



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

Annual Report 2010

Brainwave - The Irish Epilepsy Association

Shining a light on epilepsy since 1966



Contents

Messages from the Chair and CEO	Page 4
Epilepsy	Page 5
Information and Support	Page 6
Awareness	Page 8
Advocacy	Page 9
Training & 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 (CHY 6170)

was established in 1966 by a group of individuals dedicated to improving the quality of life of people with epilepsy in Ireland.

Over the 45 years since our inception, the Association has grown and expanded, now 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

I would like to welcome you to the 2010 Annual Report of Brainwave - The Irish Epilepsy Association which highlights the challenges and achievements of the Association and all those working to support and improve the lives of everyone living with epilepsy.

The Association has experienced changing times and many challenges still lie ahead but with the unwavering support of our members, volunteers, fundraisers and donors we shall continue to progress the aims and objectives of our charity. We are deeply grateful to all our supporters without whom the continuation of our information, education, research, awareness, training and outreach services would be at risk.

I would like to extend a sincere thank you to Roddy Fitzpatrick, a long standing member of Brainwave's Finance Committee and Chair of the committee from 2000 until his retirement in 2010. His dedication to the Association is deeply appreciated, and his commitment to people with epilepsy will long be remembered by all those who were fortunate to meet him.

While epilepsy affects approximately 37,000 individuals in Ireland it can often be difficult to raise awareness of the condition. One person who has actively supported and raised the profile of epilepsy has been 2FM presenter Rick O'Shea, who has been the patron of Brainwave since 2006. On my own behalf and on behalf of all those working and living with epilepsy, I would like to thank him for his invaluable support to the Association.

I would like to thank my fellow Board members, in particular our Vice-Chair Vincent Savino, our Hon. Secretary Claire Crehan-Dowdall and our Treasurer Mark Dowdall for all their support and advice during the past year.

Finally, on my own behalf and on behalf of my fellow Board members I would like congratulate our CEO Mike Glynn for his excellent vision, leadership and commitment to the Association during these challenging times. He has been unwavering in his dedication to the Association while championing the epilepsy agenda on the international stage as President of the International Bureau for Epilepsy.

Tessa Dagge



Mike Glynn, Chief Executive

2010 was both a challenging and an active year for Brainwave - The Irish Epilepsy Association. While economic developments are challenging and have affected our state funding, we have endeavoured to adapt to these circumstances to ensure we continue to improve and meet the needs of people with epilepsy.

The 18,000 enquiries handled by Brainwave staff in 2010 was significantly up on the previous year and demand for our services remains high. The year was also a busy one in terms of events. During Brain Awareness Week, Brainwave and the Royal College of Physicians (RCPI) co-operated on a joint public meeting specifically focused on the challenges faced by young adults managing their epilepsy. As part of National Epilepsy Week, Brainwave held our first film night in Dublin's Mansion House to raise awareness of epilepsy and stimulate discussion around the condition. The National Conference on the theme of Epilepsy & The Family was held in Dublin and was webcasted for the first time in order to reach a greater audience. The sixth Living With Loss seminar was held in Portlaoise.

We also launched and distributed a new Nurses Information Pack during the year, a resource which Dr. Colin Doherty, consultant neurologist and HSE's Clinical Lead for epilepsy welcomed as an invaluable resource tool to all nurses caring for individuals with epilepsy.

One of Brainwave's key objectives is to undertake and assist research into epilepsy. Funding continued in 2010 for three important Irish-based projects. Another call for epilepsy research proposals was announced in late 2010 and we hope to be able to fund more research from 2011.

As Brainwave faces into the final year of its current 5-year Strategic Plan, we look forward to working in consultation with a wide range of stakeholders during 2011 to actively shape and contribute to the next strategic plan. All feedback and suggestions shall be documented and where organisationally and financially feasible, will be incorporated into our next plan.

I would like to sincerely thank all of our members, volunteers and supporters for their continued support throughout 2010, without which Brainwave would be unable to sustain the excellence we aspire to in meeting the needs of people with epilepsy.

In conclusion, I would like to thank our Board of Directors and all the staff for their support, dedication and professionalism during the past year.

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.

The condition affects more than 6 million people in Europe and about 50 million people worldwide. 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 and will depend on many things. 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, 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 a stigma associated with the condition, 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.



When I first contacted Brainwave two years ago I was at my lowest point. After attending my first meeting, my confidence grew and I got a great lift from talking to other parents who were going through the same emotions as me. Noreen in the Dundalk office and the other parents were an inspiration and helped me overcome the fear and anxiety of my child's epilepsy.
Julie Mongan, Co. Louth

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.

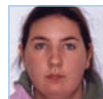
Despite this, Ireland continues to have a chronic shortage of epilepsy specialists (including consultant neurologists, consultant neurophysiologists and epilepsy specialist nurses) and there are also deficits in GP education, access to EEG & MRI scanning and limited access to epilepsy surgery.

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. 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. Many of these deaths are due to sudden unexpected death in epilepsy (SUDEP) a phenomenon similar to sudden adult death and sudden infant death.

For these reasons, the HSE's decision to appoint Dr Colin Doherty as the National Clinical Lead in Epilepsy in 2010 is to be welcomed. Dr. Doherty's role will be to improve the quality of care for people with epilepsy in Ireland and to improve access to care.

Plans are underway to introduce a population-based nurse-led service which would see the appointment of up to 25 new Epilepsy Specialist Nurses. Dr. Doherty's plans to establish a network of Regional Epilepsy Centres with centralised administration and to introduce integrated care pathways are just two of many changes in the pipeline that will also help offset the decades of neglect and underinvestment epilepsy has endured in Ireland.



Since my neurologist suggested that I contact Brainwave, I haven't looked back. Anna Kelly invited me to the local office in Limerick and the condition was fully explained to me. She also discussed lifestyle and educational issues. I always felt lacking in self confidence since I was diagnosed at 12 but Anna encouraged me to attend a Brainwave youth seminar where I met people the same age and I now feel much more confident.
Marian Moloney, 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 service staff around the country are responsible for providing support and information services to people with epilepsy and their family members 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 Specialist Nurse Helpline is available on Mondays and Wednesdays from 9.30am - 1pm, operated by Sinead Murphy, Community Epilepsy Specialist Nurse and Denise Cunningham, Clinical Nurse Specialist in Epilepsy Services.

Brainwave also maintains a large library of information resources for people with epilepsy and their families including books, leaflets, videos, CDs, posters and information packs. The newsletter Epilepsy News is produced and sent to all Brainwave members every quarter. An email newsletter is also regularly distributed. At the end of 2010, over 1,400 people had signed up for the e-bulletin.

Brainwave's website epilepsy.ie contains a wide range of information on epilepsy as well as regularly updated news and events sections. In 2010, the site registered over 48,000 visits from almost 31,000 unique visitors. A total of 290,000 page views were recorded.

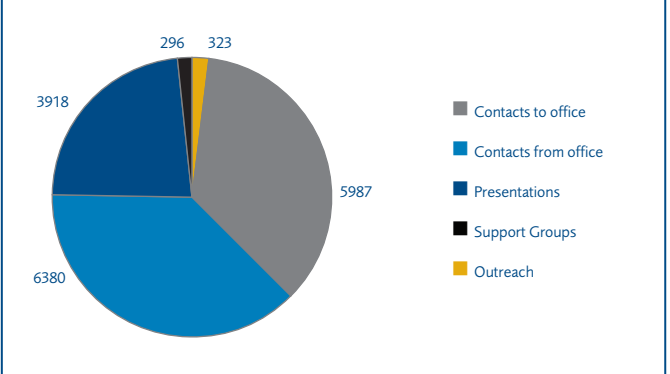
The Year in Numbers

- The total number of contacts made to or by Brainwave's nationwide network of Community Resource Officers and the National Information Officer in 2010 was **18,326**.
- In total, **22,218** people accessed a Brainwave service (this included Training For Success, Health professional training, presentations in workplaces and schools and the Specialist Nurse Helpline).
- **3,918** people attended presentations, seminars, school talks etc by Brainwave service staff during the year.
- **323** people accessed Brainwave's community outreach services
- **296** people availed of support groups organised throughout the country.
- The number of people who accessed the Epilepsy Nurse Helpline was **606**. A total of **2,844** people accessed the full range of services provided by the nurses at hospitals and in the community.

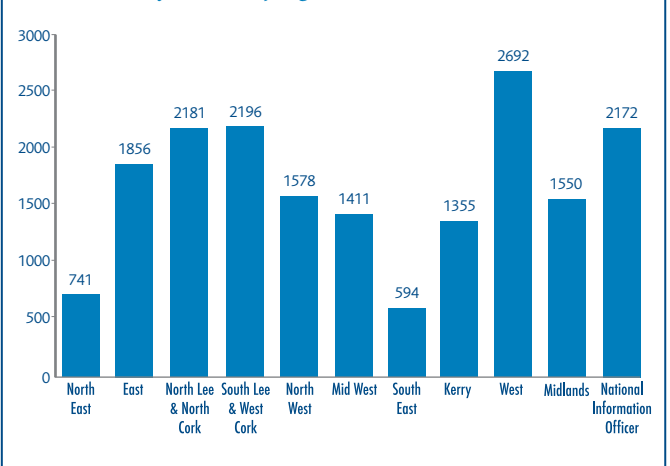


I had always felt that there was a lot of stigma against people with epilepsy, so it makes you think twice before you open up about it. By attending the Brainwave support groups I now find it easy to talk to others about my condition. I hope that I have also been able to help other people by sharing my experiences. Brainwave is a great support for people with epilepsy and has helped many to manage their epilepsy in a positive way.
Theresa Stroker, Roscommon.

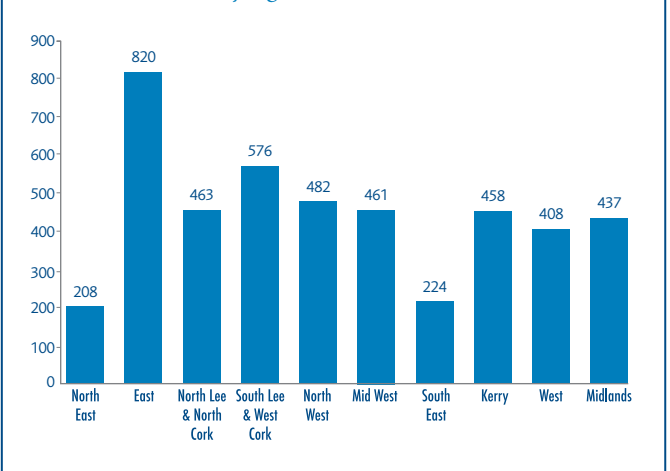
Breakdown of support contacts 2010



Total number of contacts by region



Total number of people attending presentations, support groups and outreach services by region



Information and support - continued

The Young Adult with Epilepsy Conference

In March, as part of the activities for Brain Awareness Week, the Royal College of Physicians (RCPI) and Brainwave held a joint public meeting on epilepsy called "The Young Adult with Epilepsy: Looking Forward to the Future". The meeting was held in Dublin and was chaired by RTE's Sharon Ni Bheolain. Speakers included Dr Danny Costello, Consultant Neurologist at Cork University Hospital; Maire White, Clinical Nurse Specialist in Epilepsy, Dr Norman Delanty (both Beaumont Hospital) and Brainwave advocate Emma Beamish. The meeting specifically focused on the challenges young adults face in managing their condition as they move from adolescence to adulthood. Over 150 people attended and 220 more tuned in to a live webcast from all parts of Ireland and abroad.



Pictured at the Brainwave/RCPI Public meeting "Epilepsy and The Young Adult" are: (standing) Dr Norman Delanty, Dr John Kirker, Dr Diarmuid O'Shea, Maire White, Paul Sharkey, Dr Niall Pender and Dr Dan Costello. Seated are Sharon Ni Bheolain and Emma Beamish.

National Conference

Brainwave's annual National Conference, entitled "Epilepsy & The Family" took place on Saturday October 2nd in the Aisling Hotel, Dublin. Dr. John Lynch, Consultant Neurologist at University College Hospital, Galway delivered the keynote address, giving a comprehensive overview of epilepsy, its effects on the individual and the family, epilepsy treatments and genetic aspects of the condition. Dr Gianpiero Cavalleri, Biomedical Research Lecturer in Epilepsy Genetics and Pharmacogenetics, RSCI and Dr Teresa Burke, Senior Lecturer in Neuropsychology, UCD, both Principal Investigators in research projects funded by Brainwave, also presented on the day about their work. Afternoon breakout sessions were also held on stress management, lifestyle management and benefits & entitlements. The 2010 conference was broadcasted live on the internet for the first time.

Living With Loss Seminar

Brainwave held the sixth Living With Loss seminar for families who have experienced the loss of a loved one to an epilepsy-related death or SUDEP in Portlaoise on October 9th. Peter Hanlon, Bereavement Therapist with the HSE assisted with the day and there was also input from Anam Cara, a national support group set up by bereaved parents. Dr Yvonne Langan from St James's Hospital spoke about her research into SUDEP which is being funded by Brainwave through the Barbara Doyle memorial fund.

New Community Epilepsy Specialist Nurse

A new Brainwave Community Epilepsy Specialist Nurse (CESN) was appointed in the North West in October. Eithne Cawley, CNM2 reports to consultant neurologist Dr Kevin Murphy and works with his team at Sligo General Hospital. This is a HSE West and Brainwave joint initiative and Brainwave agreed to fund the new position for the first 18 months. The new position came about as a result of years of lobbying by Brainwave to have a CESN appointed outside of Dublin. The first CESN was appointed in 2002 by Brainwave and Beaumont Hospital and a second position was created the following year by Brainwave and AMNCH.

Waterford Support Group

In September, Brainwave's Waterford Support Group celebrated its 21st birthday and to mark the occasion, members of the group past and present were invited to a reception at City Hall by Lord Mayor, Cllr Mary Roche, where they were presented with certificates of appreciation by the Lord Mayor. Waterford has been a hub of activity since the foundation of the Support Group in 1989 by a small group of committed volunteers many of whom remain involved to this day and whose commitment to the cause of epilepsy is as strong as ever. The group has done tremendous work not only in supporting people with epilepsy and raising awareness but also in raising funds for epilepsy services.



There was a lively audience questions and answers session at the 2010 National Conference.



Dr John Lynch, keynote speaker at the National Conference.

Other Events in 2010

Two youth conferences in Cavan and Galway due to be held in December 2010 were postponed due to the inclement weather and rescheduled for Spring 2011. However, over 50 events did take place throughout country, including awareness evenings, support groups, information stands and outreach days, in addition to weekly/fortnightly hospital outreaches at 7 hospitals across the country.

I don't feel quite so isolated now with the phone calls from Joan in the Kilkenny office. It really helps to be able to talk to someone outside the family. She has given me lots of useful tips and advice. I have also just joined up to an email group of other women with epilepsy and it is a great help knowing that there are others that you can talk to who will understand.
Eithne Ryan, Wexford

Awareness

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

Brain Awareness Week

The main Brainwave event for Brain Awareness Week was the "Young Adult with Epilepsy: Looking Forward to the Future" conference held in association with the RCPI (see page 6). The event was widely promoted to the public including an interview on the Drivetime show on RTE. Other events during Brain Awareness Week included awareness evenings in Tullamore, Wicklow and Cork, an art exhibition and poetry reading in Waterford and information stands, coffee mornings and outreach activities all across the country.



An epilepsy-themed film night was held at the Mansion House during National Epilepsy Week.

National Epilepsy Week

Brainwave organised an epilepsy-themed film night during National Epilepsy Week to help raise awareness of epilepsy, encourage epilepsy understanding through a novel medium and to stimulate greater discussion around the condition. The film night took place in Dublin's Mansion House. 70 people attended to watch the feature film, *The Exploding Girl* and three short films. There was also a panel discussion on the night featuring Dr. Colin Doherty, Brainwave board member Audrey Murphy, Denise Cunningham and filmmaker Aled Smith. The majority of people attending thought that films such as these could be very useful in helping to raise awareness of epilepsy in future.

Numerous other awareness events took place around the country during National Epilepsy Week including in Athlone, Balbriggan, Clonmel, Cork, Galway, Kildare, Kilkenny, Letterkenny, Longford, Roscommon, Roscrea, Thurles, Tralee, Tullamore, Waterford and Wexford.

Thinking Ahead Campaign

Brainwave, together with almost 30 other neurological charities came together under the umbrella of the Neurological Alliance of Ireland (NAI) to raise awareness of deficits in neurological services in Ireland. A campaign called Thinking Ahead was set up to highlight issues relevant to all neurological conditions and to mobilise the support of the people of Ireland to address the crisis in our neurological care services.



Patient representatives and neurology professionals with the Minister for Health at the launch of the "Future for Neurological Conditions" report.

One of the campaign's first activities was to conduct research on patients' experiences of neurological care and to use the findings to attract public and political attention. Almost 500 people took part in a survey including many members of Brainwave. By the end of the year, the thinkingahead.ie website was online and plans were in place to highlight neurological issues in the 2011 General Election.

Brainwave were also contributors to the landmark report produced by the NAI called "The Future for Neurological Conditions in Ireland: A Challenge for Healthcare; an Opportunity for Change". In the 108-page report, leading neurospecialists, academics, researchers, charities and people with neurological conditions were united in their call for a new strategic focus in the neglected area of neurological services. Two Brainwave members, Peter Phelan and Miriad Kavanagh supported the call by sharing their own experiences of the health services.

European Epilepsy Day

The announcement in 2010 of the first ever European Epilepsy Day (EED) was warmly greeted by Brainwave and other epilepsy organisations across Europe as a new avenue to raise epilepsy awareness. The annual event will take place from 2011 on the second Monday of February. By the end of 2010, Brainwave were implementing plans for a national campaign around EED 2011.

Media Coverage

Media coverage was secured across all platforms during the year. Highlights included appearances on RTE's *Afternoon Show* and on *Drivetime* on Radio 1. There were also feature articles in national and local press while issues such as generic substitution and the European Epilepsy report attracted significant attention in the medical press. An advertising campaign was also run in *Waiting Room* magazine to raise awareness of epilepsy and of Brainwave.

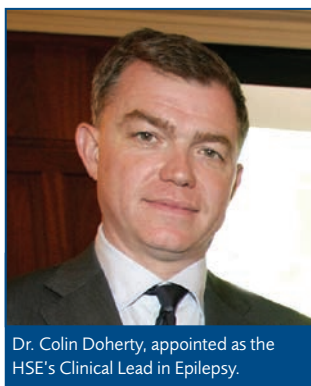


I found out about Brainwave 2 years ago when my youngest child developed epilepsy. Brainwave has constant meetings for people with epilepsy, parents and family members in the midlands. It's a great way to keep in touch and to be updated about important information that's needed badly. Brainwave has helped me so much to understand my daughter's condition. Caroline Cleary, Co Westmeath

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



Dr. Colin Doherty, appointed as the HSE's Clinical Lead in Epilepsy.



Dr. John Lynch, appointed Consultant Neurologist in Galway in 2010.

In March, Brainwave received assurances from the Department of Health & Children and the HSE that epilepsy medications would be specifically exempted from the Government's proposed system of reference pricing and generic substitution. Brainwave has advocated extensively for this exclusion using international evidence that substituting branded epilepsy medications with their generic equivalents can lead to the recurrence of seizures in some people whose epilepsy was otherwise controlled. The HSE's commitment to excluding epilepsy medications was warmly welcomed by Brainwave. In June, the Minister published a report on implementing a system of generic substitution. Legislation is required to make the changes necessary but this had not commenced by the end of 2010.

Brainwave welcomed the appointment of Dr Colin Doherty, Consultant Neurologist at St James's Hospital as the National Clinical Lead in Epilepsy under the office of Dr Barry White, HSE's National Director for Quality and Clinical Care (QCC). Three clinical programmes have been developed in the area of neurology – on epilepsy, stroke and outpatient neurology. The National Clinical Leads are responsible for developing national clinical guidelines and examining issues such as improving services and reducing waiting times. An Epilepsy Advisory Group was established by Dr Doherty and Mike Glynn represents Brainwave on this committee along with representatives from the HSE, HIQA and a number of neurologists, neurophysiologists and other epilepsy professionals.

Brainwave has long campaigned for the appointment of additional Consultant Neurologists to bring our numbers up to acceptable international standards. We were delighted with the appointment in 2010 of Dr John Lynch to the post of Consultant Neurologist at University College Hospital Galway. Dr Lynch has a special interest in epilepsy and his appointment is a major benefit to people with epilepsy in the region.

In December 2010, the Government finally introduced the necessary amendments to our driving regulations in order to bring them into line with European Commission Directive 2009/112/EC. Brainwave had continuously pressured the Department of Transport and the Road Safety Authority to make the necessary changes, which should have been in place by August 2010.

National and International Partnerships

Affecting change through campaigning is often easier to achieve working in partnership with other organisations with similar aims. In 2010, Brainwave was an active member of the following national and international organisations whose roles are advocacy based.

The Neurological Alliance of Ireland

www.nai.ie

The Neurological Alliance of Ireland (NAI) is the national umbrella organisation for groups representing the views and concerns of those whose lives are 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

DFI is the national support organisation and advocate for over 120 voluntary disability organisations in Ireland. Its mission is to act as an advocate for the full and equal inclusion of people with disabilities and disabling conditions in all aspects of Irish society. Mike Glynn, Brainwave CEO is a board member of DFI.

International Bureau For Epilepsy

www.ibe-epilepsy.org

IBE is an International organisation that works to develop, support and link national epilepsy organisations around the world. It addresses issues such as education, employment, insurance, driving and public awareness. Mike Glynn, Brainwave CEO has been President of IBE since 2009.

Joint Epilepsy Council of the UK and Ireland

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.

Medical Research Charities Group

www.mrcg.ie

The Medical Research Charities Group (MRCG) is an umbrella group of charities involved in supporting and funding medical research. The MRCG aims to increase the funding for medical research in Ireland, remove the barriers to conducting medical research and increase the profile of medical research. Peter Murphy, Brainwave's Resources Manager is a board member of MRCG.



My epilepsy was scary at first and I was very angry. Then I realised I can live with it or let it beat me. When I came to Training for Success I learned how epilepsy works, and learned more about myself and my epilepsy. I was surprised at how little I really knew. Thanks to the programme, I will never limit or second guess myself or my capabilities. Epilepsy is one part of me, it is not me in total.

Ellie Mooney, Training For Success student, Sligo

Training and education

Training For Success

2010 was another successful year for Brainwave's one-year Training For Success (TFS) pre-employment training programme for young adults with epilepsy. In the 2009-2010 academic year, 13 students took the course while the maximum 14 undertook the 2010-2011 programme.

Based in the Institute of Technology Sligo and funded by FAS, TFS 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

Since 1998, almost 170 young adults with epilepsy have benefitted from TFS. For many, it has proved to be the first step to a very successful career and opened up many positive opportunities.

The 2010-2011 academic year will see the end of the current accreditation system. Changes due to the reorganisation of FÁS will see the introduction of FETAC Accreditation for 2011-12 which will benefit future students in their progression to employment and further education.

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

2010 saw Brainwave continue delivery of the one-day training programme in epilepsy awareness and the administration Buccal Midazolam (BM). The course was first introduced in 2009 and was originally for healthcare professionals only. This year saw the first programme delivered to Primary School Teachers.



Participants at the first BM training day for teachers, held in Dundalk in June 2010.

BM is an emergency rescue medication prescribed under special license to reduce the duration or stop an epileptic seizure and prevent status epilepticus. It must be administered by a trained health professional.

Brainwave's training programme aims to facilitate the safe and appropriate administration of BM and to provide valuable information on epilepsy. Brainwave is the sole provider of this service in Ireland. In 2010, a total of 271 people were trained over 15 training days.

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

Also in 2010, Brainwave staff completed their own biannual programme update as per the JEC Guidelines for Best Practice relating to ongoing training of trainers. This ensures that Brainwave continues to provide the best possible training to all trainees.

Brainwave will continue to provide this training for as long as demand exists.

Nurses Information Pack

In 2010, Brainwave launched a new Nurses Information Pack on epilepsy. It is the fourth of Brainwave's Information packs designed for a specific audience, following previous packs for GPs, Teachers and Employers. The pack consists of numerous leaflets, charts and posters on specific aspects of understanding and managing epilepsy.



The pack was distributed by Brainwave staff to 20,000 nurses around the country focusing in particular on practice nurses, public health nurses, intellectual disability nurses, A&E nurses, paediatric nurses and neurology nurses. An online version was also made available to student nurses on request.

Colin Doherty, consultant neurologist at St James's Hospital officially launched the new resource in October, calling it an invaluable reference tool to all nurses caring for individuals with epilepsy.

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 in 2010. For example, Epilepsy Awareness presentations were made to 660 students and teachers in the Dublin region alone.



I am just coming to the end of my year at Training for Success. I entered the course with quite low self esteem and confidence but over this year, I've learnt a lot about myself and my epilepsy. My confidence and self esteem improved and I've made some great friends. It's great to be in a class of people with different types of epilepsy. You don't feel so alone and it's easy to talk and support each other. The course has helped me progress on to another course in IT Sligo.
Helen Griffin, Training For Success student, Sligo

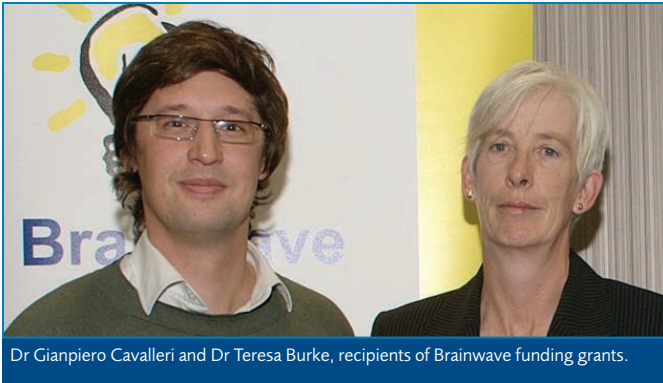
Strategic objective

- 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

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 and awarded three grants to Irish researchers in 2009. All three projects continued throughout 2010.



The projects are:

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.

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.

Successful research depends on people volunteering their time to take part and in 2010, Brainwave actively encouraged members to become more involved in these and other research projects. Working with the Medical Research Charities Group, Brainwave is also committed to public education around medical research and raising the profile of research in Ireland.

In November 2010, 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. to commence in October 2011. The Research Review Board chaired by Professor David Chadwick will meet in 2011 and it is hoped that new research will be funded under the scheme in 2011.

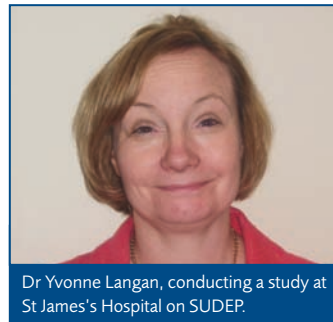
The Prevalence of Epilepsy in Ireland study

Results from the Prevalence of Epilepsy in Ireland study commissioned by Brainwave and conducted by the UCD Centre for Disability Studies (Dr. Christine Linehan) were published in the scientific journal *Epilepsia* in 2010.

Epilepsia is the journal of the International League Against Epilepsy and the most authoritative source for current clinical and research results on all aspects of epilepsy.

The study was launched and disseminated by Brainwave during National Epilepsy Week in 2009 and is regarded as the first national epilepsy prevalence study undertaken anywhere in Europe. It identifies for the first time, accurate figures on the number of people with epilepsy in Ireland. It is to date one of the most important pieces of epilepsy research conducted in Ireland.

The key finding of the study was 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.



Dr Yvonne Langan, conducting a study at St James's Hospital on SUDEP.



Denise Cunningham, Clinical Nurse Specialist in Epilepsy Services.

The Impact of Epilepsy on Quality of Life Study

In 2010, as part of her MSc in Epilepsy studies, Denise Cunningham, Clinical Nurse Specialist in Epilepsy Services (Brainwave & AMNCH, Tallaght) undertook a study to investigate the quality of life of adults with epilepsy in Ireland. 350 Brainwave members took part in Denise's study using the QOLIE-31-P questionnaire which looked not only at Overall Quality of Life but at issues such as emotional well-being, energy-fatigue, cognitive functioning, medication effects, seizure worry and social functioning. The study results highlighted a pressing need to focus more on the psychosocial consequences of the condition and to address the concerns of people with epilepsy. It will be presented at the 2011 International Epilepsy Congress in Rome.



Having had epilepsy since I was a child, I have been in contact with Brainwave throughout my life, especially when I had questions about employment and pregnancy. Brainwave is a great organisation and Agnes in my local office or the epilepsy nurses always had the answers for me. This year I helped with local fundraising, it felt good to give something back to an organisation that has really helped me.
Brenda O'Donnell, Co. Donegal

Fundraising

Brainwave's work is funded almost exclusively through state grants and a wide range of fundraising events, donations and campaigns. The fundraising environment remained difficult in 2010 but fundraising income increased by 20%. This increase was necessary to compensate for reduced state funding and made possible thanks to the mammoth efforts of staff and volunteers all across the country.

In 2010, the focus was on raising a small amount from a large number of people and on enabling more people to become involved. Traditional activities such as Rose Appeals, volunteer events, sponsored runs/ challenges and collections were key and new initiatives such as the National Raffle were organised.

As ever, Brainwave is indebted to the generosity of our fundraising volunteers who give up their time and expertise to ensure that Brainwave's core services are maintained in these difficult times. We want to sincerely thank every single person who has helped support our work in 2010.

Snapshots from 2010



Hundreds of people represented Brainwave in marathons, fun runs and other challenges all over the country and internationally in 2010. Pictured are just four of the ladies who donned the blue t-shirt for the Dublin Women's Mini-Marathon in June.



Friends and family of the late Alan Gallagher organised a cycle from Cork to Roscommon in support of Brainwave in May. Over 30 people took part and raised over €21,000 for Brainwave's research into SUDEP.



Two Rose Appeals in February and October 2010 raised over €50,000 for our work. Pictured are Jenny and Bridget who volunteered for Rose Week in Co. Wexford.



The first Brainwave Mega Raffle was held in 2010 and Brainwave Patron Rick O'Shea drew the winning ticket at the National Conference. Val & Michael Langstone were the lucky winners of €1,500. The Raffle raised almost €23,000.



The fourth annual Barrack Hill Ball Roll in Cobh in August was another huge success raising €5,500 for Brainwave.



Brainwave was selected as the beneficiary of the annual Philip Courtney Memorial tournament at Blackhill GFC, Co Monaghan in 2010 and was presented with a cheque for €4,400.



Over €6,500 was raised thanks to the efforts of Brainwave's friends in Tullamore who organised a huge summer barbeque event in June.



A race night organised by the Thurles Lions Club in 2010 raised over €1,750 for Brainwave's work in the Mid West.



The Students Union at the Institute of Art, Design and Technology Dun Laoghaire chose Brainwave as their Rag Week charity and raised almost €2,000.

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.

2010 Financial report

Brainwave reported a small surplus of €8,669 in 2010 (deficit of €4,077 in 2009), which was a good performance in the difficult economic circumstances prevailing.

Funds from the HSE were again slightly down on the previous year's level but fundraising income increased and expenditure was controlled, both of which helped to ensure that a small surplus was retained.

Brainwave - The Irish Epilepsy Association Income and expenditure account for the year ended 31 December 2010

	2010 €	2009 €
Income	1,650,764	1,569,075
Expenditure	(1,647,004)	(1,604,826)
Operating (deficit)/Surplus	<u>3,760</u>	<u>(35,751)</u>
Investment Income	4,280	4,284
Unrealised gain/(loss) on quoted investments	629	27,390
(Deficit)/Surplus on Ordinary activities before taxation	<u>8,669</u>	<u>(4,077)</u>
Tax on (deficit)/surplus on ordinary activities	-	-
(Deficit)/Surplus on ordinary activities after taxation	<u>8,669</u>	<u>(4,077)</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 2010

	2010 €	2009 €
Fixed Assets		
Tangible Assets	124,692	146,499
Financial Assets	133,819	133,190
	<u>258,511</u>	<u>279,689</u>
Current Assets		
Debtors	27,309	166,686
Cash at Bank and in hand	1,860,901	1,721,618
	<u>1,888,210</u>	<u>1,888,304</u>
Current Liabilities		
Creditors (Amounts falling due within one year)	(360,118)	(390,059)
Net Current Assets	<u>1,528,092</u>	<u>1,498,245</u>
Net Assets	<u>1,786,603</u>	<u>1,777,934</u>
Capital and Reserves		
Income & Expenditure Account	649,603	547,934
Special Reserves	1,137,000	1,230,000
	<u>1,786,603</u>	<u>1,777,934</u>

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. 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. Gianpiero Cavalleri (Geneticist)
Dr. Norman Delanty (Adult neurologist)
Dr. Patrick Dicker (Medical Statistician)
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)

* Resigned, November 2010. Michael Sheehy appointed Chairman

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 Nurses

Sinead Murphy (Beaumont Hospital)
Eithne Cawley (Sligo General Hospital)

Fundraising and Administration

Resources Manager

Peter Murphy

Key Fundraiser

Noeleen McDaid

Fundraising Assistants

Glenna Gallagher
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

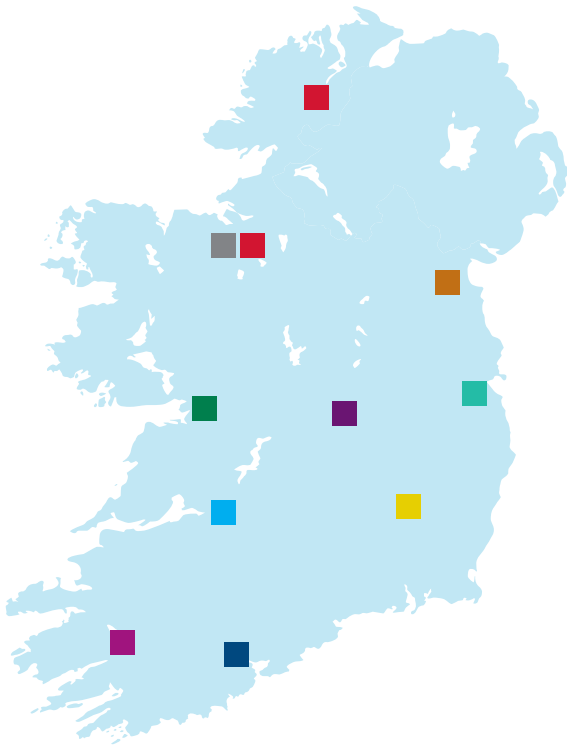
+ Retired December 2010

♦ Resigned September 2010

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 the 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: Model & Niland Arts Gallery, The Mall, Sligo
 Tel: 071 914 1858

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: Co. 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: Unit 1a, Partnership Court, Park Street, Dundalk, Co. Louth
 Tel: 042 933 7585
 Email: 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

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

Web: 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