

# Annual Report 2009

---

Brainwave - The Irish Epilepsy Association

*Shining a light on epilepsy since 1966*



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



# Contents

---

Messages from the Chair and CEO	Page 4
Epilepsy	Page 5
Information and support	Page 6
Awareness	Page 8
Advocacy	Page 9
Training and education	Page 10
Research	Page 11
Fundraising	Page 12
Financial information	Page 13
Our People	Page 14
Our Locations	Page 15

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

Over the 44 years since our inception, the Association has grown and expanded and now provides a wide range of services from headquarters in Dublin and 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**

It is my great privilege to welcome you to the first Annual Report of Brainwave - The Irish Epilepsy Association on my own behalf and on behalf of our Vice-Chair Vincent Savino, our Hon. Secretary Claire Dowdall, Hon. Treasurer Mark Dowdall and all the members of the Board of Directors.

Despite the difficult economic times we have found ourselves in over the past year, we have still had an exciting and productive year. This Annual Report reflects the great progress that Brainwave has made in providing a range of supports and services for people with epilepsy.

Since Brainwave was established in 1966, our focus has always been on improving the quality of life of people with epilepsy and their families. Over the past 44 years, the Association has grown and expanded, now providing a range of services from headquarters in Dublin and from regional offices in Cork, Dundalk, Galway, Killarney, Kilkenny, Letterkenny, Limerick, Sligo and Tullamore.

All of the progress made by Brainwave since 1966 would not have been possible without the assistance and tremendous support of our members, volunteers, fundraisers and donors, the majority of whom have direct experience of epilepsy in their family or among their friends. We deeply appreciate your loyalty and support. Now more than ever we need your continued involvement and support to continue providing our information, education, awareness, training and outreach services along with our continued funding of epilepsy research.

The whole epilepsy community was saddened by the death in August 2009 of long-serving Brainwave board member Joe Doyle. As a former TD, Senator and Lord Mayor of Dublin, Joe was a wonderful advocate for people with epilepsy, taking every opportunity possible to highlight the condition. His dedication to the cause will be missed.

On a final note, on my own behalf and on behalf of my fellow Board members, we would like to congratulate our CEO Mike Glynn who was elected President of the International Bureau for Epilepsy in July 2009. It is a tremendous honour and we know that Mike will work hard on the international stage to highlight the needs of people living with epilepsy not only in Ireland but worldwide.

*Tessa Dagge*



**Mike Glynn, Chief Executive**

In 2009, we faced some challenging economic times that have had an impact on our Association and in particular, on people living with epilepsy in Ireland. Brainwave has addressed these difficulties head on and we have put our energy into achieving the best outcomes for people with epilepsy despite reduced financial resources from the HSE and other sources of funding.

We were delighted to see The Prevalence of Epilepsy in Ireland report launched during National Epilepsy Week. This report, commissioned by Brainwave and conducted by UCD is the first national epilepsy prevalence study taken anywhere in Europe and identifies for the first time, accurate figures on the number of people with epilepsy in Ireland.

Over 12,000 enquiries were handled by Brainwave staff in 2009 and over 4,000 people attended Brainwave events. It was also a year when many new Brainwave publications were launched including New Beginnings; a Guide to your child's epilepsy and age-specific books for children, Everything a Child Needs to Know about Epilepsy and My Lights Go Out.

The National Conference took place in Limerick for the first time in 2009 and other key events included a Teens & Young Adults conference held in Croke Park and the 6th annual Living With Loss seminar, held in Cork. In March, as part of Brain Awareness Week, we marked the 200th anniversary of the birth of Irish epilepsy pioneer, Robert Bentley Todd with a memorial lecture at Trinity College, where Todd was educated.

As you will see in this report, epilepsy research is an extremely important part of Brainwave's work and that is why we have an ongoing commitment to encouraging and supporting research in Ireland. In 2009, after an extensive peer review process, Brainwave made a decision to fund three Irish epilepsy research projects under our new Research Funding Scheme, two of which are jointly funded by the Health Research Board.

I would like to say thank you to all of our members, volunteers, supporters and donors around the country, without whose continued assistance we could not afford to carry out the work we do. Finally, I would like to thank our Board of Directors and all the staff of Brainwave - The Irish Epilepsy Association for their hard work and commitment in these challenging times.

*Michael Glynn*

# Epilepsy

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

Anyone can have a seizure if the brain is exposed to a strong enough stimulus. About 1 in every 20 people will have a single seizure at some time during their lives. Seizures can take many forms, differing from one person to another. They are usually dependent on which part of the brain the electrical activity originates.

Anything that damages or injures the brain can result in epilepsy. Some of the 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.

The significance of having epilepsy varies from person to person and will depend on many things. For most 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, relationships, mobility 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. Although major strides have been made in recent times, there is still stigma associated with the condition, a further hidden burden 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.

Epilepsy can be treated effectively with antiepileptic medication. Nowadays, thanks to the advent of new drugs, up to 70% of people can become seizure free. If seizures cannot be controlled by medication, surgery may be considered in some cases.

*"Having found out about Brainwave through my parents, my life took a change for the better. Brainwave introduced me to the Training For Success course in I.T. Sligo. I recall meeting with Ina, Brainwave's CRO with my folks and being told all about the course. I wasn't sure about moving out of home but Ina reassured me that I could come home every weekend. She also said it was unlikely that I would and she was right – I've finished the course but am still living in Sligo! My local Brainwave contact is now Agnes in the Donegal office who I keep in touch with on a regular basis. All things told, the wonderful staff at Brainwave have been a great support me, my parents and siblings. They have truly helped my life in a great way".*

Andrew O'Reilly, Dublin



## Epilepsy in Ireland

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

However, Ireland has a chronic shortage of epilepsy specialists (including consultant neurologists, consultant neurophysiologists and epilepsy specialist nurses) and there are also major deficits in care, including inadequate GP education, delays in EEG & MRI scanning and limited access to epilepsy surgery.

The standard of care available to people with epilepsy in Ireland is internationally accepted as being far below that of all our European neighbours and as a result, thousands of people continue to have seizures that could be prevented if they received the same level of care as people attending the best international epilepsy treatment centres.

Although it is possible for up to 70% of all people with epilepsy to achieve seizure control, this figure is likely to be less than 50% in Ireland, based on figures from the UK and other countries. Perhaps the most overlooked consequence of this is the fact that up to 30 of the c. 75 epilepsy-related deaths that occur annually in Ireland are avoidable with better care, education and services.

With the prevalence of epilepsy shown to be increasing annually and with additional pressures expected on neurology services in the years to come due to our ageing population, it is clear that major change is required at all levels of care if people with epilepsy are to achieve optimal quality of life.

## 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

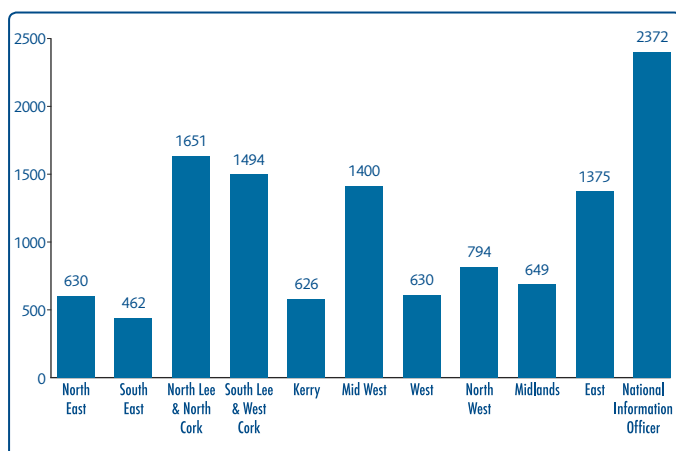
# Information and support

Brainwave's network of services staff around the country are responsible for providing support and information services to people with epilepsy in their areas. These supports include telephone and one-to-one support, support in hospital clinics, information meetings, support groups, outreach services in the community and awareness talks.

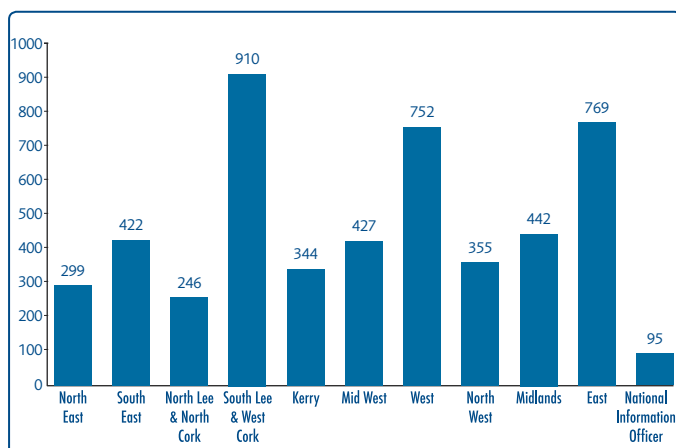
## The year in numbers

- The total number of contacts made to or by Brainwave's nationwide network Community Resource Officers and the National Information Officer in 2009 was 12,083
- 4,171 people attended presentations, seminars, school talks etc by Brainwave service staff
- 328 people accessed Brainwave's outreach services
- 252 people accessed hospital outreach clinics (service available in 7 regions only)
- 310 people availed of Brainwave support groups organised throughout the country

**Table 1: Total number of contacts with Brainwave CRO's and National Information Officer by region.**



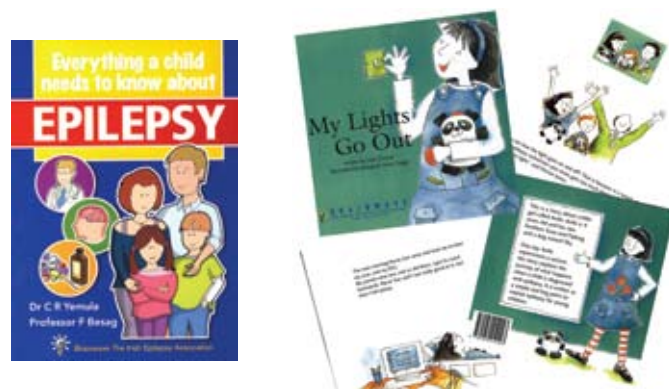
**Table 2: Total number of people attending Brainwave presentations, seminars, school talks, outreach services, hospital outreach clinics and support groups in 2009**



## New publications in 2009

Brainwave's information service also includes a comprehensive database of literature including books, booklets, leaflets, CDs and videos on a wide range of epilepsy-related issues. In 2009, a number of new publications were developed and launched.

- An information leaflet on Sudden Unexpected Death in Epilepsy (SUDEP), developed in conjunction with UK charity Epilepsy Bereaved and funded by the Barbara Doyle Memorial Fund
- New Beginnings; a guide to your child's epilepsy - a guide for parents compiled by Brainwave and the Paediatric Neurology nurses from Crumlin and Tallaght Hospitals. Supported by an unrestricted educational grant from Sanofi-Aventis, the guide was launched during National Epilepsy Week in May
- Everything a child needs to know about Epilepsy - an epilepsy book written by Dr. Chinnaiah Yemula and Professor Frank Besag aimed at helping children over the age of 6 understand their epilepsy. The book tells the story of Seamus and Niamh and the journey they have to follow when they are diagnosed with epilepsy. It was made possible through the funds raised from the Lisa Bassett Memorial walk
- My Lights go Out - a story book about a little girl called Aoife which explains the journey of what happens when a child is diagnosed with epilepsy. The book is written by Julie Greene, illustrated by Margaret Anne Suggs and edited by Brainwave's Director of Services, Aisling Farrell
- Frequently Asked Questions, Brainwave's most popular leaflet was translated and published in Polish and Chinese



## National Conference 2009

Brainwave's National Conference 2009 entitled 'Epilepsy - Diagnosing the Problem' was held on October 3rd in the Strand Hotel, Limerick. Dr. Peter Boers, Consultant Neurologist at the Mid Western Regional Hospital and Dr. Neil Austin, Senior Clinical Neuropsychologist from the Neurology Services, Adelaide and Meath Hospital, Tallaght presented on the day. A full house of over 160 people attended for the presentations and a wide range of workshops and stands. The conference was opened by the Deputy Mayor of Limerick, Cllr Michael Hourigan, whose life was personally touched by epilepsy through his son Patrick.

### Talking Heads - Teens and Young Adults Conference

The second conference for Teens and Young adults entitled 'Talking Heads' took place in Croke Park, Dublin on September 26th. For many of the young people attending, it was their first time meeting other people dealing with similar challenges. Many parents also attended and benefited from a talk on 'Letting Go' by Dr. Sandya Tirupathi from the Royal Hospital, Belfast. Meanwhile the young people attended a talk by Tony Bates, the director of Headstrong and Irish Times columnist on mental issues. Two young Brainwave members, Nikki Saarsteiner and Emma Beamish gave personal accounts of living with epilepsy. In the afternoon, two gender specific workshops, Guys Talk and Girls Talk, were facilitated by Denise Cunningham, Clinical Nurse Specialist in Epilepsy Services, Maria Keegan, Paediatric Clinical Nurse Specialist from Crumlin, Dr. Tirupathi and Tony Bates. The final speaker of the day was Consultant Neurologist, Colin Doherty. The feedback from the day was excellent and Brainwave plans to run more Teens and Young Adults conferences in the future.

### Living With Loss

On June 13th the 6th Living with Loss seminar was held in the Rochestown Park Hotel in Cork. Epilepsy Bereaved and Anam Cara assisted with the day as they had done in 2008, and a new addition to the seminar was Peter Hanlon, a bereavement therapist who works with the HSE. Peter ran a series of workshops throughout the day. The feedback from the families was excellent.

Dozens of events were also organised by Brainwave's regional offices in 2009 including the first ever Brainwave Family Fun Day, held in March at Dublin Zoo. Families came mainly from Dublin but others travelled from around Leinster and even Cork and Donegal for an action packed day out for all.

### Specialist Nurse Helpline

The Specialist Nurse helpline is available on Mondays from 9.30am - 1pm and Wednesday's from 9.30am - 1pm. During 2009 however, the service was limited as one of the Community Epilepsy Specialist Nurses was on maternity leave from June. During the year, the helpline received 516 phone calls, 27 emails and 38 personal appointments.

### Epilepsy News

Brainwave's quarterly newsletter for members, Epilepsy News received a makeover in 2009 and a readers' survey was undertaken to help ensure that the magazine continued to meet the needs of members. We were encouraged by all the positive comments saying how useful the magazine was and were delighted to receive suggestions on how it could be improved further.



L-R: Dr Peter Boers, Consultant Neurologist; Anna Kelly, Brainwave CRO; Cllr Michael Hourigan, Deputy Mayor of Limerick; Dr Neil Austin, Senior Clinical Neuro-psychologist at the 2009 National Conference.



Nikki Saarsteiner and Emma Beamish, two young adults with epilepsy who spoke at the Talking Heads youth conference at Croke Park.



Ann Connolly, Paediatric Neurology Clinical Nurse Specialist at AMNCH with young friend at the launch of the New Beginnings booklet

### Epilepsy.ie

Brainwave's website epilepsy.ie also received a major makeover in 2009 with the new site going live on April 1st. The new site offers a clearer navigation path, an expanded epilepsy information section, a new e-zine service, an online store, constantly updated news and events sections, and a new members' area. The site was supported by an unrestricted educational grant from UCB (Pharma) Ireland.

### Nurses Information Pack

2009 saw Brainwave begin preparation for an information resource pack for Nurses. The Nurses Information Pack will be the fourth in a series aimed at specific professional audiences following the success of similar initiatives for GPs, employers and teachers.

The resource will be published in 2010 and targeted towards nurses with the greatest exposure to epilepsy such as Practice Nurses; Public Health Nurses, Intellectual Disability Nurses, A&E Nurses, Paediatric nurses and of course Neurology Nurses.



*"Brainwave gave me the self confidence to believe in myself to manage my epilepsy better. I am now 15 months seizure free and looking forward to commencing the Training For Success course in Sligo". Stephens Collins, Co. Louth*

# Awareness

## Brain Awareness Week

Brainwave and the Trinity College Institute of Neuroscience (TCIN) came together during Brain Awareness Week to mark the 200th anniversary of the birth of Robert Bentley Todd, an Irish-born and educated doctor who is an important, though often under-recognised figure in the development of our modern understanding of epilepsy.

The occasion was marked with a memorial lecture to highlight his contributions and also to raise public awareness of an important issue in epilepsy today – that of photosensitivity. Brainwave President Dr. John Kirker chaired the event at The Science Gallery at Trinity College Dublin, where Todd was educated.

Consultant Neurologist Dr. Edward Reynolds, a successor to Todd at King's College London and a published expert on his work and career explained Todd's contribution to the development of our modern understanding of the electrical basis of epilepsy.

Prof. Graham Harding from Aston University, Birmingham delivered the keynote lecture calling for the introduction of broadcast guidelines in Ireland to protect people with photosensitive epilepsy.

Prof. Harding is one of the world's foremost experts in photosensitivity and has been involved in the development of guidelines in the UK and elsewhere. No production guidelines exist in Ireland, despite the fact that the most common trigger for photosensitive epilepsy is television. Prof. Harding called upon the broadcasting representatives in the audience to remedy the situation.

## National Epilepsy Week

National Epilepsy Week saw the launch of The Prevalence of Epilepsy in Ireland report at an event on May 19th in Buswell's Hotel, Dublin where Dr. Christine Linehan announced the key findings to the public.

Following the official launch, representatives from Brainwave went to Leinster House, where a presentation of the main findings was made to TDs and Senators.

The launch of the report received huge attention in the media, including on RTE television; on national and local radio and in all the major newspapers. Brainwave used the opportunity to highlight the lack of specialist services available for people with epilepsy and called for the appointment of additional Epilepsy Specialist Nurses to help fill the service gaps that exist.

*"I have been in contact with Brainwave for the past 10 years. They have always provided me with lots of information and fantastic support and advice. It is always a great help to hear of all the local events and meetings that take place in my area. I find the meetings to be well run and informative and the support groups are a great way to get in contact with other people with epilepsy. Anytime we make contact, we receive an instant response which is very reassuring". Lorna Cliffe, Co. Limerick*



## Strategic objectives

- To communicate with the wider public and 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

## Epilepsy in the Media

The RTE1 documentary series This is Me focused on epilepsy in one of its programmes in July 2009. The half-hour programme featured Brainwave member and media volunteer Emma Beamish from Dublin. Emma is a member of the Irish Women's cricket team and was diagnosed with epilepsy at the age of 14. She agreed to allow the cameras to access her life for over two months to make the programme. Over 212,000 people saw the programme, a 19% share of the total TV audience.

During the year, Brainwave's media volunteers took up many opportunities to raise awareness of epilepsy. Nikki Saarsteiner took part in an interview on TV3's Morning Show with Clinical Nurse Specialist in Epilepsy Services Cora Flynn from Beaumont Hospital. Peter Phelan from Waterford was interviewed along with Dr. Colin Doherty and Rick O'Shea for a major piece on epilepsy in the Irish Independent in August. RTE Radio did a special feature at Brainwave's National Conference featuring interviews with speakers, Brainwave staff and delegates at the conference.



Brainwave CEO Mike Glynn is interviewed by RTE Health correspondent Fergal Bowers. (R) Guests attending the Robert Bentley Todd Memorial lecture.



Brainwave members Colin Jones and John Crawford who took part in an awareness raising football exhibition in Sweden.

## Awareness Through Football

Two young Brainwave members, Colin Jones from Cork and John Crawford from Limerick took part in a football showcase event at last summer's European Under-21 Championships in Sweden. The exhibition games featured people with epilepsy playing alongside club academy players and some top-level former professional footballers. It was organised by UEFA, the IBE and ILAE to raise public awareness of epilepsy.

UEFA President Michel Platini said he hoped the initiative would "contribute to improving knowledge about epilepsy and, most importantly, emphasise that people with epilepsy are entitled and able to live a life that meets their expectations and to engage fully in social and professional activities."

## Strategic objective

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

# Advocacy

In March, Brainwave called for the introduction of broadcast guidelines to protect people with photosensitive epilepsy from flashing images and repetitive patterns on TV. Representatives from the broadcast industry and production companies attended the Robert Bentley Todd memorial lecture to hear Prof Graham Harding, a world leading expert on photosensitivity outline the need for Irish guidelines along the lines of those introduced in recent years in other countries. The Broadcasting Commission of Ireland has since indicated that introducing guidelines is an area of interest and that it would be encouraging broadcasters to take appropriate measures.

The media opportunities presented by National Epilepsy Week 2009 were utilised to highlight the lack of specialist services available for people with epilepsy. Brainwave called for the appointment of additional Epilepsy Specialist Nurses to help fill the service gaps that exist and remedy the historical neglect and lack of investment in the area of epilepsy. The creation of two specialist nurse posts in each HSE region (bringing the total from just 4 to 14) was highlighted as a cost-effective measure which would improve the quality of life of people with epilepsy. Brainwave's work campaigning for new specialist nursing positions continues into 2010 when it is hoped that at least one new specialist nursing post will be created.

For many years, Brainwave has worked to highlight the lack of Consultant Neurologists in Ireland. Good news arrived at the end of 2009, with the appointment of Dr. Dan Costello to the post of Consultant Neurologist at Cork University Hospital. Dr. Costello is an epilepsy specialist and his appointment will help improve services for people with epilepsy in the large CUH catchment area.

The Pharmacist's dispute in the summer of 2009 threatened to create a serious problem for people with epilepsy by interrupting the supply of anti-epilepsy medication. Brainwave was one of the most vocal disability charities in calling for a resolution in the interests of patients and numerous media interviews were set up to explain the concerns of people with epilepsy.

Brainwave's advocacy work in highlighting the need for an exclusion for epilepsy medications in the government's planned system of generic substitution continued in 2009. Significant developments are expected in this area in 2010.

*"Until five years ago I never had a seizure in my life. It was a very frightening time for me as I did not understand what was happening to me or why. I became a member of Brainwave, which changed my life. Brainwave listened, understood and cared; they explained the truth about seizures. Brainwave introduced me to other people who have seizures, people I could relate to and people who could relate to me. I cannot thank Brainwave enough for their services. Slowly but surely I am rebuilding my life. The staff at Brainwave should be very proud of what they do. I am so proud to be a member".*

Rachel Brady, Co. Donegal



Brainwave's Peter Murphy (L) and Mike Glynn (R) present Dan Neville TD with a copy of the Prevalence of Epilepsy in Ireland report at the Dail. Right: Prof. Graham Harding calls for the introduction of broadcast guidelines in Ireland to protect people with photosensitive epilepsy.



## National and International Partnerships

Affecting change through campaigning 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 organisations whose roles are advocacy based.

### The Neurological Alliance of Ireland

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

The Neurological Alliance of Ireland is the national umbrella organisation for groups representing the views and concerns of those affected by neurological conditions. NAI aims to secure improved care and support for people with neurological conditions. Aisling Farrell, Brainwave's Director of Services 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 and advocate for over 100 voluntary disability organisations in Ireland. Its aim is to ensure that Irish society is fully inclusive of people with disabilities and disabling conditions. Brainwave CEO Mike Glynn is a board member of DFI.

### International Bureau For Epilepsy

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

IBE an international organisation that serves to develop, support and link national epilepsy organisations around the world. It addresses issues such as education, employment, insurance, driving and public awareness. In 2009, Brainwave's CEO, Mike Glynn was elected President of IBE and his 4-year term in office began on July 1st.

### Joint Epilepsy Council of the UK and Ireland

[www.jointepilepsycouncil.org.uk](http://www.jointepilepsycouncil.org.uk)

The Joint Epilepsy Council is an umbrella organisation representing the united voice of epilepsy organisations in the UK and Ireland with the aim of improving services for people with epilepsy, their families, and carers. Brainwave is represented on the JEC's Research Group and Marketing & Communications group by Resources Manager Peter Murphy while Aisling Farrell, Director of Services sits on the Health group.



# Training and education

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

In response to huge demand from health professionals, Brainwave introduced a new training programme for healthcare professionals in epilepsy awareness and the administration Buccal Midazolam (BM) in 2009.

BM is an emergency rescue medication prescribed under special license to reduce the duration or stop an epileptic seizure and prevent status epilepticus. It is administered to the buccal mucosa (between the gums and cheek) and is receiving widespread acceptance due to its effectiveness and its social acceptability compared to alternatives such as rectal diazepam.

BM must be administered by a trained health professional but many were reluctant to administer it without training. However no such training existed in Ireland, which often meant that people with epilepsy were unable to benefit from the treatment.

To meet this unmet need, all Brainwave CROs received "train the trainer" training from the UK to enable them to conduct a one-day training course on BM administration and epilepsy awareness in Ireland. The aim of this new course is to facilitate the safe and appropriate administration of BM and to provide professionals with valuable information on epilepsy.

A total of 239 people were trained in 2009 over 19 training days. Demand for the service exceeded even our most optimistic forecasts. On many occasions we had to create a waiting list or re-allocate people to different courses. It is clear from the feedback that the training provided health professionals with a better understanding of epilepsy and practical information on how to use Buccal Midazolam safely.

Brainwave is the sole provider of this service in Ireland and will continue to provide this training for as long as demand exists. There is also a huge unmet need to train teachers to administer BM and this issue is something Brainwave also has plans to address.



Participants at the Buccal Midazolam training course organised by Brainwave in Limerick.

*"I joined Training For Success to gain a better understanding of my epilepsy. Although I did get that and got the opportunity to meet people with similar conditions to mine, I also got some very valuable guidance. Before the course I was unsure of what to do for a career. The course gave me the clarity to decide what to go for in the CAO". Brendan Travers, TFS student*

## 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
- To train Brainwave volunteers

## Training For Success (TFS)

2009 saw Brainwave's one-year pre-employment training programme for young adults with epilepsy entering its eleventh successful year.

Training For Success is the only course of its kind in Europe. It aims to help young people with epilepsy to:

- Identify their own personal goals and plan to achieve them
- Build confidence and self-esteem
- Decide upon the career of their choice
- Learn about the nature and management of epilepsy

TFS is run in partnership with the Institute of Technology, Sligo and FÁS. Honor Broderick, Programme Manager welcomed the 15 new students who started the 2009/2010 term bringing the total number of students attending TFS to 155 people to date.

## Schools Education Programme

As part of Brainwave's commitment to improving the circumstances for people living with epilepsy by raising awareness of the condition, the very successful Schools Education Programme continued throughout 2009 with Epilepsy Awareness presentations being made to primary and secondary schools throughout the country.

## Volunteer Media Training

In 2008, Brainwave began delivering media training workshops around the country for people with epilepsy and their families in order to help raise awareness of epilepsy in the media. The final planned workshop, in Waterford was held in January 2009 with 12 members attending.

## Service Learning Project between Brainwave and the Occupational Therapy Department at NUIG

Following a successful collaborative Service Learning project between Brainwave and the Occupational Therapy Department at the National University of Ireland Galway in 2008, a follow-on programme took place from September 2008 to March 2009.

Three OT students were assigned to Brainwave in Galway to implement an occupational therapy intervention, which in this case was a stress management programme for people with epilepsy. A Stress Management workshop was held in February in Aras Moyola, NUIG. The day was very successful and enjoyable and feedback from the people attending was very positive. The project highlighted the role that stress management programmes can play in helping manage epilepsy more positively.



Stress management workshop organised by Brainwave and the Occupational Therapy Department at NUIG.

## 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

# Research

## The Prevalence of Epilepsy in Ireland study

The Prevalence of Epilepsy in Ireland Report was launched during National Epilepsy Week. Commissioned by Brainwave, the study was conducted by the UCD Centre for Disability Studies and guided by an Advisory Committee of experts in epilepsy, epidemiology and neurology.

It is the first national epilepsy prevalence study undertaken anywhere in Europe and identifies for the first time, accurate figures on the number of people with epilepsy in Ireland.

Among its key findings are:

- A national prevalence of treated epilepsy of 9 per 1,000 people for those over the age of 5, meaning that there are 36,844 people over the age of 5 years living with epilepsy in Ireland
- A gradual year-on-year increase in the prevalence of treated epilepsy for each year under consideration in the study (from 8.3 per 1,000 people in 2002 to 9.0 per 1,000 in 2005)
- An average of 17 cases of epilepsy seen each week per consultant neurologist, or 442 consultations nationwide per week
- Regional variance in prevalence with the lowest rates observed in the East (7.9 cases per 1,000 people) and the highest rates in the West (10.8 cases per 1,000 people)

Understanding the prevalence of epilepsy is important in order to assess whether existing and planned services are appropriate to meet needs. The study will therefore be important to Brainwave's work in campaigning for better services for people with epilepsy.

The study was published in the online version of *Epilepsia*, the most authoritative journal for epilepsy research in late 2009, ahead of print publication in 2010.

## Research Funding Scheme

As part of our ongoing commitment to encouraging and supporting Irish epilepsy research, Brainwave launched a new Research Funding Scheme in late 2008. A Research Peer Review Board was established, chaired by Professor David Chadwick from the Walton Centre for Neurology and Neurosurgery in Liverpool; research priorities were set and a call for proposals was made.

A total of 14 applications for funding were received by the March deadline. Applications underwent a rigorous evaluation process, being formally assessed by over 40 leading international experts.

*"I meet with Evelyn (Brainwave's Community Resource Officer) on a regular basis and look forward to our chats. She fully understands the anxieties, the stresses and concerns people with epilepsy have. Evelyn is someone I can talk to about day to day worries and she always stresses the importance of making time for myself. Brainwave has been a fantastic support to me, keeping me focused on what's important to maintain good health".*

Patricia Connor, Galway



Pictured at Brainwave's Research Peer Review Board meeting. L-R: Peter Murphy, Dr. Norman Delanty, Dr. David Henshall, Prof. David Chadwick, Dr. Patrick Dicker, Dr. Bryan Lynch and Mike Glynn.  
R: Dr. Christine Linehan presents data from the Prevalence of Epilepsy in Ireland report during National Epilepsy Week.



Brainwave's Research Peer Review Board met in May to consider the applications and the three proposals that best meet the assessment criteria were selected. These were submitted to the Health Research Board (HRB) in June for joint funding under a scheme operated by the HRB and the Medical Research Charities Group (MRCG) of which Brainwave is a member.

Joint funding (50%) was approved by the HRB for two of the projects and thanks to the fundraising efforts of the family and friends of the late Barbara Doyle, it was also possible to fund the third project. The total cost of the three projects funded under the scheme is over €260,000 with just over €100,000 of this coming from the HRB.

All three projects 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.

## A pharmacogenomic study of chronic refractory epilepsy

Dr. Gianpiero Cavalleri, Royal College of Surgeons in Ireland  
€147,758 over three years, jointly funded by Brainwave and the HRB.

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

Dr. Teresa Burke, University College Dublin  
€43,400 over 18 months, jointly funded by Brainwave and the HRB.

## 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, Dublin  
€74,934 over 12 months, partly supported through the fundraising efforts of the friends and family of the late Barbara Doyle.

## Other research in 2009

Brainwave supported a study investigating the quality of life of adults with epilepsy in Ireland conducted by Denise Cunningham, Clinical Nurse Specialist in Epilepsy Services.

Dr. Deirdre O'Rourke of Beaumont Hospital presented a poster at the 28th International Epilepsy Congress in Budapest outlining her work to date on the SUDEP incidence study. The study is funded by Brainwave and will be completed in 2011. Dr. Christine Linehan's research on quality of life in epilepsy, supported by Brainwave was also presented in Budapest along with three posters by Brainwave staff.

# Fundraising

Brainwave's work is funded almost exclusively through state grants and a wide range of fundraising events, donations and campaigns. 2009 was a difficult year for fundraising and although fundraising income fell by 5%, this was still a reasonable performance given the prevailing economic climate.

Brainwave's volunteer manager responsible for fundraising in Cork, Bernard Hughes celebrated 25 years with Brainwave in 2009. Bernard's tireless work has been central to the growth and success of Brainwave both in Cork and nationwide during that time and a special celebration to mark the occasion was held. Brainwave also welcomed a new member to the fundraising team, when Glenna Gallagher joined the staff team at head office.

Brainwave is indebted to the generosity of our fundraisers, supporters and volunteers all over the country who give up their time and expertise to raise money to support a cause of epilepsy. Many of our supporters have epilepsy themselves or have a family member or friend with the condition. Others will have lost a loved one to epilepsy. We want to sincerely thank every single person who has helped support our work in 2009. It simply wouldn't be possible to do what we do without them.

## Volunteer Events

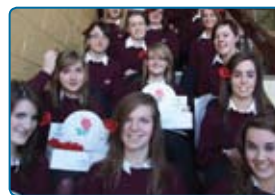
A whole range of events were organised by our supporters around the country. Only a few can be included below. (1) The Irish Rubberman Challenge, held in Wexford (2) Slimathon in Tullamore (3) Daredevil skydivers from Swords (4) The Cork Coastal Rowing Association (5) Paul and Emma, just one couple who donated to Brainwave in lieu of wedding favours and (6) finally, proceeds from a compendium of events organised by Theresa O'Brien and the group in Waterford are presented to Noeleen McDaid of Brainwave.



## Fundraising Highlights of 2009



Just three of the 300 women who represented Brainwave in the Flora Dublin Women's Mini-Marathon on a scorching June Bank Holiday Monday, raising a fantastic €33,000 in the process.



The St Valentine's Roses (February) and Rose Week (October) campaigns took place in schools, businesses, streets and shopping centres around the country raising almost €40,000.



David Kitt was one of the performers at Brainwave's Horse Show Hustle party night at Krystle nightclub in Dublin, attended by over 300 people.



Brainwave Christmas cards proved a big hit again with our supporters, helping to raise almost €10,000.



Collections have traditionally been an important element of Brainwave's fundraising and in 2009, hundreds of volunteers around the country organised and took part in collections. Over €207,000 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

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 the fundraising section on [www.epilepsy.ie](http://www.epilepsy.ie).

# 2009 Financial report

Brainwave reported a small deficit of €4,077 for 2009, which was a reasonable performance in the prevailing difficult economic circumstances.

Funds from the HSE were down on 2008 levels but fundraising income was maintained, expenditure was controlled and the value of Brainwave's investments improved by €27,390 during the year, all of which helped to ensure that a much larger deficit was not incurred.

## Brainwave - The Irish Epilepsy Association Income and expenditure account for the year ended 31 December 2009

	2009	2008
	€	€
Income	1,569,075	1,815,328
Expenditure	<u>(1,604,826)</u>	<u>(1,577,676)</u>
Operating (deficit)/Surplus	(35,751)	237,652
Investment Income	4,284	6,590
Unrealised gain/(loss) on quoted investments	<u>27,390</u>	<u>(99,244)</u>
(Deficit)/Surplus on Ordinary activities before taxation	(4,077)	144,998
Tax on (deficit)/surplus on ordinary activities	-	-
(Deficit)/Surplus on ordinary activities after taxation	<u>(4,077)</u>	<u>144,998</u>

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 2009

	2009	2008
	€	€
<b>Fixed Assets</b>		
Tangible Assets	146,499	165,503
Financial Assets	<u>133,190</u>	<u>105,800</u>
	279,689	271,303
<b>Current Assets</b>		
Debtors	166,686	69,242
Cash at Bank and in hand	<u>1,721,618</u>	<u>1,704,308</u>
	1,888,304	1,773,550
<b>Current Liabilities</b>		
Creditors (Amounts falling due within one year)	(390,059)	(262,842)
<b>Net Current Assets</b>	<u>1,498,245</u>	<u>1,510,708</u>
<b>Net Assets</b>	<u>1,777,934</u>	<u>1,782,011</u>
<b>Capital and Reserves</b>		
Income and Expenditure Account	547,934	552,011
Special Reserves	<u>1,230,000</u>	<u>1,230,000</u>
	1,777,934	1,782,011

The financial statements were approved by the board of directors on 9/7/2010 and signed on its behalf by

Directors:

Mr Mark Dowdall

Mrs Tessa Dagge

# 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. Colin Doherty (resigned October 2009)  
Mr. Joe Doyle RIP (died 8th August 2009)  
Dr. Michael Hennessy  
Dr. John Kirker  
Dr. Bryan Lynch  
Ms. Margaret McCahill  
Prof. Joe McMenamin (resigned October 2009)  
Dr. Brian McNamara  
Ms. Audrey Murphy  
Ms. Carol Saarsteiner  
Dr. Joyce Senior  
Dr. Brian Sweeney  
Dr. David Webb

## Finance Committee

Mr. Roddy Fitzpatrick (Chairman)  
Mrs. Tessa Dagge  
Mr. Mark Dowdall  
Mr. Richard Holmes  
Mr. Tony Rhatigan  
Mr. Michael Sheehy

## Research Peer Review Board

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

## Chief Executive

Mike Glynn

## Services

### Director of Services

Aisling Farrell

### 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)  
Annette Russell (South East Region)

### Clinical Nurse Specialist in Epilepsy Services

Denise Cunningham (AMNCH, Tallaght)

### Community Epilepsy Specialist Nurse

Sinead Murphy (Beaumont Hospital)

## Administration and fundraising

### Resources Manager

Peter Murphy

### Key Fundraiser

Noeleen McDaid

### Fundraising Assistant

Glenna Gallagher

### Fundraising Assistant

Catherine Healy

### Training and Communications Manager

Paul Sharkey

### Training For Success Manager

Honor Broderick

### Training For Success Facilitator

Maire Kerins

### Accounts and Administration Manager

Elizabeth Ryan

### Membership and Database Co-ordinator

Ashley Butler

### PA to CEO

Maria Parodi

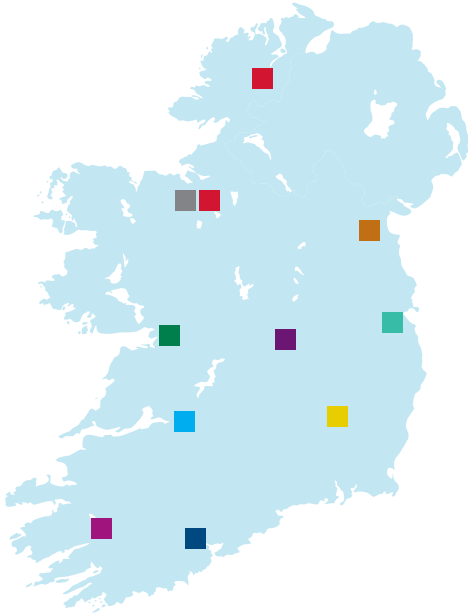
### Receptionists

Madge Geoghegan  
Joan McDermott



### Patron: Rick O'Shea

2FM presenter Rick was diagnosed with epilepsy at the age of 16. In March 2006, he answered Brainwave's call to become Patron of the charity. 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 and taking 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.



**Head office**

Address: 249 Crumlin Road, Dublin 12  
 Tel: 01 455 7500  
 Email: 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

**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

**Sligo office**

Address: St Vincent's Business Park, Finiskin Road, Sligo  
 (Will change to: Model & Niland Arts Gallery, The Mall, Sligo from October 1st 2010.)  
 Tel: 071 915 4625

**West**

Covering: Galway, Roscommon and Mayo  
 Community Resource Officer: Evelyn Monson Kirby  
 Address: Ozanam House, St. Augustine Street, Galway  
 Tel: 091 568 180  
 Email: 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

**Kerry**

Covering: Kerry  
 Community Resource Officer: Kathryn Foley  
 Address: 9/10 The Paddocks, Ballydowney, Killarney, Co. Kerry  
 Tel: 064 663 0301  
 Email: 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 (Niamh)/brainwavecork1@eircom.net (Mary)

**North East**

Covering: Louth, Meath, Monaghan and Cavan  
 Community Resource Officer: Noreen O'Donnell  
 Address: The Dundalk Club, 1 Roden Place, Dundalk, Co. Louth  
 Tel: 042 933 7585  
 Email: brainwavedk@epilepsy.ie

**South East**

Covering: Kilkenny, Wexford, Carlow, Waterford and Tipperary South  
 Community Resource Officer: Annette Russell  
 Address: Ground Floor, St. Canice's Hospital, Sion Road, Kilkenny  
 Tel: 056 778 4496  
 Email: southeast.brainwave@epilepsy.ie

**Midlands**

Covering: Offaly, Longford, Laois and Westmeath  
 Community Resource Officer: Margaret Bassett  
 Address: c/o Offaly Centre for Independent Living, Clonminch Road, Tullamore, Co. Offaly  
 Tel: 057 934 6790  
 Email: 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: gdunne.brainwave@epilepsy.ie (Geraldine)/imurphy.brainwave@epilepsy.ie (Ina)

---

**Brainwave - The Irish Epilepsy Association**

249 Crumlin Road, Dublin 12

Tel: 01 455 7500

Fax: 01 455 7013

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

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

**Charity Number**

CHY 6170

Company Limited by Guarantee

Registered in Dublin 77588

**Auditors**

Deloitte & Touche

Chartered Accountants

Deloitte & Touche House

Earlsfort Terrace, Dublin 2



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