<td>False</td>
<td>31%</td>
</tr>
<tr>
<td>People with epilepsy can take an active part in sports</td>
<td>True</td>
<td>90%</td>
</tr>
<tr>
<td>An epileptic seizure always results in loss of consciousness</td>
<td>False</td>
<td>60%</td>
</tr>
<tr>
<td>People who seize only during sleep may hold a driver’s license</td>
<td>True</td>
<td>25%</td>
</tr>
<tr>
<td>Everyone can have a seizure, given the appropriate circumstances</td>
<td>True</td>
<td>69%</td>
</tr>
<tr>
<td>Blood samples can be used to measure the concentration of anti-epileptic medication in the body</td>
<td>True</td>
<td>77%</td>
</tr>
<tr>
<td>Epilepsy is a symptom of mental illness</td>
<td>False</td>
<td>81%</td>
</tr>
<tr>
<td>If persons with epilepsy drive, they must inform the driving authorities about their condition</td>
<td>False</td>
<td>10%</td>
</tr>
</tbody>
</table>
Understanding Epilepsy

National Epilepsy Week Special Feature

Over the next two pages, we will look at the key areas of information deficit found in the study and attempt to address them. Brainwave staff and Community Epilepsy Specialist Nurses are always on hand to answer any specific questions that you may have on these or other issues.

Building Awareness

The findings of the research outlined suggest a deficit in many people's understanding of epilepsy; treatment and management of the condition and their employment rights.

Brainwave has produced a number of information leaflets to address all these issues; they are all available for download from our website www.epilepsy.ie or by calling 01 4557500. It is important for people to fully understand the condition and its possible implications so they are better prepared to explain the supports they may need in any given situation.

Brainwave’s recent Seizure-Aware campaign was designed to help the general public better understand epilepsy, in particular issues around first aid. While this was very successful it would be naïve to think it has changed everyone’s perception of epilepsy. Everyone has a role to play in educating the public and who better than the people who are living with the condition. If however as the research findings show, people with epilepsy are not as well informed as they should be, there is work still to be done.

Knowledge of Epilepsy

Getting a diagnosis of epilepsy can lead to a range of emotional reactions from shock, upset, disappointment, anger, denial or even relief. A person may have fears and concerns about the impact of the diagnosis on their life and family. It can be hard to know where to start to find answers to all the questions that arise from a diagnosis. Part of the solution is knowing the right questions to ask. Brainwave has two important resources to help. The Epilepsy Checklist provides a list of all the things a person should know about their epilepsy. The booklet You, your GP and Epilepsy can help a person prepare for medical interviews with their doctor.

Taking Control of Epilepsy

Taking control of your epilepsy is an important part of managing the condition. In addition to taking your anti-epileptic medication there may be other things you can actively do (or not do) to help reduce seizure frequency. Brainwave’s leaflet Taking Control of Epilepsy offers advice on identifying any potential triggers in your lifestyle which may impact on your seizure pattern and which you could avoid or minimise.

Two accompanying leaflets Epilepsy and Lifestyle Issues and Epilepsy and Construction looks at health & safety restrictions which may be necessary. They also look at how both adults and children with epilepsy can live a full life with the condition through the adoption of safety measures, particularly in respect of activities where having a seizure would pose a risk to one’s own safety or that of others.

Employment

There are only a few careers that remain closed to a person with epilepsy. They are airline pilot, train driver and the emergency/defence forces (Army, Navy, Gardai, and Fire Brigade etc.). The former are due to a licensing issue, while the latter are exempted under Equality Legislation. All other situations should be looked at in relation to the specific type of epilepsy and the nature of the work to be undertaken. This is why it is important that a person with epilepsy can communicate the nature of their condition.

Disclosure

There is no obligation for a person to disclose any medical condition unless it is at a medical examination. A person with epilepsy should not put themselves or anyone else at risk and will in some circumstances have to disclose to ensure their own safety. A leaflet on Disclosure discussing the pros and cons of when a person should disclose is available from Brainwave.

Safety in the Workplace

Epilepsy does not usually force employers into taking extra safety precautions in the workplace, and several notable studies have shown that the risk of employees with epilepsy having an accident is low. It is important to note that an epileptic seizure does not reduce the employee’s contribution to overall productivity or to his/her position within the workplace. However, it is important to inform workmates who will be directly affected about the condition. The employer should help the employee with epilepsy to disclose his/her condition. Some first-aid training or other information should be provided for those who might be involved should a seizure occur. Again, Brainwave can assist with this.

Insurance

It is often assumed that employing someone with epilepsy is ultimately going to result in an increased premium. This is not the case. No special insurance is required for a worker with epilepsy. At a basic level, employers should ensure that they are covered by Public Liability Insurance and Employers’ Liability. Premiums are only affected by claims, and there is no evidence to suggest claims increase by employing someone with epilepsy.

These and other employment issues are explored in Brainwave’s booklet Epilepsy and Employment.

Photosensitive Epilepsy

This is probably one of the most misunderstood aspects of epilepsy. Photosensitive Epilepsy (PSE) describes sensitivity to flashing or flickering lights as...
well as some patterns and glare. Reactions to flashing lights vary from person to person. Only about 3-5% of people with epilepsy are photosensitive. Many unnecessary restrictions have been placed on people with epilepsy including not being allowed to work with computers; not being able to attend discos etc. all because it is believed that everyone with epilepsy is affected by flashing lights. Again Brainwave has produced a very comprehensive leaflet Photosensitive Epilepsy to deal with the subject.

This is just a sample of how we are trying to provide information to help people fully understand their condition. Unfortunately there is still a stigma attached to the condition and perhaps some people don’t fully engage in the process of self-education because to do so is an acceptance of having the once described “dreaded disease”. There is no shame in having epilepsy and if it is to be brought fully ‘out of the shadows’ everyone needs to be better informed, including it would seem those living with epilepsy.

Brainwave will be holding an awareness evening in Dublin during National Epilepsy Week to deal one by one with the issues highlighted in the Research Questionnaires used in the study at St James’s Hospital (see below).

For even more information on epilepsy, check out the very comprehensive Epilepsy Information and Publications sections on epilepsy.ie

List of Brainwave publications
Available from our offices or from www.epilepsy.ie free of charge.

Alcohol & Epilepsy
Anti Epileptic Drugs (AEDs) Charts
Anti Smother Pillow Forum
Autism & Epilepsy
Be safe, Reduce Risks
Complex Partial Seizures
Construction & Epilepsy
Contraception for Women with Epilepsy
Diagnosing Epilepsy
Disclosure of Epilepsy
Driving Regulations
Entitlements
Epi-Alert Identity Bracelet Form
Epilepsy Checklist
Epilepsy in Infants
Epilepsy Surgery

Understanding Your Epilepsy: Information Evening, Dublin

Wednesday 18th May
Carmelite Community Centre, Aungier St, Dublin 2.  7.00pm – 9.00pm
Admission is free. Light refreshments served.

How many of the questions in the St James’s study questionnaires would you have answered correctly? Would you like to know more about epilepsy, its management and its consequences?

Join us during National Epilepsy Week in Dublin for an information evening which will answer these questions in more detail as well as any other questions that you may have yourself.

Present to answer your questions will be Brainwave support and information staff Paul Sharkey, Geraldine Dunne and Ina Murphy as well as Community Epilepsy Specialist Nurse Sinead Murphy.

If you would like to attend, please let us know at 01 4557500 or info@epilepsy.ie. If you would like to submit a question in advance, please email the address above.
The first planning day to help develop Brainwave’s Strategic Plan 2012 – 2016 was held on Saturday, 29th January in Dublin. The new strategic plan will set out long-term objectives for Brainwave over a five-year period.

Mike Glynn, CEO of Brainwave warmly welcomed all the Brainwave members present and outlined the objectives and achievements so far of the current Strategic Plan 2007 - 2011. The current plan is underpinned by six organisational objectives: Support & Information; Awareness; Training & Education; Research; Advocacy and Raising Funds and Mike looked at each of these sections in turn.

Dr Colin Doherty, HSE National Clinical Lead in Epilepsy, gave an enlightening and engaging presentation on the development of the National Epilepsy Care Programme since its inception in May 2010. The programme aims to improve both the quality of epilepsy care in Ireland and improve access to that care, while at the same time reducing cost and wastage within the system.

Dr Doherty’s plans include a network of Regional Epilepsy Centres, a nurse-led ambulatory service, expanded pre-surgical evaluation, centralised administration and epilepsy case management at community level.

Following lunch, Brainwave members were split into three working groups. The groups provided members with an opportunity to feed into the strategic planning process and to articulate their needs and aspirations for Brainwave over the next five years.

All the feedback and suggestions were documented and where organisationally and financially feasible, they will be incorporated into the Strategic Plan 2012 – 2016. Some of the key points expressed by Brainwave members are outlined below:

**Support & Information**
- Very beneficial to have access to Community Resource Officers regionally.
- Website is a good place to start for epilepsy information but more detailed information is needed.
- More opportunities are needed for members to meet in a relaxed social setting, particularly young people.
- Social media should be developed to allow members to communicate more.
- Nurse helpline is a beneficial service but many people may not be aware of it.
- Newsletter is generally good, particularly the personal stories. Suggestions included a children’s section and more on epilepsy research.
- Support groups are very important but other formats could be explored, e.g. support activities for different age groups.
- Consider events for parents, young adults, children who are looking after parents with epilepsy. More family days would allow children with epilepsy to interact.

**Training & Education**
- Target groups such as GPs, Gardaí, airline staff and pharmacists who need more education and training.
- There is a lack of information for children whose parent has epilepsy.
- Brainwave’s work with schools is very positive but there is still a lack of knowledge.
- More publicity of the TFS course and information about its content is needed.

**Research**
- Research is beneficial, but some suggested that resources could be spent elsewhere.
- Future research could look at alternatives to medication, how to limit side effects and gene therapy.

**Advocacy**
- Target the inappropriate use of terminology such as ‘fit’ and ‘epileptic’ in the media.
- Target TV producers and concert arenas to limit use of flashing lights.
- Continue to lobby for more neurology services around the country.

Members were also asked to ponder the question “if money were no object …”? Finding a cure was not surprisingly the ultimate objective, and if this was not possible, a drug with no side-effects. Other areas highly ranked were additional research into epilepsy, more awareness programmes and better access to specialist services.

During the remainder of the year Brainwave will engage with a range of stakeholders to further develop the plan which we hope to have finalised by the end of 2011. If you have any comments or queries on the plan, please do not hesitate to contact any member of our staff.

Dr Colin Doherty speaking about the National Epilepsy Care Programme

**Epilepsy Awareness**
- Public awareness is low and stigmatisation exists. There is a need for a media campaign with TV ads like those for stroke awareness.
- The name “Brainwave” could be a barrier to awareness as people don’t immediately associate it with epilepsy.
- The quality and design of ID bracelets needs to be updated.
- Build new partnerships and alliances to promote awareness and education.

Mike Glynn updated members on work completed under the 2007-2011 Strategic Plan

Sixty Brainwave members attended the Strategic Planning day
Following the success of recent youth conferences around Ireland, a further two events were held on Saturday March 12th in Galway and Cavan. Both were well attended and all the feedback was very positive reflecting the energy and participation during the day.

Galway (Organised by Brainwave’s Galway and Limerick Offices)
“The fact that the speakers were young made their talks more appealing”

Guest speaker Teresa Leahy, Neuroscience Nurse Specialist, National University Hospital Galway, gave a very informative talk covering a wide range of epilepsy issues. Her presentation included the initial diagnosis of epilepsy; the very crucial aspect of seizure management; and perhaps most importantly getting the most from your neurologists' appointments. The fact that the speakers were young made their talks more appealing.

Next up was Andrew Magee, IRCHSS PhD Scholar. He covered the psychosocial aspects of epilepsy amongst young adults in Ireland, touching on many important and sometimes thorny issues; driving; alcohol and drugs; education and training; employment and the all-important issue of disclosure. He also looked at some practical issues such as concentration and memory techniques. The family environment can be a very supportive and safe haven for many people with epilepsy but there comes a time when the wings have to be spread. Andrew spent some time dealing with the comfort and pressure that can be experienced within family life; moving out of the home environment and going to college. Both presentations generated a very lively discussion and the afternoon’s creative workshop, designed specifically for the audience and facilitated by Play Therapists, Lindsey McNeillis and her colleague Nora, lifted spirits even higher.

Cavan (Organised by Brainwave’s North East and North West Offices)
“I got great information from the speakers. They were very clear and what they said is very useful to me”.

Dr Kevin Murphy explains how epilepsy treatment has come a long way

Some people had never experienced this type of work before now and were pleasantly surprised. Lindsey and Nora started by bringing the group together with a series of games and a sense of cohesion was created amongst the group. This was followed by a visualisation exercise and it was then suggested that the art materials (paint, clay, crayons, pencils, etc) were used by each person in the group. Some used the visualisation and others picked other issues in their lives to work with the art materials. The evening closed after a series of music games and everyone left in an upbeat mood.

Our thanks to all the speakers at both conferences and to all the young adults pull back. He called this the “Irish mammy syndrome” and there wasn’t a person in the room who could not relate to this! He also discussed strategies for achieving healthy independence and advised newly diagnosed young people to research the condition and be informed.

Two very interesting personal stories followed from Colm O’Connor (a current Training For Success student in Sligo) and Jennifer Murphy (a former graduate of the programme). The day ended with a series of workshops dealing with stress in the school and college setting; education, employment and travel; and for parents and friends a session on fostering independence.

Dr Sandya Tirupathi from the Royal Hospital in Belfast was the afternoon speaker. She tackled the issue of “Putting Epilepsy in its Place”. She put a big emphasis on the importance of getting enough sleep, not abusing alcohol and compliance with medication. Like the other speakers, Sandya spoke about the need for the young person with epilepsy to take responsibility for their own health and safety.

The day ended with a series of workshops dealing with stress in the school and college setting; education, employment and travel; and for parents and friends a session on fostering independence.

Our thanks to all the speakers at both conferences and to all the young adults that made the events so successful.
Clinical Update on Epilepsy

As part of Brain Awareness Week in March, Brainwave and the Royal Society of Medicine (Ireland Region) came together to organise a one day conference on epilepsy for health professionals. The conference was focused on paediatric epilepsy and many of Ireland’s leading epilepsy experts presented.

Dr. David Webb, consultant paediatric neurologist at Our Lady’s Hospital, Crumlin spoke about the classification of epilepsy and used video footage to highlight the numerous other diagnoses that can be mistaken for epilepsy. He said that it important for health professionals to consider not just the symptoms but also the sequence of events and the setting in which the attack took place. In recent times, smartphones have been a useful tool in making a diagnosis as they allow people to take video footage of the symptoms.

Dr Bryan Lynch, consultant paediatric neurologist at Temple Street gave an overview of epilepsy treatments, how they work, side effects and indications. Since 1993, there have been 11 new epilepsy drugs, but still more than 30% of people do not respond to drug treatments. He said that if a person does not respond to the first three drugs, there is little chance of subsequent drugs working. He also looked at some new treatments in the pipeline such as retigabine and brivaracetam which hold promise for the future.

Dr Cathy Madigan and Dr Helena Rushe from Temple St spoke on the psychosocial consequences of epilepsy. Dr Madigan highlighted one study which showed that 28% of children with epilepsy had psychiatric problems compared with just 6% of the general population. Dr Rushe discussed some of the key growing up issues that are faced by children and adolescents including: not being able to take part in sleepovers; fearing a seizure at parties; fearing telling people about epilepsy; being teased and being slower at school.

Dr Joyce Senior from UCD spoke about the cognitive and behavioural functioning of students with epilepsy. She explained that Special Needs Assistants are being withdrawn at the moment, a move that will have a negative impact on many children with epilepsy at school.

Dr Sandya Tirupathi from the Royal Hospital Belfast spoke about the need for better transitional services for adolescents when moving from paediatric to adult services. Transferring teenagers into the adult system can be very disruptive as new healthcare professionals have to be introduced while losing ones that have become familiar and trusted. This often leads to adolescents dropping out of services altogether.

Dr. Danny Costello, consultant neurologist at CUH, Cork discussed the important issue of epilepsy mortality, in particular a recent UK study which followed up almost 1200 people diagnosed with epilepsy 20 years ago. The study found that the mortality rate was 2.2 - 2.6 times higher in people with epilepsy compared to the general population. He concluded that SUDEP was a difficult topic for health professionals to approach but that it needed to be discussed.

Brainwave member Emma Beamish spoke from the patient’s perspective, encouraging medical professionals to not simply issue instructions to patients but to explain why these instructions are necessary. Treating epilepsy was not just about treating seizures she said, but about treating the whole person. For some people, side effects can be a bigger problem than the actual seizures, she added.

A big thank you to all the speakers.

Dr. Cathy Madigan, Temple St

Ann Connolly, paediatric neurology nurse specialist, Tallaght

Dr Cathy Madigan, Temple St

Brainwave member Emma Beamish

(l-r) Brainwave President Dr. John Kirker with Dr Bryan Lynch and Dr David Webb

Dr Sandya Tirupathi from the Royal Hospital Belfast spoke about the need for better transitional services for adolescents when moving from paediatric to adult services. Transferring teenagers into the adult system can be very disruptive as new healthcare professionals have to be introduced while losing ones that have become familiar and trusted. This often leads to adolescents dropping out of services altogether.

Ann Connolly, paediatric neurology nurse specialist at AMNCH explained how telephone and email advice lines have become a major part of the service provided by Epilepsy Specialist Nurses. She concluded that epilepsy nurses are a value for money model of care that offers long-term sustainability.
Arthur Dagge

Arthur Dagge, husband of Brainwave Chair Tessa Dagge passed away suddenly in late January. Arthur developed epilepsy at a young age but did not let it interfere with his life and he achieved seizure freedom and maintained it.

Arthur was educated at Belvedere College, Clongowes and the Farm Street Jesuit Church in London, where as a young man he sought their guidance on whether he should become a priest, to be told “that while the Jesuits needed good men, that he was too good and to go find himself a wife”.

During his career he owned Dagge’s Newsagents in Glasnevin and was President of the National Federation of Retail Newsagents (NFRN) in 1975 and 1987.

He was dedicated to the Church and heavily involved in his local parish in Rathfarnham. He was also involved in the Belvedere Benevolent Association. At the time of his death he was planning the 60th year reunion of his Belvedere College leaving certificate class.

From an initial phone call enquiring whether he could aid the Special Olympics in 2003 “by sealing envelopes and sticking on stamps” Arthur became a member of the Family Services Committee at Special Olympics headquarters.

A keen gardener, Arthur was the current Public Relations officer of the Alpine Garden Society and a former President. He was an enthusiastic member and always on hand to make sure events ran smoothly, with his customary good-humour.

Brainwave extends sincere condolences to his wife, Tessa, children Bernard, Fiona and Siobhan and to his granddaughter Ruth who was the light of his life.

Deirdre Commins

The recent death of former Brainwave Community Resource Officer, Deirdre Commins has left a huge void in all the lives that she touched.

Deirdre sadly passed away in her sleep in her home on the 4th October 2010. Deirdre worked as the Community Resource Officer covering the South East region from 2003 to 2008 and although Deirdre was no longer working with Brainwave she always kept up contact with her former colleagues and is sadly missed by all.

Deirdre was a committed member of the staff team and worked tirelessly in the South East region providing support and information to people living with epilepsy. She built up many strong relationships and partnerships with other organisations in the region and her sense of humour brightened up any meeting.

Deirdre not only worked for Brainwave, she also volunteered with the Samaritans during this time which demonstrated the level of compassion that Deirdre had for others. When asked to describe Deirdre, words such as entertaining, passionate, empathetic and a people’s person come to mind. Brainwave would like to extend our deepest sympathy to the Commins family who will miss her greatly. May she Rest In Peace.

Creative Corner

I've had epilepsy a year indeed,  
It began in Spanish class with Ms.Meadd  
It was a strange start to a brand new school,  
I didn’t even know a single rule.

After the appointments in Temple Street,  
I go into town for something to eat,  
My friends are amazing dealing with it,  
My family are helping bit by bit.

I have to take tablets each day and night,  
Ten kepra a day is working just right,  
I often can’t do things I would enjoy,  
I hate the seizures, they tend to annoy.

If I’m seizure free for more than three years,  
I’ll be jumping around in joyful tears.
Noeleen a call at 01 4557500. Please read on and give Peter, Glenna or Noeleen to help Brainwave’s fundraising efforts, co-ordinated so if you think you might be able of fundraising needs to be locally co-ordinated. To be effective, this type of fundraising asks a large number of people for a small contribution. Today, the most effective fundraising appears to be the more traditional forms that ask a large number of people for a small contribution. To be effective, this type of fundraising needs to be locally co-ordinated so if you think you might be able to help Brainwave’s fundraising efforts, please read on and give Peter, Glenna or Noeleen a call at 01 4557500.

Brainwave is looking for members to assist us in setting up and coordinating local fundraising activities around the country. The recession continues to affect charity fundraising and many organisations including Brainwave are finding greater pressures on their ability to provide core services than ever before. Your help can ensure that we continue to support and represent people with epilepsy as we have done since 1966.

Today, the most effective fundraising appears to be the more traditional forms that ask a large number of people for a small contribution. To be effective, this type of fundraising needs to be locally co-ordinated so if you think you might be able to help Brainwave’s fundraising efforts, please read on and give Peter, Glenna or Noeleen a call at 01 4557500.

Volunteer Fundraising Co-ordinators wanted

What does it involve?
The role would involve recruiting & organising a team of volunteers to help with some or all of the following:
• Rose Week (October) and St Valentine’s Roses (February) campaigns
• Flag days or Bucket collections e.g. at summer sporting events
• Church gate collections (once a year)
• Local supermarket bag packing
• Selling tickets for Brainwave’s annual National Raffle (September) and Brainwave Christmas cards

You would be responsible for organising volunteers, distributing and collecting rose boxes, buckets etc, counting and lodging of cash (with one other person) and liaising with Brainwave’s fundraising staff.

Induction, support & guidance will be provided on an ongoing basis from fundraising staff. While the role is voluntary, any expenses incurred are reimbursed through Brainwave.

Skills required
We are looking for people who have a genuine interest in helping to raise awareness and funds for epilepsy. We are looking for people who are trustworthy, reliable and friendly with good communication skills. You must have the ability to work on your own initiative. You should have good organisational skills and experience in keeping records, managing bank lodgments and using email. Ideally you will have access to a car. Being well known in your area would be an advantage.

Informal Interviews and reference checks will take place. For further information, please contact Glenna, Peter or Noeleen at fundraising@epilepsy.ie or 01 4557500.

Martin’s skydive

Thanks to Martin Murphy from Enniscorthy who quite literally took the plunge for Brainwave - out of a plane from 10,000ft up! Not only did he live to tell the tale, he looks pretty chuffed with himself too. Well done Martin and thanks for going to such extreme measures to raise money for Brainwave!

Mary’s birthday bash

On the occasion of her 50th birthday celebration, Mary Conway from Castleblaney asked her family and friends to make a donation to Brainwave instead of giving her presents. Mary had her birthday party in the Oram Social Club and raised a grand total of €800 on the night. Mary was delighted with the response from her family and friends as Brainwave is a charity close to her heart. Brainwave would like to say a big thank you to Mary and wish her a belated happy birthday!

Fundraisers & Volunteers

• A big thank you to Seamus Buggy for his hardworking efforts organising a fundraising Table Quiz in Castlecomer recently. Seamus raised a fantastic €1,085.
• Thanks to David Walsh who raised over €400 so far, with more proceeds to come in, from a fundraising Hunt event in Tipperary to mark European Epilepsy Day.
• Thanks to you the students and staff of Roscommon CBS; Laurel Hill in Limerick; Colaiste na Coiribe in Galway; SHS Tullamore and Colaiste Choilm Tullamore who took part in Brainwave’s recent collections.
• Thanks to Baileys Diageo who donated €1,000 to Brainwave through their health and safety in the workplace scheme. For every month that there are no workplace accidents, a donation of €1,000 to a staff-nominated charity is made. Our thanks to Brainwave member Ben Molloy who nominated us as his chosen charity.
• Thanks to Martin Murphy from Enniscorthy who quite literally took the plunge for Brainwave - out of a plane from 10,000ft up! Not only did he live to tell the tale, he looks pretty chuffed with himself too. Well done Martin and thanks for going to such extreme measures to raise money for Brainwave!

Jason Brennan Benefit Night

11 June, Kildare

The friends and family of the late Jason Brennan are organising a benefit night in Jason’s memory on Saturday 11th June at the Derby House Hotel, Kildare.

Jason was a young man who died as a result of a seizure in February this year. Since then, his family and friends have been very active in raising awareness and funds for Brainwave in Kildare and in Jason’s home town, Bagenalstown, Co. Carlow.

The upcoming benefit night will see top bands Seven Days and the Painless Windows perform as well as plenty of other activities on the night including a sponsored head shave and special guest appearances.

Tickets for the event are available at a cost of only €5. For more information see epilepsy.ie or the mycharity page: www.mycharity.ie/event/jayobenefitnight

Brainwave Christmas cards

National Raffle (September) and summer sporting events

Regional Raffles

Roses (February) campaigns

Regional collections:

Flag days or Bucket collections e.g. at summer sporting events

Church gate collections (once a year)

Local supermarket bag packing

Selling tickets for Brainwave's annual National Raffle (September) and Brainwave Christmas cards

What does it involve?
The role would involve recruiting & organising a team of volunteers to help with some or all of the following:

• Rose Week (October) and St Valentine’s Roses (February) campaigns
• Flag days or Bucket collections e.g. at summer sporting events
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Induction, support & guidance will be provided on an ongoing basis from fundraising staff. While the role is voluntary, any expenses incurred are reimbursed through Brainwave.

Skills required
We are looking for people who have a genuine interest in helping to raise awareness and funds for epilepsy. We are looking for people who are trustworthy, reliable and friendly with good communication skills. You must have the ability to work on your own initiative. You should have good organisational skills and experience in keeping records, managing bank lodgments and using email. Ideally you will have access to a car. Being well known in your area would be an advantage.

Informal Interviews and reference checks will take place. For further information, please contact Glenna, Peter or Noeleen at fundraising@epilepsy.ie or 01 4557500.
**Regional Events**

**East Region**

(Co’s Dublin, Kildare, Wicklow)

For further information on events in this area, contact: Ina Murphy, CRO

Brainwave Head Office, 249 Cumminl Rd, Dublin 12
01 4557500
Email: imurphy.brainwave@epilepsy.ie
Mon & Tue 10am - 6pm; Thur 1.30 pm - 6pm

Upcoming Events

**Outreach Service:** St. James’s Hospital Every Wednesday: 1:30 pm - 6.00pm

**Dublin:** Parents Information & Support Evening
Monday, May 16th
Clarion Hotel, Liffey Valley, 7.30pm
Admission: €5 to cover tea, coffee & biscuits. Denise Cunningham, Clinical Nurse Specialist in Epilepsy Services will be in attendance to answer questions.

**Dublin:** Support Group for Women
Tuesday, May 17th
Brainwave Office, 8.00pm

**Nasal:** Outreach Service
Monday, 6th June
Nasal Health Centre, 11.00am – 5.00pm
By appointment only. Please phone Ina to arrange.

**Dublin:** Support Group for Men
Tuesday 21st June
Brainwave Head Office, 8.00pm

**Newbridge:** Kildare Outreach Service
Tuesday, June 28th
Health Centre, Newbridge, Co. Kildare
By appointment only. Please phone Ina to arrange.

**Balbriggan:** Outreach Service
Thursday, 30th June
Sarsfield Centre, 2.00 – 6.00pm
By appointment only. Please phone Ina to arrange.

**Wicklow:** Outreach Service
Monday, 4th July
Arklow Health Centre, Co. Wicklow
By appointment only. Please phone Ina to arrange

**Balbriggan:** Outreach Service
Thursday 25th August
Sarsfield Centre, 2.00pm – 6.00pm
By appointment only. Please phone Ina to arrange

**South East Region**

(Co’s Kilkenny, Carlow, Wexford, Waterford & South Tipperary)

For further information on events in this area, contact: Joan Ryan, CRO

The Ground Floor, St Canice’s Hospital
056 7784496, joan.ryan@epilepsy.ie
Mon & Tue 10am - 5pm; Wed & Thur 10am - 4.30pm

Upcoming Events

**Waterford:** Epilepsy Awareness Evening
Monday, 16th May
Lawlor’s Hotel, Dunganvar, Co Waterford, 7.30pm – 9.00pm
For further details please contact Joan

**Carlow:** Information Evening
Wednesday, 18th May, 7.00pm - 8.30pm
Tablot Hotel, Carlow
Guest Speaker: Denise Cunningham, Clinical Nurse Specialist in Epilepsy Services

**Cork**

For further information on events in this area, contact: Niamh Jones (CRO for 5th Lee and West Cork)

Mon and Tue 8am – 4.30 pm; Wed and Thurs 8am – 1pm
Mary Lawlor (CRO for Nth Lee and Nth Cork)

Tues/Weds/Fri 9.30am - 5.30pm; Thur 1.30pm – 5.30pm
35 Washington St. Cork.
Tel: 021 4247774
Niamh: brainwavecork1@eircom.net
Mary: brainwavecork1@eircom.net

**Upcoming Events**

**Brainwave Information & Support Service**
In response to members’ queries, Community Resource Officer, Niamh Jones will be available to meet members until 8.30pm on Monday evenings, strictly by appointment only.

**Epilepsy Information Day**
Monday, 16th May
Cork University Hospital, 10.00am - 4.00pm

**Support Group Meeting**
For people with epilepsy
Wednesday, 18th May
Brainwave Office, 35 Washington Street, 2.30 pm
Contact Mary for further details

**Parents Support Group**
Date to be confirmed – End of May/June
Bishopstown GAA Club, 7.30pm

**Epilepsy Awareness Morning for Nurses and Health Professionals**
Thursday, 21st July
Bantry General Hospital, 10.00am
For further information, please contact Niamh in the Cork Office.

**Bantry:** Outreach Service
Thursday 21st July 2011
Venue to be confirmed
Meetings by appointment after 2.00pm. Please contact Niamh to make appointment.

**Midlands**

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

For further information on events in this area, contact: Margaret Bassett, CRO

Co/OClI, Clonminch Rd, Tullamore, Co. Offaly
057 9364790
midlandbrainwave@eircom.net
Mon, Tue & Wed & Fri 10am to 2.30pm;
Thursday 9am to 5pm

**Upcoming Events**

**Portlaoise:** Outreach Service
Thursday 12th May
CIC Centre, 10.30am - 3.30am

**Athlone:** Epilepsy Awareness & Administration of Buccal Midazolam
Training for health professionals only
Wednesday 18th May
To book a place please phone Ashley at 01 4557500

**Tullamore:** Coffee Morning
Friday, 20th May
OCIL, Clonminch Rd, Tullamore, 10.30am - 1.00pm
Information Stand on display and Brainwaves CRO available to help with queries. All are welcome and admission is free

**Tullamore:** Parents Support Group
Thursday, 16th June
OCIL Clonminch Rd, Tullamore, 7.00pm

**Longford:** Outreach Service
CIC Centre
Wednesday 29th June, 10.30am - 3.30pm
By Appointment only, please ring Margaret to make an appointment.

**Kerry**

For further information on events in this area, contact: Kathryn Foley, CRO
910 The Paddocks, Ballydowdny, Killarney
084 6603031
kfoley@brainwave@epilepsy.ie
Mon, Tue, Wed 9am - 3.30pm; Thur 9am - 4.30pm

**Upcoming Events**

**Kerry:** Parent Support Group
Tuesday 17th May
Time & Venue: To be confirmed
Please contact Kathryn for further information.

**Killarney:** Ladies Yoga and Information Morning
Wednesday, 18th May
Brainwave Office, Killarney
Yoga session from 11.00am – 12.30pm
Information Session from 1.00pm - 2.00pm
Guest Speaker: Sinead Murphy, Community Epilepsy Specialist Nurse
Please contact Kathryn to book your place for this event

**Killarney:** Epilepsy awareness and the Administration of Buccal Midazolam
Training for health professionals
Wednesday 15th June
Brehon Hotel Killarney
Please contact Kathryn for further information

**Tralee:** Neurology Outpatient Clinic
Date: 1st, 2nd and 4th Monday of each month
Kerry General Hospital, Out Patients Department, Room 4.
9.00am - 1.00pm
Visit Kathryn if you wish to discuss any related epilepsy issues before or after your doctor’s appointment.

**North West**

(Co’s Donegal, Sligo and Leitrim)

For further information on events in this area, contact: Agnes Mooney, CRO

Donegal Office: Grand Central Complex, 2nd Floor, Canal Road, Letterkenny, Co. Donegal
074 9168725
donegalbrainwave@epilepsy.ie

Sligo Office: Model & Niland Arts Gallery, The Mall, Sligo
071 91 54625
Mon, Tue, Wed 9am - 5pm; Thur - 9am - 1pm

**Upcoming Events**

**Letterkenny:** Outreach Service
For further information, please contact Niamh in the Cork Office.

**Sligo:** Epilepsy Nurse Helpline
Eithne Cawley, Epilepsy Nurse Specialist is available on the helpline Friday mornings from 9.30am - 1.00pm at 071 9141858.

**Sligo:** Coffee Morning
North Connaught Youth & Community Services Centre, Rockwood Parade
Wednesday 18th May, 11am - 12.30pm
Eithne Cawley, Epilepsy Nurse Specialist will be available for one to one consultations by appointment only. Please contact Agnes to make an appointment.

**Letterkenny:** Information Stand
Thursday 19th May
Letterkenny Shopping Centre from 12.00pm - 6.00pm.

**Letterkenny:** Awareness Evening
The Station Hotel, Pearse Road, Letterkenny
Thursday 19th May, 7.30pm
Guest speaker: Dr Mark F. Hogan, Clinical Psychologist
Regional Events

Western Region
(Co’s Galway, Mayo, Roscommon)
For further information on events in this area, contact: Evelyn Monson Kirby, CRO
Ozam House, St Augustine Street, Galway 091 568180
crogalway.brainwave@epilepsy.ie
Tuesday, May 17th, Time: 2.50pm
Galway: Information Stand
Eye Square Shopping Centre, Galway City
Monday, May 18th. From 10.00am

Mid West Region
(Co’s Limerick, Clare and North Tipperary)
For further information on events in this area, contact: Anna Kelly, CRO
Social Services Centre, Henry St., Limerick
061 - 313773. brainwavelk@eircom.net
Mon 9.30am - 5.00pm; Wed 8.30am - 5.30pm;
Thur - 12.00pm - 5.00pm; Fri 11.30am - 3.30pm

North East Region
(Co’s Louth, Meath, Cavan, Monaghan)
For further information on events in this area, contact:
Noreen O’Donnell, CRO
Unit 1a Partnership Court, Park Street, Dundalk Co Louth.
042 9337585 brainwavedk@eircom.net
Mon, Tue & Wed 9am - 6pm

Upcoming Events

Galway: Outreach Services NUHG Outpatients
Brainwave’s CRO Evelyn will be available to meet with you at Dr Counihan’s clinic on the 2nd Monday of each month (1.30pm to 5.30pm) and at Dr Hennessy’s clinics on the 2nd and 4th Friday of each month (9.30am to 1.30pm) Please enquire at the Nurses Station/Reception in the Neurology Department.

Castlebar: Support Group
Wednesday May 11th
Venue to be confirmed, 7.30pm
Contact Evelyn for details

Epilepsy Awareness Presentation
Monday May 16th
Muinteras, Leitmermore, Time: 10.30am

Workshop for professionals - Improving the Muinteras, Leitermore, Time: 10.30am
Monday May 16th
Epilepsy Awareness Presentation
Venue: Educate Together, Clarinbridge, Co Galway
Tuesday, May 17th, Time: 2.50pm

Thurles: Epilepsy Awareness Day
Friday, May 20th
Anner Hotel, Thurles, 11.00am - 3.45pm
Epilepsy Specialist Nurses Maria Keegan & Grainne Griffin from Crumlin Hospital will present sessions as outlined below.
Morning session: 11.00 - 12.30
Session 1: Childhood Epilepsy and the Family, for parents and family members in a group setting
Session 2: Individual appointments available for families dealing with complex issues around epilepsy
Afternoon session: 2.00 - 3.45

Upcoming Events

Clarinbridge: Epilepsy Awareness Presentation
Venue: Educate Together, Clarinbridge, Co Galway
Tuesday, May 17th, Time: 2.50pm

Gorey: Support Group
Venue to be confirmed, Time: 10.30am

Epilepsy Awareness Presentation
Monday May 16th
Muinteras, Leitermore, Time: 10.30am

Workshop for professionals - Improving the Management of Epilepsy
Tuesday May 17th
Nurses Home, NUHG, 10.00am - 12.00pm
Facilitators: Teresa Leahy, Neurosciences Nurses Specialist, UHG & Evelyn Monson Kirby

Brainwave Membership Form

Membership Category
☐ 1 Year renewal membership subscription @ €12.70
☐ 2 Year New membership subscription @ €20.00 (new members only)
☐ 1 Year New membership subscription @ €12.70

* 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
Get on a winner this summer!
Support the Brainwave

NIGHT AT THE DOGS

Friday 1st July
Harold’s Cross Stadium

Tickets:
Standard entry: €10
Entry & Sausage + Chips: €15
Family (2 adults & 2 children u12) €20

For info and tickets, see epilepsy.ie or call Glenna at 01 4557500.

Get your friends together for an unbeatable night out, while supporting Brainwave