



**B R A I N W A V E**  
THE IRISH EPILEPSY ASSOCIATION

# Annual Report 2011

Brainwave – The Irish Epilepsy Association

*Shining a light on epilepsy since 1966*



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**Brainwave - The Irish Epilepsy Association (CHY 6170)**  
was established in 1966 by a group of people dedicated to improving the quality of life of people with epilepsy in Ireland.

In the 46 years since our inception, the Association has grown and expanded, today providing a wide range of services from headquarters in Dublin and from regional offices in Cork, Dundalk, Galway, Killarney, Kilkenny, Letterkenny, Limerick, Sligo and Tullamore.

## **Our Vision**

Brainwave's vision is to achieve a society where no person's life is limited by epilepsy.

## **Mission Statement**

Brainwave is committed to working for, and meeting the needs of everyone with epilepsy in Ireland and their families and carers.

## **Our Objectives**

- To provide support, information and advice to people with epilepsy.
- To provide information and advice to health professionals in dealing with epilepsy.
- To improve public understanding of epilepsy (in order to eliminate fear and prejudice) through awareness campaigns and education programmes.
- To undertake, encourage and assist research into the causes of, cure for and management of epilepsy and into the social and psychological effects of the condition.
- To promote legislative and civil rights for people with epilepsy and to campaign to eliminate all discriminatory practices and policies affecting them.
- To provide support for people with epilepsy in the area of training and employment.
- To operate as a public forum and an advocate for the condition of epilepsy.
- To raise funds to support our work in an awareness-creating manner.

# A message from



## **Tessa Dagge, Chairman**

The 2011 Annual Report of Brainwave – The Irish Epilepsy Association highlights the work of the Association during the past year, the final one of our 2007-2011 Strategic Plan.

A lot has been achieved in this time and 2011 was another busy year for the Association. Despite the challenging

economic climate, we endeavoured to continue and develop our service provision to members and all those living with epilepsy. All initiatives undertaken by Brainwave rely on the steadfast support of our members, volunteers, donors and staff to succeed. As Chair of the Association I would like to express my gratitude to all our supporters who continue to sustain our work and without whose support our services would be under threat.

The Board of Directors, Finance & Audit sub-committee, staff and members were deeply saddened by the death of our esteemed President and long serving board member, Dr John Kirker. In 1967, Dr. Kirker joined what was then called The Irish Epilepsy Association and began an association and a friendship that continued for over 44 years. Dr. Kirker spent much of his career and retirement working tirelessly for people with epilepsy and has left an enduring legacy through his many achievements for which Brainwave is extremely grateful.

In 2011, we were delighted to welcome Norma Mitchell to the Board of Directors and Michael McLoughlin to the Finance and Audit Committee. Their input and enthusiasm will help carry our organisation forward into our next 5-year cycle.

I would like to thank all my fellow Board members for their continued support and commitment. In particular, I would to acknowledge the work undertaken by my fellow Officers, Vincent Savino, Vice-Chair, Claire Crehan-Dowdall, Hon. Secretary and Mark Dowdall, Hon. Treasurer.

I also want to recognise the invaluable work of our Patron, 2FM presenter Rick O'Shea who continues to work untiringly to raise the profile of epilepsy and of Brainwave.

In conclusion, I would like to give special thanks to our CEO Mike Glynn who has met most efficiently the many challenges posed during the year. His work nationally and internationally as President of the International Bureau for Epilepsy to enhance the lives of all those living with epilepsy is exemplary and an inspiration to all.

*Tessa Dagge*



## **Mike Glynn, Chief Executive**

2011 was a time of change for Brainwave – The Irish Epilepsy Association. The economic climate challenged us to be innovative and explore new ways to maintain and develop our services. Despite reduced HSE funding and the considerable pressure on our fundraising, the Association has risen to the challenges.

With the Association's 2007-2011 Strategic Plan entering its final year, a clear priority was to consult with members and other stakeholders to elicit their views and agree a new 5-year plan that accurately reflects a shared vision for the future of Brainwave and a clear statement of our priorities for the next five years.

This period will also see the roll-out of the National Epilepsy Care Programme led by Dr. Colin Doherty, National Clinical Lead in Epilepsy. I am pleased to represent Brainwave and our members on the Programme's Clinical Advisory Group and I look forward to the publication in 2012 of the Programme's Model of Care outlining the significant changes we can expect in the years ahead to revolutionise epilepsy care in Ireland. Brainwave will of course continue to represent the needs of people with epilepsy throughout this change process.

The inaugural European Epilepsy Day (EED) took place in 2011 and to mark it, Brainwave launched the hugely successful "Seizure Aware" campaign. Along with activities for National Epilepsy Week and Brain Awareness Week, EED promises to be a hugely significant opportunity to change public perceptions and promote a greater understanding of epilepsy internationally.

Another major achievement was the 'Managing Chronic Health Conditions at School' resource pack, produced in collaboration with three other health charities and distributed to all primary schools nationwide. Brainwave's National Conference took place in Dundalk, youth conferences were held in Galway and Cavan and the annual 'Living with Loss' seminar took place in Limerick. The portfolio of research being funded by Brainwave also expanded with the awarding of a research grant to Prof. David Henshall at the RCSI.

Sadly the year also marked the loss of Dr. John Kirker who had been involved with Brainwave in many different capacities since its earliest days. He will be greatly missed by all.

I would to thank our members, volunteers and donors for their support over the past year. I would also like to thank our Board of Directors, Finance & Audit sub-committee and the hard-working Brainwave staff team for their commitment and energy during 2011.

*Michael Glynn*

# Epilepsy

Epilepsy is a general term used for a group of disorders, all of which are characterised by recurrent, unprovoked seizures involving episodic abnormal electrical activity in the brain.

The condition affects more than 6 million people in Europe and about 50 million people worldwide. People with epilepsy are of all ages, but the condition especially affects children, adolescents and the elderly.

About 1 in every 20 people will have a single seizure at some time during their lives. Seizures can take many forms depending on which part of the brain the electrical activity originates. Anything that damages or injures the brain can result in epilepsy. Some of the more common causes include head injuries, strokes, brain infections and birth defects. Other more rare causes are brain tumours and some genetic conditions like tuberous sclerosis. However, in up to half of all cases, no cause can be found.

Epilepsy is a treatable condition and with around twenty antiepileptic drugs on the market, up to 70% of people can become seizure free. If seizures cannot be controlled by medication, surgery may be considered in some cases.

The significance of having epilepsy varies from person to person. For many people, epilepsy will only affect them for a short period in their lives. For some however, the consequences can be more lasting, particularly if the seizures cannot be controlled.

Depending on the type and frequency of seizures; the age of onset and the degree of seizure control that can be achieved, epilepsy can affect a person's education, employment, psychological and social functioning, self-esteem and independent living. A diagnosis of epilepsy will also involve learning to cope with the physical impact of seizures and the medications prescribed to control them. Numerous studies have shown that people with epilepsy have 2 - 3 times higher mortality than the general population.

Even today there is a stigma associated with epilepsy, a hidden burden which discourages many people from seeking the care and support they require and often leading to discrimination.

In addition to the impact that epilepsy can have on the person living with the condition, it can also cause serious psychological, social and economic consequences for their families and carers.



*"I joined Brainwave three years ago on behalf of my son Ruairi. We as a family have attended several Brainwave outings which have been great fun and are a great way of meeting other families. Brainwave events show children that they are not alone and that their disability does not mean they cannot have a normal life. We have always felt that Brainwave and all the staff have been so friendly and caring in any dealings we have had."*

Sarah Beveridge, Dublin

## Epilepsy in Ireland

Brainwave's Prevalence of Epilepsy in Ireland report, published in 2009 found that there are 36,844 people over the age of five with epilepsy in Ireland, making it the most common serious neurological condition.

Despite this, epilepsy services in Ireland have been historically neglected. Issues such as the lack of epilepsy specialists (including consultant neurologists, consultant neurophysiologists and epilepsy specialist nurses); deficits in GP education; difficulties in accessing EEG & MRI scanning and epilepsy surgery have meant that the standard of care available in Ireland has been far below that available in other European countries. If optimum care is provided, it is possible for up to 70% of all people with epilepsy to achieve seizure control. In Ireland, this figure is likely to be considerably less. In addition, many of the estimated 130 epilepsy-related deaths (including those from Sudden Unexpected Death in Epilepsy; Status Epilepticus and as a result of accidents) that occur annually in Ireland are avoidable with better care, education and services.

These difficulties were finally addressed with the establishment by the HSE of the National Epilepsy Care Programme led by Dr Colin Doherty, under the direction of the Office of Clinical Strategy and Programmes.

The Programme has been charged with developing and implementing a comprehensive change programme for transforming epilepsy care. It will aim to improve access to expert care and information; improve the quality of care across the entire healthcare spectrum and to improve value-conscious care by shifting care where possible from hospital based care to the community. The Programme's Draft Model of Care will be published in early 2012 and will outline specific plans to introduce a population-based nurse-led service; to establish a network of Regional Epilepsy Centres and improve access to surgery for those with highly complex epilepsy.

The Programme represents the most significant opportunity in the history of the state to implement a top-class epilepsy service in Ireland and offset the decades of neglect and underinvestment epilepsy has endured in Ireland.



*"While attending for my son's first EEG, I saw the Brainwave poster in the waiting room and made contact. The next day Anna met us and answered so many questions that we had. Since then we have attended a lot of events which have helped to overcome the shock, and show us we are not alone in facing this awful illness. Brainwave have also been very helpful in encouraging Jack's teachers to overcome any fears or misconceptions they had about epilepsy."*

Oonagh Ruddle, Co Limerick

# Information and support

## Strategic objectives

- To provide support, information and advice to people living with epilepsy, their families and carers.
- To enhance epilepsy related services in order to improve the support we provide.

### Overview

Brainwave's network of services staff in head office and around the country (see page 15) provide a wide range support and information services to people with epilepsy and their family members. These supports include telephone, email and one-to-one support, support in hospital clinics, information seminars, support groups, community outreach and awareness activities. Staff also act as advocates for individuals with epilepsy, assisting in the areas of employment, law, education and entitlements.

The Specialist Nurse Helpline is available on Mondays from 9.30am – 1pm and Wednesday's from 9.30am – 1pm, operated by Sinead Murphy, Community Epilepsy Specialist Nurse and Denise Cunningham, Clinical Nurse Specialist in Epilepsy Services.

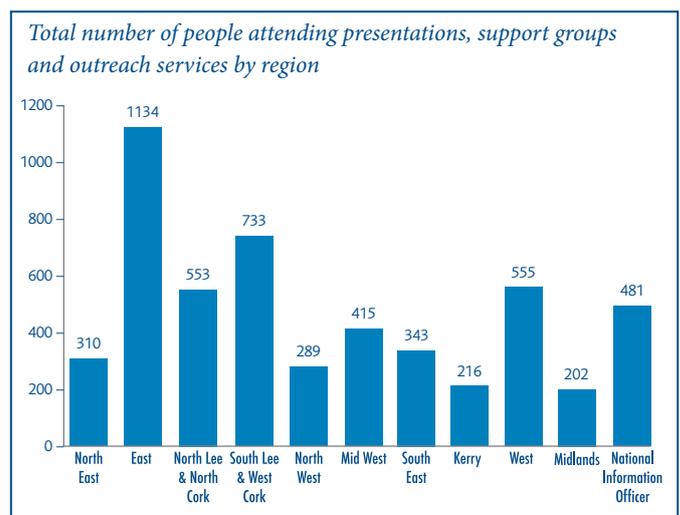
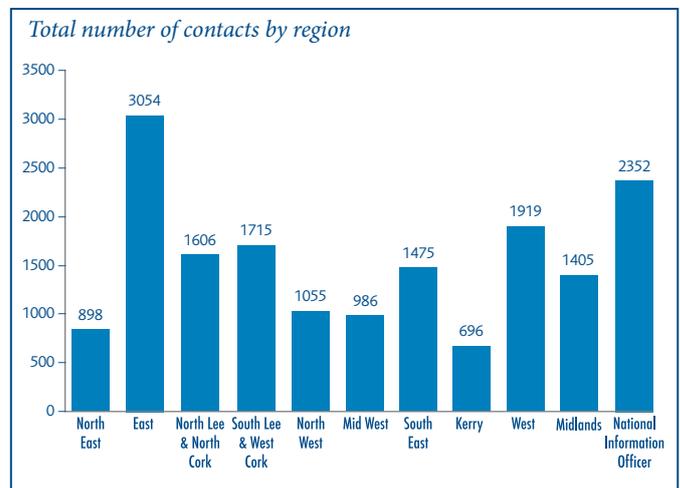
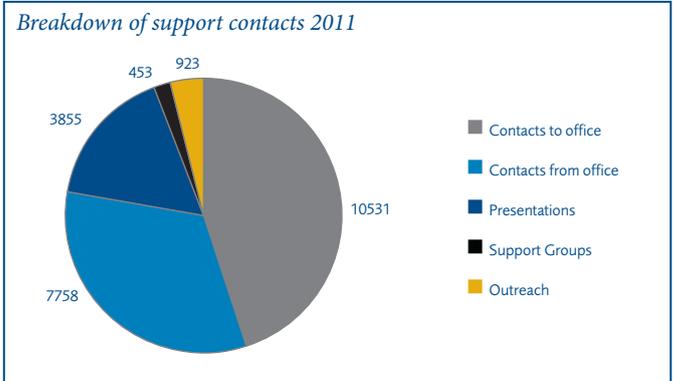
Brainwave maintains a large library of information resources on general and specific issues for people with epilepsy and their families including books, leaflets, CDs, posters, information packs and board games. There are also resources available for parents, children, teachers, employers, nurses and doctors. Brainwave supplies a variety of aids to assist someone who has epilepsy, including identity bracelets and special safety pillows.

The newsletter Epilepsy News is sent to all Brainwave members quarterly. An email newsletter is also regularly distributed. At the end of 2011, over 1,800 people had signed up for the bulletin.

Brainwave's website epilepsy.ie contains a large database of information on all aspects of epilepsy as well as regularly updated news and events sections. In 2011, the site registered over 62,000 visits (up from 48,000 in 2010) and there were over 38,000 unique visitors (up from 31,000 in 2010). A total of 332,000 page views were recorded, compared to 290,000 in 2010.

### The Year in Numbers

- The total number of contacts made to or by Brainwave's nationwide network Community Resource Officers (CROs) and the National Information Officer in 2011 was 23,520 (18,326 in 2010).
- In total, 26,584 contacts were made with a Brainwave services (this includes CRO contacts, Training For Success, Health professional training, presentations in workplaces and schools and the Specialist Nurse Helpline).
- 5,231 people attended presentations, seminars, school talks etc by Brainwave service staff during the year (3,918 in 2010).
- 923 people accessed Brainwave's community outreach services (323 in 2010).
- 453 people availed of support groups organised throughout the country (296 in 2010).
- The number of people who accessed the Epilepsy Nurse Helpline was 1,128 (606 in 2010). A total of 3,845 people accessed the full range of services provided by the nurses at hospitals and in the community.



*"I have been a member of Brainwave's Parent Support Group for almost six years since our son Rory was diagnosed with epilepsy on his tenth birthday. This group and Brainwave's staff have been an enormous help to us as we dealt with the fallout of the diagnosis and its effect on the entire family. I can honestly say I learnt so much from them and from other parents."*

Elaine O'Herlihy, Cork

### Schools Resource Pack

Brainwave and three other charities came together in 2011 to produce a new resource pack for schools on the management of chronic health conditions. Along with epilepsy, the resource pack also deals with diabetes (Diabetes Federation of Ireland), asthma (Asthma Society of Ireland) and anaphylaxis (Anaphylaxis Ireland).

The pack, entitled 'Managing Chronic Health Conditions at School' aims to help teachers and parents to work together and provide a safe and enjoyable school environment for students with any one of these conditions.

This pack contains information on developing or updating the school's guidelines on managing students with chronic health conditions and includes standardised healthcare plans that can be adapted to meet the school's information needs. It also contains practical information including an Emergency Plan for teachers and guidance on safe storage and safe disposal of medications.

With the support of the INTO, the pack also includes a 9 minute DVD on managing each condition at school. Every primary school in Ireland received the pack in 2011 and it is also available to download from each charity's website.

### National Conference

Brainwave's National Conference, entitled 'Epilepsy & You' took place on September 10th at the Fairways Hotel in Dundalk. The conference was highly interactive and included presentations from Dr. Norman Delanty, Consultant Neurologist and Mark Mulrooney, Consultant Neuropsychologist, both from Beaumont Hospital and from Fionnuala Marston, winner of the 2011 Woman's Way Mum of the Year award. There were also a series of workshops on parenting, women's issues, living well with epilepsy and mindfulness in addition to one-to-one appointments with Epilepsy Specialist Nurses.

### Youth Conferences

Two youth conferences were held in Galway and Cavan during Brain Awareness Week 2011. Both were very well attended and received. The Galway event featured speakers Teresa Leahy, Neuroscience Nurse Specialist, who spoke on seizure management and Andrew Magee, IRCHSS PhD Scholar who covered psychosocial aspects of epilepsy. There was also a specially designed creative workshop in the afternoon. In Cavan, speakers included Dr Kevin Murphy, consultant neurologist, Dr Cathal McAuliffe, Neuropsychologist and Dr Sandya Tirupathi from the Royal Hospital, Belfast. Colm O'Connor and Jennifer Murphy both spoke about their personal experiences of living with epilepsy, while the day also included a series of workshops for young adults and parents.



*"It's great to have a local Brainwave contact. Agnes has always been there for me when I knocked on her door. When I go to my hospital appointment, it's good to see a non medical person and the friendly face of Brainwave."*

Pat Mc Carthy, Co Donegal



Brainwave CEO Mike Glynn and students from St Enda's School in Dublin launch the Schools Resource Pack.



Brainwave CRO Agnes Mooney (l) with Mum of the Year Fionnuala Marston, who spoke at Brainwave's National Conference.



Enjoying the Family Fun Day in the Phoenix Park, June 2011.

### Living With Loss Seminar

Brainwave held the seventh annual Living With Loss seminar in Limerick in June, facilitated by Peter Hanlon, Bereavement Therapist. The seminars are attended by families who have experienced the loss of a loved one to an epilepsy-related death and they have proven to be positive experiences for those attending in terms of learning to deal with and cope with the sudden loss of a loved one.

### Other Activities in 2011

Brainwave continued to provide a regular outreach service to 7 hospitals – Beaumont, St James's, Galway, Kerry, Letterkenny, Limerick and Kilkenny. Support groups for people with epilepsy continued in Cork, Kerry, Tullamore, Galway, Waterford, Dublin, Castlebar, Roscrea, Roscommon, Letterkenny and Dundalk. Support groups for parents took place in Cork, Kerry, Dublin, Tullamore and Limerick and there was also a group for friends and family members in Dublin.

Dozens of other information sessions and workshops took place around the country and some regions began to focus on organising social events such as the Family Fun Days held in the Phoenix Park, Dublin in April and June.

## Strategic objectives

- To communicate with the wider public & local and national decision makers.
- To increase public awareness of epilepsy and epilepsy related issues.
- To increase awareness of Brainwave to people with epilepsy, their families, carers and health professionals.



Rick O'Shea with Rebecca and Christopher from St Enda's Primary School, Dublin at the launch of European Epilepsy Day on February 14th 2011.

## European Epilepsy Day

The first ever European Epilepsy Day (EED) took place on February 14th 2011, coinciding with the feast day of St Valentine, patron saint of epilepsy.

Brainwave launched the 'Seizure Aware' campaign to improve the public's understanding of epilepsy and seizure first aid. The analogy of a computer crashing was chosen as the theme for a nationwide radio and TV advertising campaign, featuring Brainwave's Patron, 2FM presenter Rick O'Shea. The ads invited people to visit [epilepsy.ie](http://epilepsy.ie) where a new microsite encouraged people to become Seizure Aware.

The micro-site contained basic information on epilepsy and what to do in the event of someone having a seizure. Information was presented both in text and through the use of videos recorded by Rick O'Shea, Dr Norman Delanty, Sinead Murphy CESN, and Brainwave's Paul Sharkey. During the campaign almost 5,000 visits were recorded on the site and over 25,000 pages were viewed.

A launch photocall took place and awareness events were also held to mark EED in Dublin, Cork, Tullamore and Sligo. Media coverage was secured in the national and local media.

EED proved to be a successful awareness opportunity and the year ended with plans underway for an even bigger campaign for 2012.

## Social Media

In early 2011, Brainwave launched pages on Facebook, Twitter and YouTube. The use of popular social media channels presents new opportunities for raising epilepsy awareness, educating the public about epilepsy and interacting with members and supporters. The facebook page in particular has proved to be very popular with over 1,200 likes by the end of 2011.

## National Epilepsy Week

National Epilepsy Week (NEW) 2011 focused on improving epilepsy understanding among those living with the condition. Brainwave conducted an online quiz to test if people with epilepsy and their families were well informed about the disorder and to encourage people with epilepsy to think more about their epilepsy knowledge.

Almost 300 people took the quiz and from the results, it was clear that although epilepsy knowledge was generally strong, there was a need for better awareness around issues like personal safety and legal & employment issues. A meeting was organised in Dublin to shed light on these issues and information was provided through Epilepsy News and [epilepsy.ie](http://epilepsy.ie).

Many other awareness events were held during NEW around the country including in Bantry, Carlow, Castlebar, Cork, Dundalk, Galway, Killarney, Letterkenny, Sligo, Thurles, Tullamore and Waterford.

## Epilepsy Without Words

Brainwave member James Leahy, from Co Dublin won 3rd prize in the prestigious Epilepsy Without Words international photography competition organised by the International Bureau for Epilepsy to raise awareness of epilepsy. James's photo finished ahead of over 300 entries and along with 60 other leading photos was displayed at the 2011 International Epilepsy Congress in Rome. The photos also went on display at a number of events in Ireland to raise awareness.

## Epilepsy in the Media

Dozens of opportunities were availed of during the year to highlight epilepsy in the national and local media.

The highlight was the outstanding Life With Epilepsy, a documentary broadcast on RTE1 in October featuring Brainwave members Miriad Kavanagh from Wicklow and the Maher family from Dublin. The documentary focused on the realities of living with and coping with a life-changing condition such as epilepsy.

Also in 2011, it was announced that the This is Me documentary broadcast on RTE in 2009 had won the IBE/UCB International Excellence in Epilepsy Journalism award. The programme examined how Brainwave member Emma Beamish had learned to live with her epilepsy through ups and downs since being diagnosed aged 14.

Brainwave member Fionnuala Marston from Co. Donegal was crowned Woman's Way/John West Mum of the Year in 2011 and appeared on popular TV show Saturday Night with Miriam where she discussed her epilepsy in detail.



Brainwave members Aaron Maher and Miriad Kavanagh featured in the RTE documentary Life With Epilepsy.

# Advocacy

Advocacy at European level was the focus during 2011. On February 14th, Brainwave was one of the 26 epilepsy organisations from across Europe that came together at the European Parliament in Strasbourg to launch European Epilepsy Day and highlight the importance of supporting the 6 million people in Europe with epilepsy. The following day, a number of events were held to educate MEPs about epilepsy and meetings took place between epilepsy organisations and their national MEPs. Mike Glynn, Brainwave CEO & IBE President and Nico Moshe, ILAE President held meetings with two key Commissioners to highlight the need for research, education and improved services for people with epilepsy.

As a result of this work, a Written Declaration on Epilepsy was submitted to the European Parliament in May by Gay Mitchell MEP, Chair of the European Advocates for Epilepsy Group on behalf of Epilepsy Advocacy Europe which is co-chaired by Mike Glynn. The Declaration called on the European Commission and European Council to take steps in the areas of prevention, diagnosis and treatment of epilepsy, as well as ensuring equal opportunities for people with epilepsy. In September, the Declaration was passed by the Parliament with a large majority of 459 signatures including all 15 Irish MEPs. The document is invaluable for Brainwave's advocacy efforts at local and European level.

In Ireland, the work of the National Epilepsy Care Programme progressed in 2011. Set up by the HSE in 2010 and led by Consultant Neurologist Dr Colin Doherty, the Programme is charged with addressing Ireland's historic deficiencies in epilepsy care through a comprehensive change programme. Brainwave has campaigned for many years for better quality care and better access to care. We are encouraged by the progress made to date, in particular the plans to recruit an additional 20 Advanced Nurse Practitioners, something Brainwave has advocated for over a decade. Other plans include the establishment of a network of Regional Epilepsy Centres, centralised administration and the expansion of pre-surgical evaluation. Mike Glynn, Brainwave's CEO is a member of the Programme's Clinical Advisory Group.

Through our involvement with the Neurological Alliance of Ireland (NAI), Brainwave continues to campaign for action to address the crisis in Ireland's neurological care services. In 2011, Brainwave continued to work on the NAI's Thinking Ahead campaign to protect these services from further funding cuts and actively supported the NAI's Ten Point Action Plan for neurological care.



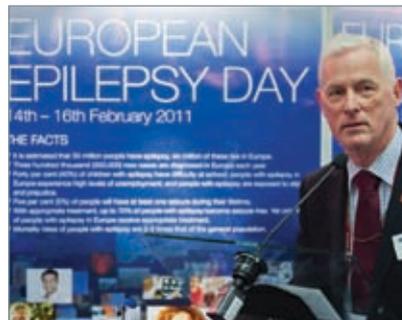
*"Before I got in touch with Brainwave, I never saw myself as someone who needed support. Now I really wish that I had availed of the services of Brainwave a lot sooner. Noreen was very patient while listening to me talking about my frustration and fears. It is great to know that I can talk to someone who understands. Through Brainwave I gained knowledge received support to be a lot more open with people about my epilepsy."*  
Emer Lynch, Co Louth

## Strategic objective

- To promote legislative and civil rights for people with epilepsy and to campaign to eliminate all discriminatory practices and policies affecting them.



Gay Mitchell MEP (centre) submitted the Written Declaration on Epilepsy to the European Parliament. All Irish MEPs supported the declaration including Sean Kelly, Mairead McGuinness and Jim Higgins (pictured).



Mike Glynn, Brainwave CEO and IBE President speaking at the launch of European Epilepsy Day at the European parliament in Strasbourg.

## National and International Partnerships

Affecting change is often easier to achieve working in partnership with other organisations with similar aims. Brainwave is an active member of the following national and international advocacy organisations.

### International Bureau for Epilepsy

[www.ibe-epilepsy.org](http://www.ibe-epilepsy.org)

IBE is an international organisation that works to develop, support and link national epilepsy organisations around the world. Mike Glynn, Brainwave CEO has been President of the IBE since 2009.

### The Neurological Alliance of Ireland

[www.nai.ie](http://www.nai.ie)

NAI is the national umbrella organisation for groups representing the views and concerns of those whose lives are affected by neurological conditions. Peter Murphy, Brainwave's Deputy CEO is a board member of the NAI.

### Disability Federation of Ireland

[www.disability-federation.ie](http://www.disability-federation.ie)

DFI is the national support organisation for over 120 voluntary disability organisations in Ireland, advocating for the full and equal inclusion of people with disabilities in all aspects of society. Mike Glynn, Brainwave CEO is a board member of DFI.

### Medical Research Charities Group

[www.mrcg.ie](http://www.mrcg.ie)

The MRCG is an umbrella group of charities concerned with the funding and promotion of medical research in Ireland. Peter Murphy, Brainwave's Deputy CEO is a Board Member of MRCG.

# Training and education

## Strategic objectives

- To provide information and advice to health professionals in dealing with epilepsy.
- To provide education to all people dealing with epilepsy.
- To deliver training programmes for people with epilepsy.

### Training For Success

2011 proved another very successful year for Brainwave's one-year pre-employment training programme, Training For Success (TFS). Designed for young adults with epilepsy to enable them to improve their prospects for employment or further education and training, TFS is run in partnership with the Institute of Technology Sligo and is funded by FAS. In both the 2010-2011 and 2011-2012 academic years, the maximum of 14 students undertook the programme.

TFS is the only course of its kind in Europe and has been in existence since 1998. The programme provides students with a variety of modules including career planning; computer applications; communications; creative writing; drama; art; health & fitness; epilepsy awareness and work experience.

Many young people with epilepsy experience underlying difficulties with confidence and self-image. The roots of this wound can be very deep and can be caused many factors. Brainwave believes that the training and education of young people with epilepsy must focus on empowerment and enable individuals to rebuild a positive self image. TFS therefore places great importance on the area of personal development that is holistic in nature. Students are encouraged to envisage a clear idea of where they are heading and to develop and act on a career plan for the future.

### Health Professional Education

As part of Brain Awareness Week in March, Brainwave and the Royal Society of Medicine came together to organise a one day conference on epilepsy for health professionals. The conference was focused on paediatric epilepsy. Many of Ireland's leading epilepsy experts presented including Dr. David Webb, Our Lady's Hospital, Crumlin; Dr Bryan Lynch, Dr Cathy Madigan and Dr Helena Rushe, Temple Street; Dr Sandya Tirupathi, Royal Hospital Belfast; Dr Joyce Senior, UCD; Ann Connolly, AMNCH and Dr. Danny Costello, Cork University Hospital.



Clinical Nurse Specialist in Epilepsy Services Denise Cunningham conducts a training day in Epilepsy Awareness & the Administration of Buccal Midazolam.

### Training for Health Professionals in Epilepsy Awareness and the Administration of Buccal Midazolam

Since 2009, Brainwave has been providing a training programme for health professionals and allied health professionals in Epilepsy Awareness and the administration of Buccal Midazolam (BM).

BM is an emergency rescue medication prescribed under special licence to reduce the duration or stop an epileptic seizure and prevent status epilepticus. The medication must be administered by a trained health professional. The aim of the programme is that participants develop a greater understanding of epilepsy in general, understand the role of BM and receive instruction in the correct administration of BM.

Strong demand for the training programme continued through 2011. A total of 325 people were trained over 26 training days around the country which included open and in-house training courses. Since 2009, over 750 health professionals and allied health professionals have been trained.

Brainwave is the only organisation providing this important training to health professionals and allied health professionals in Ireland. The training is delivered in accordance with the Joint Epilepsy Council's (JEC) guidelines on training standards for the administration of BM.

### Schools Education Programme

2011 was another very busy year for the Schools Education Programme, which aims to raise awareness of the condition for those with the responsibility for ensuring a safe education environment. In 2011 2,054 teachers and students attended Epilepsy Awareness presentations nationwide.



Students from TFS took part in awareness raising activities at the Institute of Technology Sligo to mark the first European Epilepsy Day on February 14th 2011.



*"Training for Success was a great year in every way for me. I achieved all the goals I set for myself, and I've made friends that I certainly won't forget. This course would suit anybody with epilepsy but particularly someone hoping to find a career that it suited to their characteristics"*

Colm O'Connor, TFS Student

# Research

The Brainwave Research Funding Scheme, launched in 2008 supported four research projects during 2011. This included three ongoing projects and one new one. The existing projects were:

### A pharmacogenomic study of chronic refractory epilepsy

Dr. Gianpiero Cavalleri, Royal College of Surgeons in Ireland.

### Heritability of cognitive endophenotypes in temporal lobe epilepsy: A neuropsychological investigation

Dr. Teresa Burke, University College Dublin.

### Baroreflex sensitivity in individuals with epilepsy: Does it play a role in sudden unexpected death in epilepsy (SUDEP)?

Dr. Yvonne Langan, St. James's Hospital.

The projects of Dr Cavalleri and Dr Burke are jointly funded by Brainwave and the Health Research Board (HRB) under the Joint Funding Scheme operated by the Medical Research Charities Group (MRCG) of which Brainwave is a member. Dr. Langan's work is partly supported through the fundraising efforts of the friends and family of the late Barbara Doyle. These three projects represent a total investment of over €265,000.

In October 2011, a decision was taken to fund a fourth project under the scheme:

### Genome-wide DNA methylation analysis of hippocampus from patients with pharmacoresistant temporal lobe epilepsy

Prof. David Henshall, Royal College of Surgeons in Ireland.

A grant of €74,312 is being made available to Prof Henshall over 18 months from January 2012. It is hoped that the work will lead to new information about the way genes are controlled in epilepsy and translate into treatments for people with difficult to control seizures. The project is being jointly funded by the HRB and Brainwave.

All applications for research funding received by Brainwave are rigorously reviewed by international experts and by Brainwave's Research Review Board, chaired by Professor David Chadwick before funding is committed. Only the proposals that meet the highest standards of excellence can be awarded funding. All four of the projects currently being funded have the potential to add significantly to existing scientific knowledge of epilepsy and aid in the search for better outcomes for people living with the condition.

In fact, Dr Cavalleri's work led to a significant discovery in 2011, when his team identified a gene that could indicate if epilepsy patients on the drug carbamazepine are likely to experience side effects.



*"Brainwave has been a great help to me since I was diagnosed with epilepsy. Joan in the Kilkenny office provided us with a lot of information at the start and her continued support has helped me come to terms with my condition."*

Geraldine Dempsey, Co Wexford

## Strategic objective

- To undertake, encourage and assist research into the causes of, cure for and management of epilepsy and into the social and psychological effects of the condition.



Members of Brainwave's Research Review Board, (l-r) Prof. David Chadwick (Chairman), Prof David Henshall, Dr Cathy Madigan, Ms Margaret McCahill and Dr Pat Dicker.



Denise Cunningham presented her research The Impact of Epilepsy on the Quality of Life of the Adult population in Ireland at the International Epilepsy Congress in Rome.

His team will also be part of a major international collaboration bringing experts in epilepsy genetics closer together to improve knowledge in the area and develop new directions for treatment.

In November 2011, Brainwave issued a new call for applications for epilepsy focused research projects of up to three years duration to a maximum of €50,000 p.a. Areas highlighted in the call were psychosocial aspects of epilepsy; SUDEP; epilepsy and intellectual disability and the impact of epilepsy specialist nurses. The Research Review Board will meet in 2012 to review applications and it is hoped that new research can be funded from 2012.

Successful research depends on people volunteering their time to take part and in 2011, Brainwave continued to encourage members to become more involved in epilepsy research. For example, almost 300 people took part in the Epilepsy Knowledge Scale survey conducted for National Epilepsy Week 2011. Meanwhile the Impact of Epilepsy on Quality of Life Study conducted by Denise Cunningham, Clinical Nurse Specialist in Epilepsy Services involving 350 Brainwave members was presented at the 2011 International Epilepsy Congress.

Brainwave is also committed to public education around medical research and raising the profile of research in Ireland. This is achieved predominantly through Epilepsy News and epilepsy.ie.

# Fundraising

Brainwave's work is funded almost exclusively through state grants and a wide range of fundraising events, donations and campaigns. Although 2011 was another very difficult year, fundraising income was again increased by 5%. This helped Brainwave to compensate for reduced state funding and ensure that services were not significantly affected.

The strategy of raising 'a little from a lot' and encouraging more people to get involved was maintained in 2011. Strong performance from activities such as Rose appeals, churchgate collections, mini-marathons, the Christmas appeal, the national raffle and a range of fundraising events contributed greatly but the success of meeting fundraising goals was possible largely as a result of members' and supporters' efforts in continuing to raise money for our work.

We would like to sincerely thank all our fundraising volunteers around the country who gave up their time and expertise in 2011 to do what they could in spite of the difficult economic times.

## Snapshots from 2010



See This Here Boy, the autobiography of Meath businessman Eddie Battersby, raised €10,000 for Brainwave in 2011. Eddie decided to support Brainwave having lost his sister-in-law Sinead as a result of epilepsy.



Brainwave's friends in Ballyjamesduff, led by Mattie Lynch and family raised a fantastic €18,500 for Brainwave by cycling from Mizen Head to Malin Head and organising a tractor/Honda 50 Run.



Brainwave received €6,400 from the spectacular annual Barrack Hill Ball Run in Cobh in August. Our thanks to Paddy and Lil Histon, Jim Sheeley and all the organisers for their support.



The Rose & The Thorn by Don Mullan and Brainwave member Audrey Healy was launched by Sen. David Norris and RTE's Aine Lawlor during National Epilepsy Week with proceeds going to Brainwave.



The friends and family of the late Jason Brennan raised over €21,000 for Brainwave in 2011 with a series of fundraisers in Carlow and Kildare in memory of Jason who passed away in February.



Hundreds of people represented Brainwave in marathons, fun runs and other challenges at home and abroad in 2011. Pictured are just six of the many ladies who fundraised through Dublin Women's Mini-Marathon.



An original fundraising event by Jenny Gallagher was to organise an Oscar-themed party. The Gallagher family and their friends have raised over €30,000 in memory of Alan Gallagher who died in 2009.



Two Rose Appeals in February and October raised over €43,000 for our work. Pictured are students from Colaiste Choilm in Tullamore who took part in the collections.



Brainwave, The Dublin Photography School & Nikon teamed up for the first Brainwave charity calendar in 2011. Photos featured in the calendar were selected following a nationwide photography competition and almost €4,000 was raised.

## How can you support our fundraising?

- Make a donation
- Become a member
- Represent Brainwave
- Volunteer your time
- Organise an event
- Support Brainwave events
- Recommend us for your workplace charity of the year

**If you would like to get involved, we'd love to hear from you!**

Remember, we will endeavour to support your initiative in any way possible. Call us at **01 455 7500** for more information or check our fundraising section on **[www.epilepsy.ie](http://www.epilepsy.ie)**.

# 2011 Financial report

Brainwave reported a surplus of €32,560 in 2011 (€8,669 in 2010), which was another good performance in the difficult economic circumstances.

Grant income from the Department of Health and the HSE fell by €48,410 in the year but fundraising and other income increased by €73,648 to compensate for this. In addition, there was a decrease in overall expenditure to €1,633,245. This ensured that that a small surplus was retained ahead of another challenging year in 2012.

## Brainwave - The Irish Epilepsy Association

### Income and expenditure account for the year ended 31 December 2011

	2011 €	2010 €
Income	1,667,996	1,650,764
Expenditure	<u>1,633,245</u>	<u>(1,647,004)</u>
<b>Operating (deficit)/Surplus</b>	<b>34,751</b>	<b>3,760</b>
Investment Income	3,911	4,280
Unrealised gain/(loss) on quoted investments	<u>(6,102)</u>	<u>629</u>
<b>(Deficit)/Surplus on Ordinary activities before taxation</b>	<b>32,560</b>	<b>8,669</b>
Tax on (deficit)/ surplus on ordinary activities	<u>—</u>	<u>—</u>
<b>(Deficit)/ Surplus on ordinary activities after taxation</b>	<b>32,560</b>	<b>8,669</b>

All recognised gains and losses are disclosed in the income and expenditure account and derive from continuing activities.

## Brainwave - The Irish Epilepsy Association

### Balance Sheet as at 31 December 2011

	2011 €	2010 €
<b>Fixed Assets</b>		
Tangible Assets	116,327	124,692
Financial Assets	<u>127,717</u>	<u>133,819</u>
	<b>244,044</b>	<b>258,511</b>
<b>Current Assets</b>		
Debtors	26,777	27,309
Cash at Bank and in hand	<u>1,956,582</u>	<u>1,860,901</u>
	<b>1,983,359</b>	<b>1,888,210</b>
<b>Current Liabilities</b>		
Creditors (Amounts falling due within one year)	<u>(408,240)</u>	<u>(360,118)</u>
<b>Net Current Assets</b>	<b>1,575,119</b>	<b>1,528,092</b>
<b>Net Assets</b>	<b>1,819,163</b>	<b>1,786,603</b>
<b>Capital and Reserves</b>		
Income & Expenditure Account	682,163	649,603
Special Reserves	<u>1,137,000</u>	<u>1,137,000</u>
	<b>1,819,163</b>	<b>1,786,603</b>

# Our people

## Board of Directors

Mrs Tessa Dagge (Chairman)  
Mr Vincent Savino (Vice-Chairman)  
Mr Mark Dowdall (Treasurer)  
Ms Claire Crehan-Dowdall (Secretary)  
Dr Norman Delanty  
Dr Michael Hennessy  
Dr John Kirker +  
Dr Bryan Lynch  
Ms Margaret McCahill  
Dr Brian McNamara  
Ms Norma Mitchell  
Ms Audrey Murphy  
Ms Carol Saarsteiner  
Dr Joyce Senior  
Dr Brian Sweeney  
Dr David Webb

## Finance Committee

Mr Michael Sheehy (Chairman)  
Mrs Tessa Dagge  
Mr Mark Dowdall  
Mr Richard Holmes  
Mr Michael McLoughlin  
Mr Tony Rhatigan

## Research Peer Review Board

Prof. David Chadwick (Chairman)  
Dr. Gianpiero Cavalleri (Geneticist)  
Dr. Norman Delanty (Adult neurologist)  
Dr. Patrick Dicker (Medical Statistician)  
Prof. David Henshall (Basic Neuroscientist)  
Dr. Christine Linehan (Health services researcher)  
Dr. Bryan Lynch (Paediatric neurologist)  
Dr. Cathy Madigan (Neuropsychologist)  
Ms. Margaret McCahill (Patient representative)

+ Deceased November 2011

## Chief Executive

Mike Glynn

## Services

### Director of Services

Aisling Farrell \*  
Helen Quinn \*\*

### National Information Officer

Geraldine Dunne

### Community Resource Officers

Margaret Bassett (Midlands Region)  
Kathryn Foley (Southern Region, Kerry)  
Niamh Jones (Southern Region, Cork)  
Anna Kelly (Mid West Region)  
Mary Lawlor (Southern Region, Cork)  
Evelyn Monson-Kirby (West Region)  
Agnes Mooney (North West Region)  
Ina Murphy (Eastern Region)  
Noreen O'Donnell (North East Region)  
Joan Ryan (South East Region)

### Clinical Nurse Specialist in Epilepsy Services

Denise Cunningham (AMNCH)

### Community Epilepsy Specialist Nurses

Sinead Murphy (Beaumont Hospital)

## Fundraising and Administration

### Resources Manager

Peter Murphy

### Key Fundraiser

Noeleen McDaid

### Fundraising Assistants

Glenna Gallagher  
Catherine Healy

\* Resigned September 2011

\*\* Appointed October 2011

### Training and Communications Manager

Paul Sharkey

### Training For Success Manager

Honor Broderick

### Training For Success Facilitator

Maire Tansey

### Accounts and Administration Manager

Elizabeth Ryan

### Membership and Database Co-ordinator

Ashley Butler

### PA to CEO

Mary Malone

### Receptionists

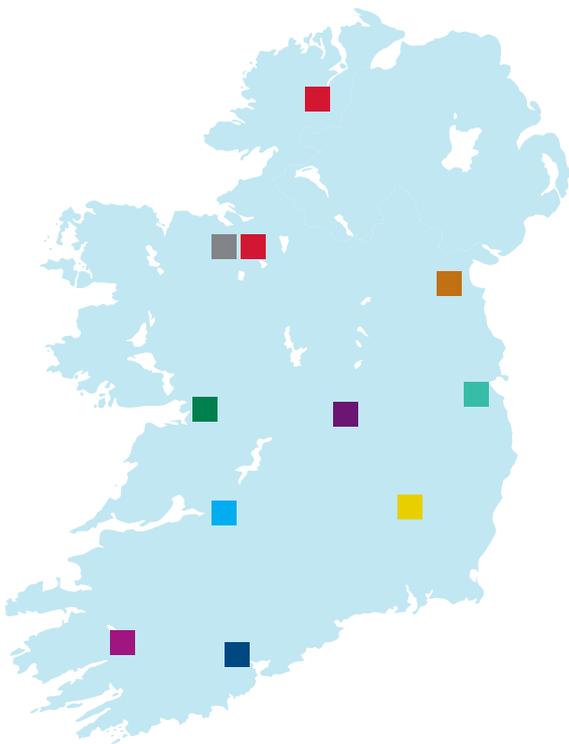
Madge Geoghegan  
Joan McDermott

## Patron: Rick O'Shea

2FM presenter Rick was diagnosed with epilepsy at the age of 16. In 2006, he answered Brainwave's call to become the charity's Patron. Since then, Rick has been active in helping to raise awareness of the condition, taking part in dozens of media interviews, speaking at national and international epilepsy events, recording radio ads and awareness videos and playing a lead role in numerous Brainwave fundraising events. "It is an honour to be able to help Brainwave in shedding a little light on epilepsy and why it doesn't have to stop you from leading a full, successful life", says Rick.



# Locations



## Online:

Web: [www.epilepsy.ie](http://www.epilepsy.ie)

Email: [info@epilepsy.ie](mailto:info@epilepsy.ie)

Facebook: [facebook.com/epilepsy.ie](https://facebook.com/epilepsy.ie)

Twitter: [@Brainwave\\_irl](https://twitter.com/Brainwave_irl)

YouTube: [youtube.com/BrainwaveEpilepsy](https://youtube.com/BrainwaveEpilepsy)

## Head office

Address: 249 Crumlin Road, Dublin 12

Tel: 01 455 7500

Email: [info@epilepsy.ie](mailto:info@epilepsy.ie)

## Specialist Nurse Helpline

Tel: 01 455 4133

Monday and Wednesday 9.30am - 1pm

## Training For Success

Manager: Honor Broderick

Address: Institute of Technology Sligo, Ballinode, Sligo

Tel: 071 915 5303

Email: [broderick.honor@itsligo.ie](mailto:broderick.honor@itsligo.ie)

## North West

Covering: Donegal, Leitrim and Sligo

Community Resource Officer: Agnes Mooney

### Letterkenny office

Address: Grand Central Complex, Floor 2B, Canal Road, Letterkenny, Co. Donegal

Tel: 074 916 8725

Email: [donegal.brainwave@epilepsy.ie](mailto:donegal.brainwave@epilepsy.ie)

### Sligo office

Address: Model & Niland Arts Gallery, The Mall, Sligo

Tel: 071 914 1858

## West

Covering: Galway, Roscommon and Mayo

Community Resource Officer: Evelyn Monson Kirby

Address: Westside Resource Centre, Seamus Quirke Road, Westside, Galway

Tel: 091 587 640

Email: [crogalway.brainwave@epilepsy.ie](mailto:crogalway.brainwave@epilepsy.ie)

## Mid-West

Covering: Limerick, Clare and Tipperary North

Community Resource Officer: Anna Kelly

Address: Social Service Centre, Henry St., Limerick

Tel: 061 313 773

Email: [brainwavelk@epilepsy.ie](mailto:brainwavelk@epilepsy.ie)

## Kerry

Covering: Co. Kerry

Community Resource Officer: Kathryn Foley

Address: Brainwave - The Irish Epilepsy Association,

9/10 The Paddocks, Ballydowney, Killarney, Co. Kerry

Tel: 064 663 0301

Email: [crokerry.brainwave@epilepsy.ie](mailto:crokerry.brainwave@epilepsy.ie)

## Cork

Community Resource Officers:

South Lee and West Cork: Niamh Jones/North Lee and North Cork: Mary Lawlor

Address: 35 Washington Street, Cork

Tel: 021 427 4774

Email: [brainwavecork@eircom.net](mailto:brainwavecork@eircom.net) (Niamh)/[brainwavecork1@eircom.net](mailto:brainwavecork1@eircom.net) (Mary)

## North East

Covering: Louth, Meath, Monaghan and Cavan

Community Resource Officer: Noreen O'Donnell

Address: Unit 1a, Partnership Court, Park Street, Dundalk, Co. Louth

Tel: 042 933 7585

Email: [brainwavedk@epilepsy.ie](mailto:brainwavedk@epilepsy.ie)

## South East

Covering: Kilkenny, Wexford, Carlow, Waterford and Tipperary South

Community Resource Officer: Joan Ryan

Address: Ground Floor, St. Canice's Hospital, Sion Road, Kilkenny

Tel: 056 778 4496

Email: [southeast.brainwave@epilepsy.ie](mailto:southeast.brainwave@epilepsy.ie)

## Midlands

Covering: Offaly, Longford, Laois and Westmeath

Community Resource Officer: Margaret Bassett

Address: c/o OCIL, Clonminch Road, Tullamore, Co. Offaly

Tel: 057 934 6790

Email: [midlandbrainwave@eircom.net](mailto:midlandbrainwave@eircom.net)

## East

Covering: Dublin, Kildare and Wicklow

Community Resource Officer: Ina Murphy

Brainwave's National Information Officer: Geraldine Dunne

Address: 249 Crumlin Road, Dublin 12

Tel: 01 455 7500

Email: [gduenne.brainwave@epilepsy.ie](mailto:gduenne.brainwave@epilepsy.ie) (Geraldine)/[imurphy.brainwave@epilepsy.ie](mailto:imurphy.brainwave@epilepsy.ie) (Ina)

**Brainwave - The Irish Epilepsy Association**

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Twitter: [@Brainwave\\_irl](https://twitter.com/Brainwave_irl)

**Charity Number**

CHY 6170

**Company Limited by Guarantee**

Registered in Dublin 77588

**Auditors**

Deloitte & Touche

Chartered Accountants

Deloitte & Touche House

Earlsfort Terrace

Dublin 2