epilepsy Ireland

Shining a light on epilepsy

Annual Report 2012

CONTENTS

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

In the 47 years since our inception, the Association has grown and expanded, today providing a wide range of services from headquarters in Dublin and from regional offices in Cork, Dundalk, Galway, Killarney, Kilkenny, Letterkenny, Limerick, Sligo and Tullamore.

Our Vision

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

Mission Statement

Epilepsy Ireland 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

Note:

From February 2013, Epilepsy Ireland is the trading name of Brainwave – The Irish Epilepsy Association Ltd. For the avoidance of confusion, the organisation is referred to in the 2012 Annual report as Epilepsy Ireland.

A MESSAGE FROM

Tessa Dagge, Chairman

The 2012 Annual Report of Epilepsy Ireland demonstrates not only the vast amount of work undertaken during the past year but also showcases the Association's new name introduced in early 2013.

Our excellent volunteer fundraisers rose to the challenges posed by the continuing depressed economic climate and proactively fundraised in a diversity of ways with the support of Epilepsy Ireland staff. Their tireless work and that of all our members, supporters and staff continue to sustain and develop our services. As Chair of the Association, I would like to extend my gratitude to them all. It was an honour and a thrill that President Michael D. Higgins chose to acknowledge the work that is being done when he invited 50 of our volunteers, members and staff to meet with him at Áras an Uachtaráin in October.

One of Epilepsy Ireland's key objectives is to raise awareness of epilepsy and to further this aim we established the Epilepsy Awareness sub-committee in 2012. The committee's remit is to advise the Board on issues around raising awareness and lead on the planning and implementation of awareness activities. I look forward to working with this new sub-committee into the future.

My sincerest congratulations to Rick O'Shea, 2FM presenter and Patron of Epilepsy Ireland who considerably raised the profile of epilepsy in 2012 with his memorable victory in the final of Celebrity Mastermind on TV3. On behalf of all our members, I would like to thank Rick for his continued devotion to the cause.

As Chair of the Association I would also like to acknowledge the work and support provided by both my fellow Board members and Finance & Audit sub-committee members. In particular, I would like to acknowledge the dedication of my fellow Officers, Vincent Savino, Vice-Chair; Claire Crehan-Dowdall, Hon. Secretary and Mark Dowdall, Hon. Treasurer.

While the Board guides the strategic direction of the Association, the day-to-day operation is the remit of our CEO, Mike Glynn. I would like to extend a special thank you to him on his excellent leadership during 2012. His work as CEO and as President of the International Bureau for Epilepsy has not only raised the profile of epilepsy nationally and internationally but is an inspiration to all those working in the epilepsy field.

Tessa Dagge

Mike Glynn, Chief Executive

Following a long consultation process with all our stakeholders, Epilepsy Ireland launched our five-year Strategic Plan covering the years 2012 - 2016. The Plan contains significant new goals and builds upon those already achieved over the past decade. Although resourcing the Plan will prove challenging in the current climate, progress has already been made in implementing many of the actions called for. One such development that we are excited about is the new Online Support Group which aims to connect people around the country to discuss their epilepsy and learn from the experiences of others.

In developing the Strategic Plan, the issue of public understanding of epilepsy was never far from the agenda. To mark the 2nd annual European Epilepsy Day on February 13th, we launched a public awareness campaign called Shatter the Stigma of Epilepsy. Our message was simple: People with epilepsy can live a full and active life in terms of work, education and social and family life. The theme of stigma was carried on throughout the year and was the focus of numerous events nationally for National Epilepsy Week and the National Conference.

2012 also saw the publication of the National Epilepsy Care Programme's Model of Care, a document which aims to transform the planning and delivery of epilepsy services in Ireland. Significant steps have been achieved already, particularly in the recruitment of over 20 new Epilepsy Specialist Nurses. I am pleased to represent Epilepsy Ireland on the Programme's Clinical Advisory Group, which held one of its bi-monthly meetings at Epilepsy Ireland during the year.

The issue of generic substitution of anti-epileptic drugs (AEDs) re-emerged in mid-2012 with the publication of the Health (Pricing and Supply of Medical Goods) Bill. We immediately launched a campaign to exclude AEDs from the Bill and at the year end, we are hopeful that the wellbeing of people with epilepsy will be protected.

I would like to thank our members, volunteers and donors for their vital support during 2012. Our Board and our Committees have given selflessly of their time and expertise which is deeply appreciated. Finally, I want to thank all of our staff around the country for their continuing dedication and hard work during what was a busy and productive 2012.

Michael

ABOUT EPILEPSY

Epilepsy is a general term used for a group of disorders, all of which are characterised by recurrent, unprovoked seizures. Seizures are episodes of abnormal electrical activity in the brain that briefly alter a person's consciousness, movements or actions. How a seizure affects an individual will depend on the area of the brain in which the seizure originates.

More than 50 million people worldwide have epilepsy. Research conducted by Epilepsy Ireland in 2009 found that there are 36,844 people over the age of five with epilepsy in Ireland.

Epilepsy affects people of all ages, but is more prevalent in children, adolescents and the elderly. It is also more common in people with an intellectual disability. In about 60% of cases, no specific cause can be identified. In the remaining 40% of people, common causes include head injuries, strokes, brain infections, birth defects and genetic conditions like tuberous sclerosis.

Epilepsy is a treatable condition and the majority of people can become seizure free using medications or in some cases through surgery. For some people however, the consequences of epilepsy can be long lasting and significant, affecting the person's education, employment, psychological & social functioning, self-esteem and independent living. A diagnosis of epilepsy will also involve learning to cope with the physical impact of seizures and the medications prescribed to control them. There is also an enduring social stigma associated with epilepsy that can be as problematic as the seizures themselves.

Studies have shown that people with epilepsy have a higher risk of mortality than the general population. There are an estimated 130 epilepsy-related deaths in Ireland each year, about half of which are due to a phenomenon called SUDEP (Sudden Unexpected Death in Epilepsy).

Despite its wide prevalence, epilepsy services in Ireland have been traditionally neglected and under-resourced, something that the recently established HSE National Epilepsy Care Programme is tackling under the leadership of Dr Colin Doherty. This welcome initiative aims to improve access to expert care; improve the quality of that care across the entire healthcare spectrum and to deliver services in a cost-effective manner. The Programme's Draft Model of Care, published in early 2012 outlined specific plans to introduce a population-based nurse-led service; to establish a network of Regional Epilepsy Centres and improve access to surgery for those with highly complex epilepsy.

Ciara Corcoran, Co. Limerick

Epilepsy Ireland has really helped me learn how to live with and manage my epilepsy. They have taught me not to be afraid of it, that it does not define me or make me different from anyone else. Through Epilepsy Ireland and with the help of Anna, I have been able to meet other young people with the condition and help raise awareness about epilepsy.

Be Seizure Aware

10 Common Epilepsy Myths

1. All seizures involve falling to the ground and convulsions

MYTH. A convulsive (tonic-clonic seizure) is just one many different types of seizures. Seizures involve different parts of the brain and physical symptoms will depend on which part of the brain is involved.

2. All people with epilepsy must avoid flashing or flickering lights

MYTH. Only about 3-5% of people with epilepsy are photosensitive.

3. Epilepsy is a form of mental illness

MYTH. Epilepsy is an umbrella term covering different types of seizure disorders. It is a functional, physical, neurological condition.

4. Epilepsy is contagious

MYTH. You cannot catch epilepsy from another person!

5. You should put something in a person's mouth during a seizure

MYTH. A person will not swallow their tongue during a seizure and you should never force something into the person's mouth as this will damage teeth and gums or even break their jaw.

6. You can stop a seizure by holding the person down

MYTH. It is impossible to stop a seizure using force. Instead, protect the person from injury by removing nearby harmful objects and cushion the person's head.

7. Epilepsy will always affect a person's employment prospects

MYTH. There are very few careers that people with active epilepsy cannot hold (e.g. member of the Garda or Army or in some cases, jobs involving driving). Otherwise, people with epilepsy work at all levels and in all careers.

8. Epilepsy will affect a person's ability to take part in sports or other leisure activities

MYTH. In most cases, it won't. A lot will depend on the degree of seizure control and the type of sport activity involved.

9. All seizures require immediate medical attention

MYTH. An uncomplicated seizure in someone who has epilepsy is not a medical emergency. It stops naturally after a few minutes without ill effects. An ambulance is needed only if the seizure lasts for more than five minutes.

10. You can't die from epilepsy

MYTH. Unfortunately, there are approximately 130 epilepsy-related deaths each year in Ireland. Many are as a result of accidents, injuries or drowning while others are due to prolonged seizures (status epilepticus) or SUDEP (Sudden Unexpected Death in Epilepsy).

Morgan Coyle, Co Donegal

I am 14 years old and I have epilepsy. When I found out in January that I had epilepsy I was scared and frightened. I felt my life was over, but I was wrong. I still get to do everything any normal teenager does. Epilepsy does not stop me from chasing my dreams. I attended an Epilepsy Ireland event for young people recently and I found it really helpful.

INFORMATION AND SUPPORT

Overview

The Epilepsy Ireland network of service staff both locally and nationally provide a diverse range of information and support services to people with epilepsy, their families and carers. We operate a network of 10 locally-based Community Resource Officers (CROs), each of whom is responsible for delivering our information and support service within their region (see page 14 for details). Services provided include telephone, email and one-to-one support, information seminars, support groups, community outreach, hospital-based outreach and awareness activities. Service staff also act as advocates for individuals with epilepsy, assisting in the areas of employment, entitlements, law and education.

In 2012, the Specialist Nurse Helpline was available on Mondays from 9.30am - 1pm; it is operated by Sinead Murphy, Community Epilepsy Specialist Nurse. Denise Cunningham, Clinical Nurse Specialist in Epilepsy Services, operated the Specialist Nurse Helpline on Wednesdays until July 2012.

Since its inception, Epilepsy Ireland has built up a large library of information services on general and specific issues for people with epilepsy and others with an interest in or a direct involvement with epilepsy. These resources include leaflets, books, CDs, posters, information resource packs and board games. Resources have been developed specifically to cater for the needs of parents, children, employers, nurses, doctors and teachers. When a person with epilepsy engages with Epilepsy Ireland, they are offered a variety of aids to assist them, including special safety pillows and identity bracelets.

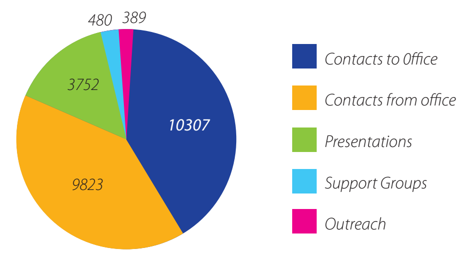
The Epilepsy News magazine is sent to all members quarterly; it is designed to be both informative and engaging. During the Strategic Planning consultation process it was suggested that magazine be updated and at the end of 2012 work was underway to further improve the magazine. Our email newsletter is an additional information resource that is available to anyone who signs up for it via epilepsy.ie. At the end of 2012, the bulletin was being distributed regularly to 2,415 people.

Epilepsy Ireland's website epilepsy.ie has a large database of information resources which endeavors to respond to the needs of all visitors to the site. The site is also regularly updated with news and with the diverse range of events organised by our service staff nationwide. In 2012, the site registered over 71,000 visits (up from 62,000 in 2011) and there were over 46,000 unique visitors (up from 38,000 in 2011). A total of 334,000 page views were recorded.

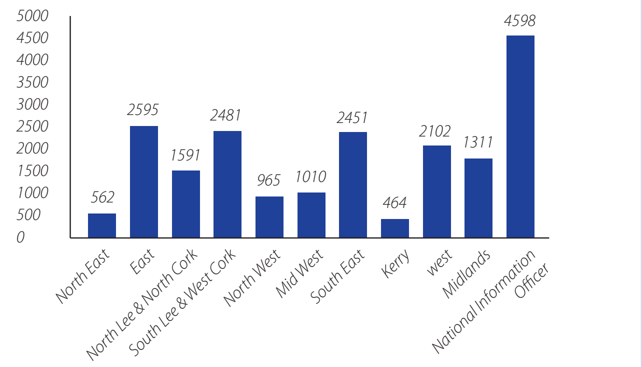
The Year in Numbers

- The total number of contacts with all Epilepsy Ireland services for the year (includes CRO support contacts, Training for Success, health professional training, events, community presentations and the Specialist Nurse Helpline) was **24,751** in 2012.
- The total number of contacts made to or by Epilepsy Ireland's network of Community Resource Officers and the National Information Officer in 2012 was **20,130**.
- Attendance at presentations, seminars, school talks and other events facilitated by Epilepsy Ireland staff was **4,621**.
- Epilepsy Ireland community outreach services were accessed by **389** people in 2012.
- Support groups were accessed by **480** people in 2012.
- The Epilepsy Specialist Nurse service was accessed by over **1,180** people in 2012.

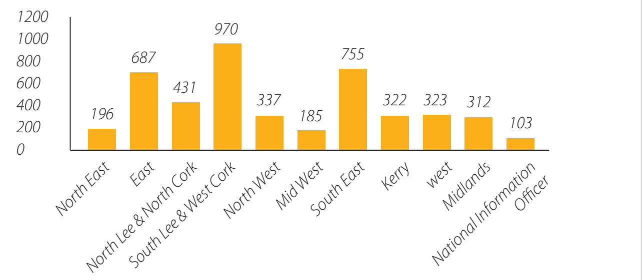
Breakdown of Support Contacts 2012



Total Number of contacts by region 2012



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



Online Support Groups

In response to members' needs identified in our strategic planning process and influenced by developments in technology, Epilepsy Ireland established the Epilepsy Online Support Group in October 2012. This service allows people with epilepsy who are over 18 and living in Ireland to receive confidential, non-judgemental emotional & practical support from other participants who are going through similar experiences. The service is free and aims to bring people together to talk, share experiences and exchange information.

Sessions are held weekly and facilitated by two members of the Epilepsy Ireland service staff team. Up to ten people can attend each session which lasts 90 minutes. There was significant interest in the groups in the first 3 months to the end of the year with almost 200 people signed up to take part in the groups. A review of the new service will take place in 2013 when it is hoped to expand and refine the service.

Social Activities

Social activities that bring people with epilepsy and their families together were also highlighted as an unmet need during the Strategic Planning process in 2011. Efforts were made in 2012 to introduce more social and family activities. In January, Epilepsy Ireland members joined people from other disability groups for a great day in Funderland, Dublin and in June, the Cork team held a thoroughly enjoyable family fun day in Trabolgan for children with epilepsy, their siblings and family members. A family fun day was also held at Farmleigh in Dublin's Phoenix Park which proved to be very successful. Visits to the cinema, bowling outings and a family picnic were other events organised to provide informal networking opportunities for members.

National Conference

Epilepsy Ireland's National Conference, "Managing Epilepsy, Shattering Stigma" took place on September 8th in the Ashling Hotel, Dublin. The keynote speaker was Dr John Paul Leach, Consultant Neurologist from the Southern General Hospital in Glasgow. Dr Colin Doherty updated the conference on the National Epilepsy Care Programme and Rosalind McKenna, Amnesty International discussed the rights of people with epilepsy in Ireland. Delegates also heard from four people with epilepsy about their own personal experiences of living with the condition.

Supporting Young Adults

In recent years, Epilepsy Ireland has endeavoured to provide specific supports to teenagers and young adults in managing their epilepsy. In March, a seminar entitled "I Control My Life" was held in Limerick for young adults. The keynote speaker was Dr Elijah Chalia, Consultant Neurologist, who discussed medications and their side effects with the group. There were also personal accounts from young adults with epilepsy and interactive workshops throughout the day. In November, a follow-up event focusing on Careers and Education was held, also in Limerick and was met with huge demand. This practical seminar focused on issues such as choosing a career, employment rights and responsibilities, disclosing epilepsy, lifestyle issues and specific opportunities for further education. A third event for young adults, "Moving on with epilepsy" was held in Galway, which in addition to educational aspects, introduced creative workshops to help participants explore their epilepsy through art.

Information events

Epilepsy Ireland's North East region and Epilepsy Action Northern Ireland came together to organise and all-Ireland epilepsy awareness meeting entitled "Achievement in Epilepsy", focusing on how lifestyle affects people's management of their epilepsy. A seminar for parents of children with epilepsy was held in Clonmel with Consultant Neurologist Dr Peter Widdess-Walsh, while an event for women with epilepsy entitled Empowering through Knowledge & Nurturing was organised in Kilkenny. Dozens of other information seminars, presentations and workshops also took place around the country.

Some of the participants at the Moving On With Epilepsy event for young adults in Galway.

Dr John Paul Leach was the keynote speaker at the 2012 National Conference.

The family day in Trabolgan brought together children with epilepsy and their parents in a relaxed, fun setting.

Sarah Shortall, Co. Offaly

Epilepsy Ireland has played a huge part in helping me accept and overcome my epilepsy. They provide a personal service, making available advice and assistance which is only a phone call or a click away. By meeting other people with epilepsy and being able to be open and share our experiences with each other also provides a certain element of comfort. Its great knowing you are among people who understand and can relate to what you are going through.

Carol Hughes Dunne, Co Monaghan

Recently I got back in touch with Epilepsy Ireland. I have had a heavy load to carry and with their help it is getting lighter and easier to carry. It is comforting to know that your local office is only a call away. The support is amazing. I've found them be my life buoy because I felt like I was drowning but the advice and support which they provided helped me greatly. I owe a lot to Epilepsy Ireland.

AWARENESS

European Epilepsy Day

The 2nd annual European Epilepsy Day (EED) took place on February 13th. Epilepsy Ireland launched a new public awareness campaign called "Shatter the Stigma of Epilepsy" to tackle the outdated attitudes that often still exist towards epilepsy. The EED message was simple: People with epilepsy can live as full and active a life in terms of work, education, activities, social and family life.

To highlight this key message, an advertising campaign was launched with radio ads featuring four Epilepsy Ireland members and Patron Rick O'Shea broadcast on national and local stations. Advertising in national newspapers was also a key element of the campaign.

The epilepsy.ie site received an overhaul with a new "Shatter the Stigma of Epilepsy" microsite established for the campaign. Six videos were recorded featuring interviews with Epilepsy Ireland members discussing attitudes to epilepsy, challenges the condition poses and the common misunderstandings that exist about epilepsy. The campaign generated huge website traffic and European Epilepsy Day was the busiest day in the site's history.

Media interest in the campaign was strong, with features prominent in most national papers and almost 20 radio interviews conducted around the campaign. Many interviews focused on the results of Epilepsy Ireland's survey of almost 500 people with epilepsy which found that over half of people with epilepsy experience social stigma. The "Shatter Epilepsy Stigma" initiative was very successful in meeting its objectives and the theme was continued throughout the year.

Brain Awareness Week

Brain Awareness Week took place from March 5th - 11th and Epilepsy Ireland was active in promoting the week with a number of events around the country. Continuing the theme of Epilepsy & Stigma, a seminar on the issue was held in Dublin led by Dr. Niall Pender of Beaumont Hospital. Other activities included events for parents in Cork, Arklow and Galway, an art & film workshop in Letterkenny and a live radio broadcast in Tullamore.

National Epilepsy Week

National Epilepsy Week (NEW) was focused on improving epilepsy understanding amongst those living with the condition and activities were organised in all regions around the country to reach out within the community.

Social Media

Social media continued to grow in importance throughout 2012 as a tool for raising epilepsy awareness. Facebook, Twitter and Youtube have proven to be particularly useful in sharing information, communicating with people with epilepsy and a wider audience. At the year end, Epilepsy Ireland had almost 2,000 likes on Facebook and almost 1,000 followers on Twitter.

Epilepsy in the Media

A concerted effort at recruiting new volunteers to discuss their epilepsy in the media was made in 2012 and this enabled us to keep epilepsy in the public eye throughout the year.

The RTE documentary, *Life with Epilepsy* which featured Epilepsy Ireland members Miriad Kavanagh and the Maher family was announced as the winner of the IBE/UCB International Excellence in Epilepsy Journalism award for 2012.

Epilepsy Awareness sub-committee

With a greater emphasis put on epilepsy awareness, the Board established a sub-committee in 2012 to lead on planning & implementing awareness raising activities and to advise the Board on issues around awareness. The committee is chaired by member Cathy Grieve, who has years of experience working in journalism and media production. Other committee members Eoin Kernan, Rachel Ashe, Tony Caravousanos, Rick O'Shea, Audrey Muddiman and Carol Saarsteiner also have wide experience in relevant fields such as marketing, advertising, broadcasting and political advocacy.

Visit to Áras an Uachtaráin

The growth in epilepsy awareness was echoed when Epilepsy Ireland received an invitation from the President of Ireland to meet with him at Áras an Uachtaráin in October. 50 Epilepsy Ireland volunteers, members and staff were greeted by the President who displayed a thorough understanding of epilepsy, the difficulties people face and the work of Epilepsy Ireland. He strongly supported our efforts at improving public understanding, saying that stigma is simply unacceptable in this day and age. He encouraged Epilepsy Ireland to continue to fight the "mountain of ignorance" that still exists, particularly in relation to the language used around epilepsy.

Fifty Epilepsy Ireland members, supporters and staff met with President Higgins at Áras an Uachtaráin in October.

Cathy Gaffney, Dublin

We found out Jenny had complex partial seizures when she was five and it was all so new to us. We really needed information on how best to help Jenny and keep her safe. While the doctors and nurses were a true God-send, it was great to have the opportunity to call down to Epilepsy Ireland and ask Geraldine everything we needed to. We gained confidence in our skills for managing her seizures, and the advice given has proved to be invaluable. The support has meant a huge amount to our family but it is Jenny that has benefited the most.

ADVOCACY

Epilepsy Ireland has spent much of the past 20 years campaigning for better services for the 37,000 people in Ireland with epilepsy. The historical neglect was finally addressed two years ago with the setting up of the HSE's National Epilepsy Care Programme. The Programme is led by Dr Colin Doherty and Epilepsy Ireland's CEO Mike Glynn is a member of the Programme's Clinical Advisory Group. The Draft Model of Care, its vision for the future of epilepsy care in Ireland was published in 2012. The document includes plans to reform the service into six regional epilepsy centres, to introduce new integrated care pathways for epilepsy management, to expand pre-surgical evaluation and to move towards a system of managed primary care delivered by GPs and Advanced Nurse Practitioners (ANPs) specialised in epilepsy. Progress to the end of 2012 is encouraging with 20 candidate ANPs recruited and the Epilepsy Electronic Patient Record rolled out to epilepsy centres nationally. The Epilepsy Monitoring Unit at Beaumont Hospital was also upgraded and a new Unit was established at Cork University Hospital although neither had been opened by the end of 2012.

The most pressing advocacy campaign in 2012 centered around the publication of the Heath (Pricing & Supply of Medical Goods) Bill in July. The Bill will introduce a system of generic substitution for interchangeable medicines. Epilepsy Ireland has campaigned for many years to have anti-epileptic drugs (AEDs) excluded from generic substitution due to safety concerns highlighted in numerous international studies. Although we received assurances from the previous government that this would be the case, the draft legislation makes no mention of AEDs. In order to achieve a specific exemption, Epilepsy Ireland launched a campaign to inform politicians about the dangers of switching between different versions of AEDs. Amendments were drafted and communicated to TDs and a briefing session attended by over 30 representatives was held at Leinster House. A media campaign highlighting the issue was also put in place along with plans to improve public and professional understanding of the issues involved.

Through our involvement with the Neurological Alliance of Ireland (NAI), Epilepsy Ireland continues to campaign for improved neurological care services in Ireland alongside almost 30 other representative groups. In 2012, we participated in an awareness day at Leinster House aimed at highlighting the deficits in neurology care and were active in the NAI's My Charity Matters campaign to highlight the important role played by charities in delivering neurological services.

Epilepsy advocacy at European level continued in 2012 following the successes of European Epilepsy Day (EED) and the Written Declaration on Epilepsy in 2011. Irish involvement was again significant. Gay Mitchell MEP hosted EED activities in the European Parliament and continued to lead the European Advocates for Epilepsy Special Interest Group in the Parliament, whose membership had grown to over 30 MEP members by the year end. Mike Glynn, Epilepsy Ireland CEO continued as Co-Chair of Epilepsy Advocacy Europe, a Joint Task Force of the International League Against Epilepsy and the International Bureau For Epilepsy which aims to enhance public awareness and support epilepsy research in Europe.

National and International Partnerships

Epilepsy Ireland is an active member of the following national and international organisations through which effective advocacy is conducted on behalf of people with epilepsy:

International Bureau for Epilepsy
www.ibe-epilepsy.org
Mike Glynn, Epilepsy Ireland's CEO has been President of the IBE since 2009.

The Neurological Alliance of Ireland
www.nai.ie
Peter Murphy, Epilepsy Ireland's Deputy CEO is a board member.

Disability Federation of Ireland
www.disability-federation.ie
Mike Glynn, Epilepsy Ireland's CEO is a board member.

Medical Research Charities Group
www.mrcg.ie
Peter Murphy, Epilepsy Ireland's Deputy CEO is a board member.

Cathy Grieve, Epilepsy Ireland member; Prof Norman Delanty, Beaumont Hospital and Mike Glynn, Epilepsy Ireland, presented at Leinster House on the issue of generic substitution in epilepsy

The National Epilepsy Care Programme's Clinical Advisory Group.

Laura Hall, Wicklow

Epilepsy really affected my confidence when I was growing up. I was so nervous to do anything is case I had a seizure. I felt like the only one who had epilepsy but Epilepsy Ireland helps bring everyone together. They really helped me and my family in so many ways - a lot of people forget how tough it is on the family. To help raise awareness, I recently went on the radio to talk to Ryan Tubridy about my epilepsy and I'm now organising a fundraiser as well!

TRAINING AND EDUCATION

Participants receive their certificates in Epilepsy Awareness & the Administration of Buccal Midazolam

The Epilepsy Ireland/ Royal Society of Medicine conference for Health Professionals in Cork was opened by Deputy Lord Mayor of Cork, Cllr Michael Ahern

Training For Success students from the 2011/2012 term who graduated in November

Training For Success

2012 was a challenging, yet successful year for Epilepsy Ireland's pre-employment training programme. Training For Success (TFS) remains the only course of its kind in Europe. First developed in 1998, it continues to provide a practical and inspirational experience for young people with epilepsy who, because of their condition have experienced difficulties in progression of their educational and career aspirations.

The programme, run in partnership with the Institute of Technology Sligo and funded by FAS began offering FETAC Level 4 Certification for those attending in 2012. It offers a number of modules aimed at developing practical, interpersonal and communication skills to help develop the individual personal confidence.

In both the 2011-2012 and 2012-2013 academic years, the yearly maximum of 14 students undertook the programme. TFS was shortlisted for the AONTAS Adult Education Star Award (national category) in 2012. The results will be released in early 2013.

Health Professional Training

Since 2009, Epilepsy Ireland has been providing a training programme in Epilepsy Awareness & the Administration of Buccal Midazolam (BM) to health professionals and allied health professionals. The programme is the only of its kind in Ireland and is delivered in accordance with the Joint Epilepsy Council guidelines on training standards for the administration of BM. The aim of the training programme is for participants to develop a greater understanding of epilepsy in general, understand the role of the emergency rescue medication BM and receive instruction in the correct administration of BM.

Our commitment to providing expert training in the administration of emergency medication continued in 2012 with a significant increase in training days provided. 36 training sessions were delivered nationwide, compared with the 26 in 2012. The increase was due to the programme being delivered in Epilepsy Ireland's Head Office on an almost monthly basis. In total, 336 people received the training in 2012. This includes trainees from previous years who undertook the 2-year refresher course. At the end of 2012, Epilepsy Ireland has delivered a total of 97 training days, providing this important training to 1,141 people.

Living Well With Epilepsy Toolkit

In 2012, Epilepsy Ireland began work on a new resource tool aimed at those who are newly diagnosed with epilepsy. The toolkit will provide information to adults and parents about the condition of epilepsy, support them in its management and help the person maximise their relationship with their medical team. It will aid the newly-diagnosed person with epilepsy to move from epilepsy patient to epilepsy expert. The new toolkit will support the work and objectives of the National Epilepsy Care Programme in delivering quality and accessible services for people with epilepsy. In 2012, a project team consisting of Epilepsy Ireland staff and epilepsy nursing professionals was established to lead on the development of the toolkit, which will be officially launched in 2013.

Health Professional Training

During National Epilepsy Week, Epilepsy Ireland and the Royal Society for Medicine came together to organise an epilepsy training day in Cork for healthcare professionals entitled "Developments in a Difficult Climate". The day included sessions delivered by leading epilepsy experts on epilepsy in people with intellectual disabilities, seizures in children, AED interactions, and the role of EEG.

Martin Dalton, TFS Student

> *I'm writing this near the end of my year with Training For Success. I think that the information I have gotten over the year on the course is invaluable and even more so if you have been recently diagnosed with epilepsy. I discovered my career over the past year and if it was not for this course, I would never be cheffing.*

RESEARCH

New Research Awards

In 2012, Epilepsy Ireland announced two new awards under the Research Funding Scheme.

An evaluation of the role of the Epilepsy Specialist Nurse and the impact on patient quality of life

Principal Investigator: Prof. Agnes Higgins, School of Nursing & Midwifery, Trinity College Dublin

A grant of €149,996 has been awarded to Prof Higgins and her team over three years to assess the role of the Epilepsy Specialist Nurse (ESN), to determine if there are differences in outcomes between people who have access to an ESN and those that don't and to determine the cost-effectiveness of the role.

Demystify the veil of secrecy: a mixed method inquiry of parent-child dialogue about epilepsy and its associated stigma

Principal Investigator: Dr Veronica Lambert, School of Nursing & Human Sciences, Dublin City University

A grant of €92,990 has been awarded to Dr Lambert and her team over three years to look at the differences in perceptions and communications that exist between families when it comes to discussing and disclosing epilepsy.

Both awards were made following a competitive application process during 2012. The projects will be jointly funded by Epilepsy Ireland and the Health Research Board (HRB) under the Joint Funding Scheme operated by the Medical Research Charities Group (MRCG) of which Epilepsy Ireland is a member.

Epilepsy Ireland is also an official collaborator on another new HRB-funded epilepsy project being undertaken Dr Lambert at DCU entitled "Talking about Epilepsy", due to begin in 2013.

Ongoing Research Projects

Since the establishment of the Research Funding Scheme in 2008, four projects have previously been funded in addition to those outlined above. Three of these were ongoing in 2012:

- ***A pharmacogenomic study of chronic refractory epilepsy***
  Principal Investigator: Dr. Gianpiero Cavalleri, Dept of Molecular & Cellular Therapeutics, Royal College of Surgeons in Ireland
- ***Baroreflex sensitivity in individuals with epilepsy: Does it play a role in sudden unexpected death in epilepsy (SUDEP)?***
  Principal Investigator: Dr. Yvonne Langan, Consultant Neurophysiologist, St. James's Hospital
- ***Genome-wide DNA methylation analysis of hippocampus from patients with pharmacoresistant temporal lobe epilepsy***
  Principal Investigator: Prof. David Henshall, Associate Professor of Physiology, Royal College of Surgeons in Ireland

The projects of Dr Cavalleri and Prof Henshall are jointly funded by Epilepsy Ireland and the HRB. Dr. Langan's work is partly supported through the fundraising efforts of the friends and family of the late Barbara Doyle. These three projects represent a total investment of over €301,000. To date, a total of €601,000 has been invested in Irish epilepsy research since 2009. All three existing projects are due to be completed in 2013.

Research Review Board

Applications received under the Research Funding Scheme are rigorously reviewed by international experts and by the Epilepsy Ireland Research Review Board, chaired by Professor David Chadwick (Liverpool) before finally being assessed by a panel of experts convened by the HRB and MRCG. Only proposals that meet the highest standards of excellence are awarded funding. All the projects funded to date have the potential to add to existing scientific knowledge of epilepsy and aid in the search for better outcomes. In 2012, Prof. Henshall's ground-breaking work on miroRNAs and DNA methylation was published in two scientific journals, Nature Medicine and Journal of Neuroscience.

2013 Call for Proposals

In late 2012, new research priorities were established ahead of next call for proposals planned for January 2013. It is hoped to make further awards on one of more of the following themes:

- SUDEP/ Status Epilepticus
- Psychosocial aspects of epilepsy
- Epilepsy in the Intellectual Disability population
- Epilepsy and the older person
- Effects of generic to generic substitution of AEDs

Principal Investigators currently funded under the Epilepsy Ireland Research Funding Scheme. Clockwise from top: Dr. Gianpiero Cavalleri, Dr. Yvonne Langan, Prof. David Henshall, Prof Agnes Higgins, Dr. Veronica Lambert.

FUNDRAISING

2012 was a difficult year for fundraising and a 15% decrease in overall fundraising income was recorded for the year. However this was the first time since the economic recession began that fundraising income fell from the previous year.

Fundraising encompasses numerous activities, campaigns and donations. In recent years, the focus has very much been on raising relatively small amounts from a large number of sources, for example church gate collections, the national raffle and Rose Appeals.

Supporter fundraising continues to be an important source of funds for our work and in 2012, hundreds of people all over the country supported epilepsy by participating in events or by organising their own event. Just a tiny percentage can be featured here, but we are hugely grateful to all our fundraising volunteers who gave up their time and expertise in 2012 to do what they could in spite of the difficult economic climate.

How can I help?

Epilepsy Ireland relies on the efforts of supporters to continue providing our services, raising awareness and funding research. We need your help! There are many ways that you can support our work:

- Make a donation
- Volunteer your time
- Support our events and campaigns
- Organise your own event
- Represent Epilepsy Ireland
- Become a member
- Recommend us for your workplace charity of the year

We'd love to hear from you, so if you value the work that we do, get in touch today! Call us at 01 4557500 for more information or check the fundraising section on www.epilepsy.ie.

Snapshots from 2012

Clockwise: 1. The 3rd annual Tour De Gaggs cycle in memory of Alan Gallagher took place in June. Alan's friends and family have raised almost €40,000 for Epilepsy Ireland to date.

2. Rick O'Shea, pictured with staff and members of Epilepsy Ireland, won €7,500 for our work by winning TV3's Celebrity Mastermind final.

3. Hundreds of people represented Epilepsy Ireland in marathons, fun runs and other challenges in 2012. Pictured are just six of our supporters who took part in the Cork women's mini-marathon.

4. Two Rose Appeals in February and October raised over €34,000 for our work. About to hit the street are students from Christ The King Secondary school in Cork, pictured with Epilepsy Ireland's Bernard Hughes.

5. During the summer, teams of volunteers assisted with bucket collections at sporting events in Dublin. Pictured here are Katie and Leonie, having fun at Croke Park.

6. One of many events during the year which supported our work was the Navan Dog Show, whose series of evenings raised over €2,500.

7. Epilepsy Ireland's Peter Murphy draws the winning ticket in the 2012 annual National Raffle, which raised almost €17,000 in 2012.

2012 FINANCIAL REPORT

Epilepsy Ireland reported a surplus of €36,316 in 2012 (€32,560 in 2010), which was another good performance in the difficult economic circumstances. Income from all sources fell by €99,526 to €1,502,217. However, expenditure was also reduced by €93,792 to €1,539,453. This ensured that that a small surplus was retained ahead of another challenging year in 2013.

Brainwave - The Irish Epilepsy Association Ltd t/a Epilepsy Ireland

Income & Expenditure Account for the year ended 31 December 2012

	2012	2011
	€	€
Income	1,502,217	1,601,743
Expenditure	(1,539,453)	(1,633,245)
Operating (deficit)/ surplus	**(37,236)**	**(31,502)**
Investment Income	4,604	3,911
Interest Income	45,016	66,253
Unrealised gain/ (loss) on quoted investments	23,932	(6,102)
(Deficit)/ Surplus on Ordinary activities before taxation	**36,316**	**32,560**
Tax on (deficit)/ surplus on ordinary activities	-	-
(Deficit)/ Surplus on ordinary activities after taxation	**36,316**	**32,560**

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

Brainwave - The Irish Epilepsy Association t/a Epilepsy Ireland

Balance Sheet as at 31 December 2012

	2012	2011
	€	€
Fixed Assets		
Tangible Assets	135,579	116,327
Financial Assets	151,649	127,717
	287,228	244,044
Current Assets		
Debtors	29,211	26,777
Cash at Bank and in hand	1,811,037	1,956,582
	1,840,248	1,983,359
Current Liabilities		
Creditors (Amounts falling due within one year)	(271,997)	(408,240)
Net Current Assets	1,568,251	1,575,119
Net Assets	**1,855,479**	**1,819,163**
Capital and Reserves		
Income & Expenditure Account	739,079	682,163
Special Reserves	1,116,400	1,137,000
	1,855,479	**1,819,163**

OUR PEOPLE

Board of Directors

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

Finance & Audit sub-Committee

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

Epilepsy Awareness sub-Committee

Ms Cathy Grieve (Chair)
Mr Eoin Kernan (Vice-Chair)
Ms Rachel Ashe
Mr Tony Caravousanos
Ms Audrey Muddiman
Mr Rick O'Shea
Ms Carol Saarsteiner

Research Peer Review Board

Prof. David Chadwick (Chairman)
Dr. Gianpiero Cavalleri
Prof. Norman Delanty
Dr. Patrick Dicker
Prof. David Henshall
Dr. Bryan Lynch
Dr. Cathy Madigan
Ms. Margaret McCahill

Staff

Chief Executive
Mike Glynn

Deputy Chief Executive
Peter Murphy

Services

Director of Services
Helen Quinn*

National Information Officer
Geraldine Dunne

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

Clinical Nurse Specialist in Epilepsy Services
Denise Cunningham (AMNCH, Tallaght)**

Community Epilepsy Specialist Nurse
Sinead Murphy (Beaumont Hospital)

Training & Communications Manager
Paul Sharkey

Training For Success Manager
Honor Broderick

Training For Success Facilitator
Maire Tansey

Administration & Fundraising

Accounts & Administration Manager
Elizabeth Ryan

Membership & Database Co-ordinator
Ashley Butler

PA to CEO
Mary Malone

Receptionists
Madge Geoghegan
Joan McDermott

Key Fundraiser
Noeleen McDaid

Fundraising Assistants
Glenna Gallagher
Catherine Healy

* Resigned August 2012
** Resigned July 2012

Patron

Rick O'Shea

2FM presenter Rick was diagnosed with epilepsy at the age of 16. In March 2006, he answered Epilepsy Ireland'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 Epilepsy Ireland fundraising events and awareness campaigns. "It is an honour to be able to help Epilepsy Ireland in shedding a little light on epilepsy and why it doesn't have to stop you from leading a full, successful life", says Rick.

LOCATIONS

● Head Office
Address: 249 Crumlin Road, Dublin 12.
Tel: 01 455 75500
Email: info@epilepsy.ie

Specialist Nurse Helpline
Tel: 01 455 4133 Monday 9.30am – 1pm

● North West
Covering: Donegal, Leitrim & Sligo
Community Resource Officer: Agnes Mooney

Letterkenny Office:
Grand Central Complex, Floor 2B, Canal Road, Letterkenny,
Co Donegal.
Tel: 074 9168725
Email: amooney@epilepsy.ie

Sligo Office
Model & Niland Arts Gallery, The Mall, Sligo.
Tel: 071 9141858

● West
Covering: Galway, Roscommon & Mayo
Community Resource Officer: Evelyn Monson Kirby

Westside Resource Centre, Seamus Quirke Road, Westside, Galway.
Tel: 091 587640
Email: emonsonkirby@epilepsy.ie

● Mid-West
Covering: Limerick, Clare & Tipperary North
Community Resource Officer: Anna Kelly

Social Service Centre, Henry St., Limerick.
Tel: 061 313773
Email: akelly@epilepsy.ie

● Kerry
Covering: Co. Kerry
Community Resource Officer: Kathryn Foley

9/10 The Paddocks, Ballydowney, Killarney, Co. Kerry.
Tel: 064 6630301
Email: kfoley@epilepsy.ie

● Cork
Community Resource Officers:
South Lee & West Cork: Niamh Jones
North Lee & North Cork: Mary Lawlor

35 Washington Street, Cork.
Tel: 021 - 4274774
Email: Niamh - njones@epilepsy.ie / Mary - mlawlor@epilepsy.ie

● South East
Covering: Kilkenny, Wexford, Carlow, Waterford & Tipperary South
Community Resource Officer: Joan Ryan

C/o HSE, St. Joseph's, Waterford Rd, Kilkenny.
Tel: 056 7789904
Email: jryan@epilepsy.ie

● Midlands
Covering: Offaly, Longford, Laois & Westmeath
Community Resource Officer: Margaret Bassett

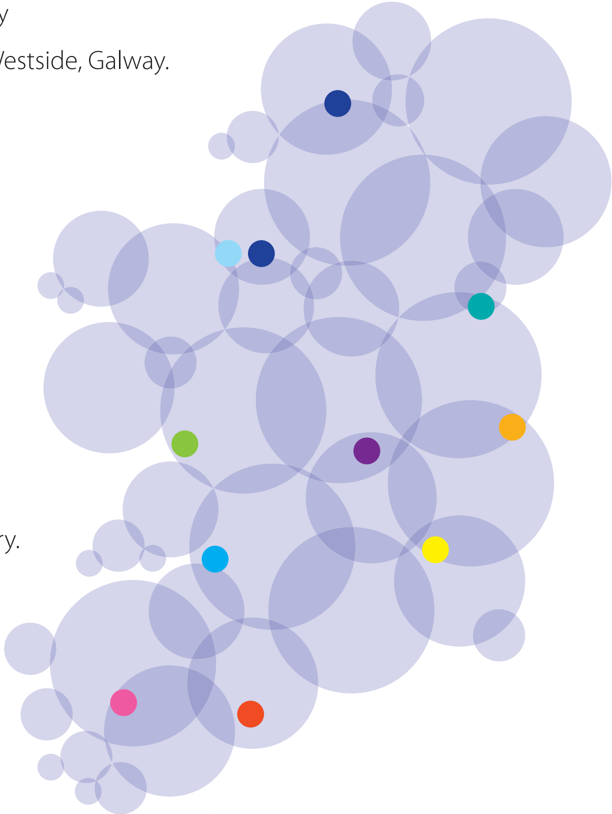
c/o Carers Association Market Square , Tullamore, Co. Offaly.
Tel: 057 9346790
Email: mbassett@epilepsy.ie

● East
Covering: Dublin, Kildare & Wicklow
Community Resource Officer: Ina Murphy
Epilepsy Ireland National Information Officer: Geraldine Dunne

249 Crumlin Road, Dublin 12.
Tel: 01 - 4557500
Email: Geraldine: gdunne@epilepsy.ie / Ina: imurphy@epilepsy.ie

● North East
Covering: Louth, Meath, Monaghan & Cavan
Community Resource Officer: Noreen O'Donnell

Unit 1a, Partnership Court,, Park St, Dundalk, Co. Louth.
Tel: 042 - 9337585
Email: nodonnell@epilepsy.ie



● Training For Success
Manager: Honor Broderick

Institute of Technology Sligo, Ballinode, Sligo.
Tel: 071 915 5303
Email: Broderick.honor@itsligo.ie

Online
Web: epilepsy.ie
Online Support Group: support.epilepsy.ie
Facebook: facebook.com/epilepsy.ie
Twitter: @epilepsyireland
Youtube: youtube.com/BrainwaveEpilepsy

epilepsy
Ireland

249 Crumlin Road
Dublin 12
Tel: 01 4557500
Fax: 01 4557013
info@epilepsy.ie
www.epilepsy.ie
facebook.com/epilepsy.ie
@epilepsyireland

Charity Number:
CHY 6170

Company Limited by Guarantee
Registered in Dublin 77588

Auditors
Deloitte & Touche
Chartered Accountants
Deloitte & Touche House
Earlsfort Terrace
Dublin 2