



Annual Report 2014

Shining a light
on epilepsy



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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

Governance

Epilepsy Ireland is committed to achieving and maintaining the highest standards of governance. In November 2014, the organisation was audited for the PQASSO (Practical Quality Assurance System for Small Organisations) Quality Mark Level 1. This was attained in January 2015. PQASSO is the leading quality assurance system developed for the non-profit sector, enabling charities like Epilepsy Ireland to demonstrate standards of excellence in areas such as governance practices, financial and risk management, systems for measuring outcomes, paths to continuous improvement and more.

A MESSAGE FROM



Mark Dowdall
Chairman

As Chairman of Epilepsy Ireland it is my pleasure to present this annual report which outlines the successes and challenges faced by the Association in 2014.

The year was a landmark one for charities in Ireland, with increased public scrutiny on the sector and welcome developments such as the establishment of the Charity Regulator.

At Epilepsy Ireland, we strive to ensure best practice in how we govern our organisation. Elected by our membership, our Board of Directors take their responsibilities to those we support and represent, and to our donors and supporters, most seriously. This is highlighted by our ongoing work towards adopting the Governance Code and SORP (Statement of Recommended Practice), the best-practice framework for charities in preparing annual accounts.

As 2014 came to a close, our three-year journey in achieving the PQASSO quality mark for charities was almost complete and we expect in 2015 to become one of the first Irish charities to achieve the prestigious standard.

In order to best achieve our mission, we must ensure that we are governed by a Board with expertise in and passion for the cause of supporting people with epilepsy and I am delighted that we were able to welcome three such new members to our Board in 2014. Dr Christine Linehan is the Director of the UCD Centre for Disability Studies and a Lecturer in the UCD School of Psychology. Derry Gray is a partner at BDO, the leading accountancy and business advisory firm and an Executive Committee Member and Elected Council Member of Dublin Chamber of Commerce. Cathy Grieve chairs our Awareness sub-committee and has had a very successful career in front line journalism and in business, while living with epilepsy for the past 12 years.

Margaret McCahill, a long-standing member of our Board of Directors resigned in 2014 after 15 years on the Board. I would like to thank her for the expertise she brought as a pharmacist, her contributions to our work, our publications and in particular, her success as Chair of the Group on Driving and Epilepsy which brought about a change in legislation.

I would like to thank the members of our Finance and Awareness sub-committees and Board of Directors for their tireless work in 2014. I would especially like to thank my fellow Officers for their ongoing support; Vincent Savino, Vice-Chair, Claire Crehan-Dowdall, Hon. Secretary and Michael McLoughlin, Hon. Treasurer.

I would like to conclude by thanking the people who use our services, all of our staff, our CEO, management and volunteers for contributing to another year of growth and progress towards our goal of providing support for all people with epilepsy.



Mike Glynn
Chief Executive

2014 marked yet another challenging year for Epilepsy Ireland and for the service users we support. Epilepsy Ireland strove to cope with increased demand for our services that coincided with on-going reductions in funding. The positive news is that not only did we continue to support those that need us but we also increased our service provision.

The main service development of the year was the launch of the STEPS Epilepsy Self-Management Programme, designed to help people with epilepsy manage their condition and to gain skills to improve their quality of life. In 2014, the programme was rolled out in all of our regions and initial feedback has been extremely positive. At the year end, further developments such as STEPS for Parents and an Epilepsy Ireland smartphone app were in the pipeline.

Increasing epilepsy awareness was a priority in 2014 and we were delighted that Ireland Rugby Head Coach Joe Schmidt fronted Irish activities for European Epilepsy Day (EED) asking everyone to be a TEAM player when it comes to seizure first aid. The campaign was hugely successful in bringing much-needed attention to epilepsy and was recognised with a special commendation at the 2014 Irish Healthcare Awards.

Our advocacy agenda in 2014 was also a busy one. The Epilepsy Monitoring Unit (EMU) in Beaumont Hospital was finally re-opened in February after 18 months of campaigning. Sadly, the EMU at Cork University Hospital had still not been opened by the year's end and we are continuing our efforts. A number of other advocacy issues arose during the year including policy work around the availability of SNAs in epilepsy and safety issues concerning the epilepsy drug sodium valproate.

In research, we partnered with SUDEP Action, University College Cork and the University of Sheffield to establish the Epilepsy Deaths Register for Ireland, while our research funding scheme supported one new study in 2014, bringing the total research investment since 2009 to €780,000.

I would like to thank all of our staff team for their dedication and support in meeting the challenges of recent times. Thanks are also due to our Board and sub-committees who contribute their stewardship and support on a totally voluntary basis. Finally, I would like to thank our members and everyone who supported Epilepsy Ireland in 2014, whether financially or by volunteering their time. We are only able to do what we do with public support, and we are indebted to all who support the cause of epilepsy.

WHAT IS EPILEPSY?

Epilepsy is a general term used for a group of disorders 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. Partial seizures initially affect only one part of the brain and these can be 'simple' (consciousness is not affected) or 'complex' (consciousness is affected). If both hemispheres of the brain are affected from the outset, these are called generalised seizures, and involve the loss of consciousness. About 1 in every 20 people will have a seizure at some time during their lives.

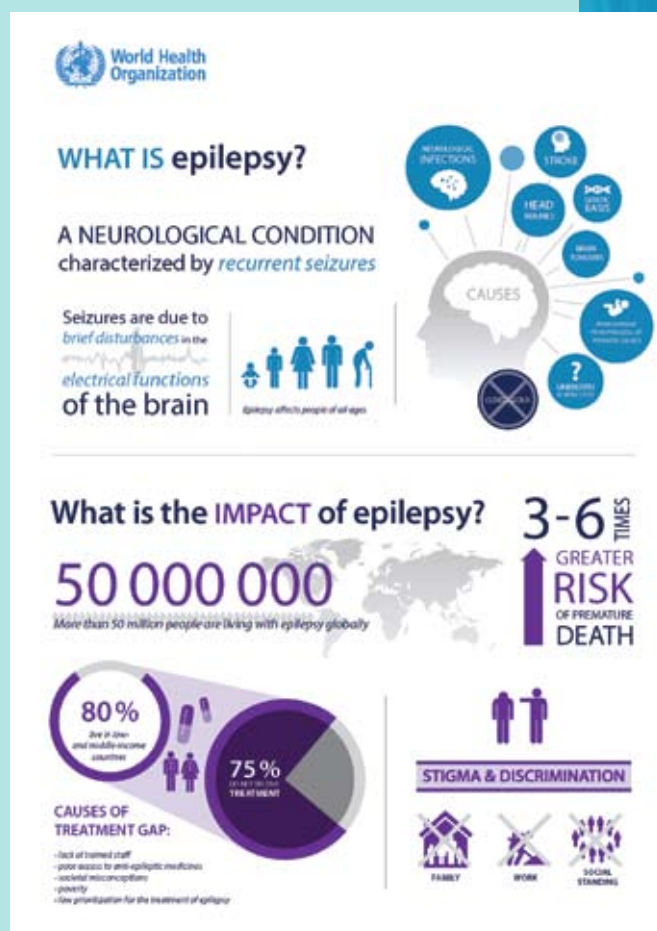
Epilepsy is one of the most common neurological conditions. Worldwide, more than 50 million people live with epilepsy. In Ireland, 37,000 people over the age of five have epilepsy and there are an estimated 1,600-2,900 new diagnoses each year. It can affect people of all ages, but is more prevalent in children, adolescents and the elderly. It is also more common in people with an intellectual disability. Common causes include head injuries, strokes, brain infections, birth defects and genetic conditions like tuberous sclerosis. Genetic mutations are also known to play a role in some cases. However, in about 60% of cases, no specific cause can be identified.

Epilepsy is a treatable condition and the majority of people can become seizure-free thanks to medications or in some cases through surgical intervention. However, Epilepsy Ireland estimates that there are at least 10,000 people in Ireland living with uncontrolled seizures. For this group in particular, the consequences of an epilepsy diagnosis can be long-lasting and significant. It can affect the person's education, employment, psychological & social functioning, self-esteem and independent living. People with epilepsy must also cope with the physical impact of seizures, the side-effects of medications, and for many, the social stigma that can be associated with it. In addition to the impact that epilepsy can have on the person with epilepsy, it can also cause serious psychological, social and economic consequences for their families and carers.

People with epilepsy also 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 SUDEP (Sudden Unexpected Death in Epilepsy). SUDEP is still not fully understood but it is more common in young adults, in males, in those with uncontrolled seizures, and those with generalised seizures.

The financial cost of epilepsy is also significant. In Europe, more than €15 billion is spent annually on the treatment of epilepsy, which equates to 0.2% of total GNP, and a figure comparable to that of lung and breast cancer combined.

Epilepsy health services have historically been neglected in Ireland, a situation which is changing due to the ongoing work of the National Epilepsy Clinical Care Programme. The programme aims to improve access to expert care in Ireland and to improve the quality of that care. In recent years, it has been responsible for the introduction of a range of standard operating procedures, pathways for seizure management in the emergency department and has secured 20 new Advanced Nurse Practitioner positions dedicated to epilepsy care.



Infographic © World Health Organization

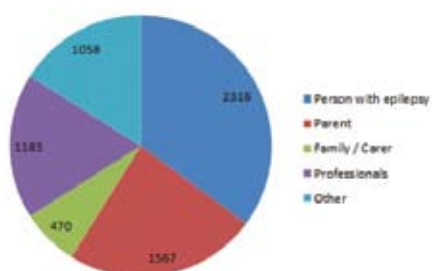
SUPPORT & INFORMATION

The services team had a busy and exciting year in 2014. We engaged with a range of groups in delivering our services, including people with epilepsy, parents and families, medical professionals, teachers and the wider community. We are active in providing one-to-one support, group education programmes, epilepsy awareness talks, online and local support groups. 2014 was the first full year in operation of our new Living Well With Epilepsy programme for people newly diagnosed with epilepsy, while our new STEPS Self-Management Programme for people with epilepsy was launched. Our team of Community Resource Officers worked tirelessly throughout the year to support those in the community living with epilepsy.

The Year in Numbers

- **14,694:** Total contacts with all Epilepsy Ireland services for the year (including CRO support contacts, Training for Success, health professional training, events, community presentations and the Specialist Nurse Helpline).
- **6,594:** Total one-to-one contacts made to Epilepsy Ireland's community resource officers and the National Information Officer.
- **682:** Total number of contacts reached through the Epilepsy Ireland Outreach services.
- **5,146:** People who attended presentations, seminars, school talks and other events facilitated by Epilepsy Ireland staff.
- **76** attendees at 12 STEPS self-management programmes.
- **333:** Participants in the Living well with Epilepsy programme, delivered in 379 sessions.
- **41:** Number of Online Support Group run during 2014. The group was accessed by 206 individuals.
- **1,468:** Total number of people supported by the Epilepsy Ireland Specialist Nurse

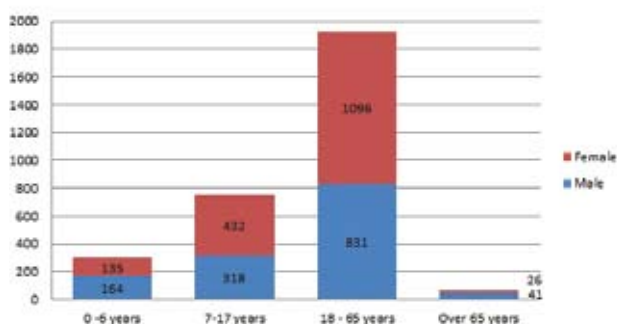
In 2014, there were 14,694 individual contacts with our services. This includes all the services that we provide. Our one-to-one service attended to 6,594 contacts made from 2,888 individuals. The core of our work with individuals is to provide the information and support that people need in living their life to the fullest. This one-to-one work includes personal advocacy, assisting in queries relating to education, employment, entitlements and accessing mainstream services.



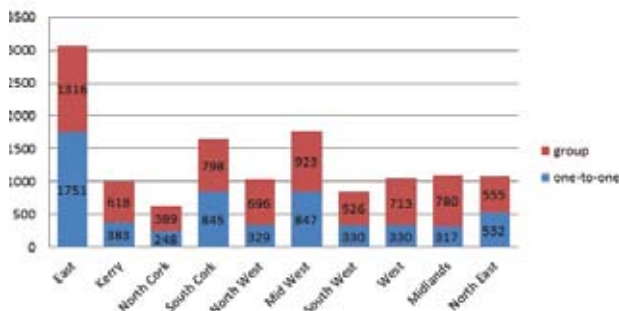
Who contacted our one-to-one service in 2014?

In addition our Epilepsy Specialist Nurse attended to a further 1,468 individual contacts, both through our epilepsy helpline and through her work in Beaumont Hospital and in clinics in the maternity hospitals. Our one-to-one service can be accessed by telephone, email, post, social media, hospital outreach, community outreach or by visiting our offices.

Our one-to-one support and information service provided support to 3,043 unique individuals. Some of these service users are people with epilepsy and others are contacting us on behalf of another (e.g. sibling, child, friend or patient). See the demographic and regional breakdown below.



Service User Profile 2014



One to One and group contacts by region

Living Well with Epilepsy Programme

We offered one-to-one support to a total of 1,900 new service users. This included 505 people with epilepsy, 388 parents of children with epilepsy, 168 family members, 391 professionals and 448 others. Many of these individuals were newly diagnosed. Our main tool for working with people who are newly diagnosed is our Living Well with Epilepsy Programme and Toolkit which was developed during 2013. During the first full year of its use, we engaged with 333 individuals for toolkits, and delivered 379 sessions. The programme is delivered as a comprehensive service for those newly diagnosed to learn how to self-manage their condition.

STEPS Self-Management Programme

A very exciting new initiative in 2014 was the development of a new specialised self-management programme for people with epilepsy. This course consists of 12 modules delivered over six sessions and covers all aspects of learning how to manage epilepsy, set in a broader health management context. Participants learn how to manage seizures, triggers and risks, along with managing stress, negative thinking, emotions, and planning for the future. In our first year, we ran the programme in 12 regional locations and had 76 attendees.

Outcome evaluations show self-reported improvements in understanding epilepsy, understanding the health system & services and managing risk & safety. Improvements have also been reported in the actions taken by people to manage their own triggers, seizures, health care and safety issues. Participants have also reported higher scores on feelings of wellbeing and emotional health, feeling supported, confidence in managing their own epilepsy and feeling in control of their own epilepsy. Outstanding results have been reported by the participants and we plan to extend this programme with a STEPS for Parents programme for 2015.

Support Groups and Online Support Groups

We ran 41 support groups at various locations across the country for people with epilepsy, parents and families. 348 service users attended the groups. We also delivered 41 online support sessions in 2014 to 206 attendees. Our support groups aim to facilitate people in meeting each other and coming together to share their experiences in a safe and supportive environment.

National Conference

Our national conference in Dublin in October was attended by 180 delegates and focused on the important theme of 'Being Safe, Reducing Risk'. Our keynote speakers were Dr Aidan Neligan, Clinical Epileptologist and Neurologist, and Prof. Henry Smithson, Professor of General Practice. The conference featured interactive workshops on safety and self-management as well as lively and interactive debates on key issues.

School and Community Epilepsy Awareness

Our school and community work is central to our ability to support people with epilepsy and their families. We attend schools and community groups on request to provide education about epilepsy. In 2014, we went to 98 schools and 68 community groups nationally, and delivered presentations to 3,392 individuals.

Working with Young People

In 2014, a number of events were organised focusing on bringing together teens, families and parents. In Limerick, a hugely popular family event was held in April at the University of Limerick, attended by almost 100 parents and 120 young people. While parents attended talks by expert speakers, the children participated in an exciting adventure programme.

A parent and teens day was also held in Cork in October and a young adults' adventure day was held in July in Petersburg, Galway.

Other Events & Programmes

Numerous seminars and information events were held during the year to provide opportunities for education and awareness-raising amongst members, professionals and the broader community. These included:

- Questions & Answers session with Epilepsy Specialist Nurse in Sligo
- Information Seminar for professionals and parents in Letterkenny
- Information Seminar in Limerick focusing on women's issues
- Mindfulness support group for parents in Tullamore
- Information seminar for people with epilepsy, parents and professionals in Monaghan
- Community Self-Management Wellness day in Co Louth
- Information seminars in Galway, Roscommon and Ballinrobe
- Two Information days for professionals, parents and people with epilepsy in Tullamore
- Educational event for teachers in Tullamore
- Memory workshops to support people with epilepsy in Killarney
- We participated with other neurological charities in the Neurological Alliance of Ireland Wellness Days in Limerick and Kilkenny.



The first group to complete the new STEPS self-management programme in Letterkenny, Co. Donegal with Epilepsy Ireland CRO Agnes Mooney.



Over 330 newly diagnosed people with epilepsy availed of our 'Living Well With Epilepsy' educational programme in 2014, the service's first full year in operation.

AWARENESS & ADVOCACY

European Epilepsy Day

Improving public understanding of how to respond to a seizure was the focus for the 4th annual European Epilepsy Day (EED) on February 10th. Ireland Rugby Head Coach Joe Schmidt came on board to launch the **TEAM** campaign, voice a radio ad and to publicly discuss his own family's experience of epilepsy.

The campaign urged everyone to be a **TEAM** player.

T: Take care to protect the person

E: Ensure you stay with them

A: Allow the seizure to run its course

M: Move the person onto their side when the (tonic-clonic) seizure is over

Ads were placed in national newspapers, online and on national and local radio. Coverage was secured on key radio and TV shows including the Six-One news, Ireland AM, Morning Ireland, the Ryan Tubridy Show and the Pat Kenny Show. Almost all of the daily newspapers highlighted the campaign, many by interviewing the growing number of Epilepsy Ireland media volunteers.

On social media, almost 7,000 people engaged with Epilepsy Ireland on Facebook during the 10-day campaign and messages about seizure first aid reached over 250,000 users. A particular online highlight was seeing #epilepsy trending on Twitter on February 10th.

New videos on first aid were made and used online on the *Seizure Aware* microsite, which was visited by over 5,000 people during the campaign and almost 27,000 times in total during the year. February 10th set a new record as the busiest ever day on epilepsy.ie and in total, over 18,000 visits from 12,000 unique individuals were recorded during the campaign.

EED was also celebrated around the country with information stands, coffee mornings, seminars and outreach events happening in all regions. First aid posters were distributed to schools, workplaces, restaurants and retailers around the country.

The campaign was recognised with a special commendation at the 2014 Irish Healthcare Awards, Patient Association Project category. Following the impact made by the campaign, plans were agreed in 2014 to further expand the campaign in 2015 to coincide with the first ever International Epilepsy Day.

Promoting 'Being Safe & Reducing Risk'

Following the Seizure Aware campaign, we adapted the theme of 'Be Safe, Reduce Risk' for awareness activities aimed at people with epilepsy for the remainder of 2014. The theme was prominent in features in the Epilepsy News magazine, in a range of online and offline resources, in regional events and at the National Conference in October. The aim was to highlight issues around personal safety including SUDEP (Sudden Unexpected Death in Epilepsy) and to promote positive steps to reduce the risks involved.

Online and Social Media

Epilepsy Ireland continues to increase our emphasis on social media for raising epilepsy awareness and communicating with the wider public. Facebook connections almost doubled during the year to 6,200, while followers on Twitter increased to over 2,000. Over 37,000 video views were recorded on YouTube.

The epilepsy.ie website received 86,000 visits in 2014, a 5% increase over 2013. A total of 57,000 unique visitors accessed the site, representing a 7% increase. The site is updated on an almost daily basis with the latest news and events. It also hosts a large database of information on epilepsy and the Seizure Aware microsite, which is the most visited section of the site.

Epilepsy Awareness sub-committee

Awareness activities are directed by the Epilepsy Awareness sub-committee which is chaired by Cathy Grieve. Thank you to Cathy and to committee members Eoin Kernan, Rachel Ashe, Tony Caravousanos, Rick O'Shea, Audrey Muddiman and Carol Saarsteiner for their hard work during the year.



Ireland Rugby coach Joe Schmidt meets his new TEAM, Sean, James and Joar, to launch European Epilepsy Day in February.



The Seizure Aware campaign received a special commendation at the 2014 Irish Healthcare Awards.

Epilepsy Monitoring Units

Following a prolonged advocacy campaign led by Epilepsy Ireland, the Epilepsy Monitoring Unit (EMU) at Beaumont Hospital was officially re-opened in 2014. The unit had been closed for over a year due to staff recruitment issues but had begun admitting patients in 2013. Efforts continued throughout 2014 to ensure the opening of the EMU at Cork University Hospital which had been completed in 2012, but never opened, also due to the HSE's recruitment moratorium which prevented the hiring of essential nurses and technicians. Despite a number of commitments by the Minister and by CUH to open the EMU in 2014, deadlines continued to be missed and at the year end, the Unit was still not admitting patients. The Unit was expected to finally open in early 2015.

Epilepsy, Pregnancy & AEDs

In 2014, Epilepsy Ireland joined forces with the Disability Federation of Ireland, Genetic and Rare Diseases Organisation, Medical Research Charities Group, and the Organisation for Anti-Convulsant Syndromes Ireland to form the FACS (Fetal Anti-Convulsant Syndrome) Forum Ireland. The Forum was formed to campaign for better warnings and information about the risks associated with epilepsy drugs in pregnancy, particularly sodium valproate which was the subject of a European Medicines Agency (EMA) review in 2013-2014.

FACS Forum Ireland began a campaign urging the Department of Health to take immediate action to address the issue of FACS in Ireland, both in terms of prevention and also supports for those affected. In November 2014, EMA issued a ruling based on research findings, to strengthen warnings on the use of valproate in women and girls. Following this, the Forum met with the HPRA to seek assurances that accurate information on the risks be distributed immediately to healthcare professionals and to patients; and to seek a further strengthening of warnings in the drug's product

information leaflet for patients. Epilepsy Ireland also began using our communication channels to raise awareness of the issue among our member and service users and work was ongoing at the end of the year.

Policy activities

In 2014 Epilepsy Ireland prepared policy submissions on Special Needs Assistants, Universal Health Insurance and Medical Cards. Our medical card submission was based on data gathered from a study undertaken of almost 300 people with epilepsy.

Epilepsy & Neurology Services

Epilepsy Ireland works alongside almost 30 other representative groups in the Neurological Alliance of Ireland (NAI) to campaign for and achieve improved neurological services. Advocacy issues addressed by NAI in 2014 included reduced funding for neurological charities, the impact on people with neurological conditions of ongoing cuts in health and social welfare budgets and the need for renewed investment in neurological and neurorehabilitation services.

Epilepsy Ireland is also represented on the HSE's National Epilepsy Care Programme, led by Dr Colin Doherty. In 2014, the Programme published its Model of Care, outlining a 10-year vision for the transformation of epilepsy care in Ireland.

Working with other organisations

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
- The Neurological Alliance of Ireland
- Disability Federation of Ireland
- Medical Research Charities Group
- Joint Epilepsy Council of the UK and Ireland

EPILEPSY IRELAND 2014: KEY STATISTICS

14,694: Total contacts with Epilepsy Ireland services in 2014	1,468: Individual contacts with our Epilepsy Specialist Nurse in 2014
55%: The increase in uptake of EI's health & allied health professional training programme in 2014	86,222: Total number of visits to epilepsy.ie in 2014, from 57,231 unique users
856: Participants on Epilepsy Awareness and the administration of Buccal Midazolam programme in 2014	68%: Percentage of Epilepsy Ireland's income spent on services, awareness raising, training, research and advocacy. 14% is spent on administration & governance and 18% on fundraising
€780,000 Fundraised income invested in Irish epilepsy research since 2009	98: Schools engaged with in 2014, with 1,966 pupils & teachers attending awareness sessions
224: Total number of Training for Success students 1998 - 2014	26,910: Video views in 2014 of Be Seizure Aware first aid video
333: Participants in the new Living Well With Epilepsy toolkits programme, 2014	

TRAINING & EDUCATION

Training For Success

Training For Success (TFS), Epilepsy Ireland's pre-employment training programme 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 SOLAS offers FETAC Level 4 Certification over a number of modules. TFS continues its original remit of developing practical, interpersonal and communication skills to help develop the individuals personal confidence.

In both the 2013-2014 and 2014-2015 academic years, the yearly maximum of 14 students undertook TFS. However, 2014 was a challenging, yet successful year for the programme.

Following the 2013 decision of the Institute of Technology Sligo to withdraw from its partnership with Epilepsy Ireland, intensive discussions took place in 2014 and it was agreed to extend the partnership until the end of the 2014-15 academic term. TFS will then (August 2015) face into a new phase of its very successful history, managed directly by Epilepsy Ireland. The Institute has agreed to continue to host the programme on its extensive campus, which will provide continuity in one the most important aspects of the programme's success – its location.



TFS student Sean Higgins, pictured with some of his classmates from the 2013-14 term, received a Certificate of Distinction for his exemplary performance on the programme.

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 one of its kind in Ireland and is delivered in accordance with the Joint Epilepsy Council of the UK & Ireland 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 different emergency rescue medications (Epistatus and Buccolam) and receive instruction in the correct administration of these medications.

Our commitment to providing expert training in the administration of emergency medication continued in

2014 and the programme is now well established as a core Epilepsy Ireland service. A total of 87 training sessions were delivered nationwide, compared with 55 in 2013. Overall, 856 people received the training in 2014, compared with the previous year's 554, an increase of 55%. At the end of 2014, Epilepsy Ireland has delivered a total of 239 training days, providing this important training to 2,551 health and allied health professionals.

Schools Education Programme

2014 was another busy year for the Schools Education Programme, which aims to raise awareness of epilepsy for those with the responsibility for ensuring a safe education environment. During the year, 1,866 teachers, SNAs and students attended Epilepsy Awareness presentations nationwide.

Health Professionals Training Day

During National Epilepsy Week in May, Epilepsy Ireland partnered with the Royal Society of Medicine (RSM) to organise Epilepsy West, a one-day epilepsy conference at the National University of Ireland Galway the aimed at medical professionals working in the field of epilepsy or related areas. This was the fourth collaboration between Epilepsy Ireland and the RSM in recent years and the event featured an outstanding programme of expert speakers including consultant neurologists Drs Michael Hennessy, John Lynch, Peter Widdess-Walsh and Kevin Murphy; paediatric consultant neurologist Dr Liz O'Mahony; world renowned authority on epilepsy and intellectual disability, Prof Mike Kerr; Prof Henry Smithson from UCC and Dr Christine Linehan, UCD.



Staff from Offaly Centre for Independent Living and Daingean NS (above) and Coonamahon Centre & Cregg House (below) were just two of 87 groups who successfully completed the training course on Epilepsy Awareness and Emergency Medication in 2014.



RESEARCH

Research Funding Scheme

Since the launch of the Epilepsy Ireland Research Funding Scheme in 2009, a total of €780,000 has been committed to eight Irish projects that have passed a rigorous review process. The scheme aims to improve knowledge of epilepsy, stimulate new treatment avenues and improve the quality of life for people living with the condition. As such, the studies supported are diverse, ranging from genetic and molecular research to health services research and psychosocial issues like disclosure and stigma.

One new research project was funded in 2014. Epilepsy Ireland agreed a partnership with the RCSI and the Irish Research Council to support a study by Dr Sinead Heavin on potential biomarkers that determine how well people respond to the epilepsy drug Levetiracetam. The total funding for the study is €101,790, with Epilepsy Ireland contributing €30,596 over two years. The study will specifically investigate the miRNA molecule and if a link can be found, it would represent the first such molecular diagnostic tool for epilepsy, potentially allowing the tailoring of treatment based on an individual's genetic and molecular make-up.

At the end of 2014, three other research projects were ongoing:

- **An evaluation of the role of the Epilepsy Specialist Nurse and the impact on patient quality of life (2013-2015)**
Prof. Agnes Higgins from Trinity College is assessing the role of the Epilepsy Specialist Nurse to determine if there are differences in outcomes between people who have access to an ESN and those that don't.
- **Demystify the veil of secrecy: a mixed method inquiry of parent-child dialogue about epilepsy and its associated stigma (2013-2015)**
Dr Veronica Lambert from DCU is examining the differences in perceptions and communications that exist between families when it comes to discussing and disclosing epilepsy.
- **The collaborative development of an evidence-based educational resource for self-disclosure strategies for people with epilepsy (2014-2016)**
Dr Naomi Elliott from Trinity College is exploring the concerns that adults with epilepsy have about disclosing their epilepsy and investigating the most successful disclosure strategies.

Six of the eight projects funded to date have been jointly funded with the Health Research Board under the HRB/MRCG Joint Funding Scheme. Although Epilepsy Ireland had planned to fund additional projects under the scheme in 2015, the 2014 call for proposals was cancelled by the HRB. A new call for proposals is planned for autumn 2015.

After five years in operation, the Research Funding Scheme has generated some very significant outcomes including:

- Dr Yvonne Langan (St James's Hospital) found that both heart rate variability (HRV) & baroreflex sensitivity

(BS) are reduced in people with epilepsy, potentially increasing the risk of SUDEP (Sudden Unexpected Death in Epilepsy). The link between BS and SUDEP had not been previously studied.

- Prof. David Henshall & Dr Suzanne Miller-Delaney's (RCSI) study on DNA methylation represented the first analysis of genome-wide DNA methylation changes in temporal lobe epilepsy and helped explain how gene expression is controlled in epilepsy. The study was published by the journal *Brain* in 2014.
- Dr Gianpiero Cavalleri's (RCSI) work contributed to a number of important genetic discoveries. His work as part of an international consortium in identifying the role of the gene protocadherin in epilepsy was one of the key discoveries of the year and was published in the *Lancet Neurology*.

Other research activities

Work progressed throughout 2014 on establishing the Epilepsy Deaths Register for Ireland (EDRI). The EDRI is funded by Epilepsy Ireland in partnership with UK charity SUDEP Action, University College Cork and the University of Sheffield. The register will gather information from bereaved families and from coroners, making the information available for use in research to help better understand the causes behind SUDEP and other epilepsy deaths. It will also help improve public awareness of risk, and in time, improve medical advice and treatment plans for those at the most risk.

Epilepsy Ireland CEO Mike Glynn and board member Dr Christne Linehan were two of the authors of a White Paper published in 2014 by the International League Against Epilepsy and the International Bureau for Epilepsy on the medical and social needs of people with epilepsy and intellectual disability. Epilepsy Ireland members were major contributors to the report.

In addition to directly funding research, Epilepsy Ireland also supports local research in non-financial ways, such as recruiting participants and communicating research developments to our members. In 2014, there were 12 research-related articles published in the *Epilepsy News* magazine, over 50 online articles and three calls for volunteers. Epilepsy Ireland also continues to be an official collaborator on the HRB-funded project being undertaken by Dr Veronica Lambert at DCU entitled *Talking about Epilepsy*.



Prof David Henshall and Dr Suzanne Miller-Delaney published their work on gene activity in epilepsy in *Brain*.



Epilepsy Ireland is co-funding Dr Sinead Heavin's study on biomarkers determining drug responsiveness.

FUNDRAISING

Income from fundraising in 2014 was €602,827, an increase of 3% from 2013. Fundraising encompasses annual campaigns such as Rose appeals, the members' raffle, text-to-donate and the Christmas campaign. It also includes national church-gate collections which continue to be an important source of funding. Individual donations, corporate support and event fundraising are also significant elements of the fundraising mix. One new fundraising channel was added in 2014 - the initiation of the Cash Giveaway Draw, a monthly draw supporting Epilepsy Ireland's research activities.

Volunteer-led events also continue to be a key part of our fundraising. Hundreds of people all over the country yet again supported epilepsy by participating in events or by organising their own events. We are very grateful to all our fundraising volunteers who supported our work in 2014 and we're delighted to highlight some examples here.

How can I help?



There are many ways that you can support our work in providing support services, raising awareness and funding research.

- Make a donation
- Volunteer your time
- Support our events and campaigns
- Organise your own event
- Represent us in a fun run or cycle
- Recommend us for your workplace charity of the year

If you'd like to know more, please download our leaflet *Play your part*

for Epilepsy from epilepsy.ie or call us at 01 4557500. We'd love to hear from you!



Celebrity chefs Nuala Carey, Rick O'Shea, Gavin Duffy and Joe Schmidt, pictured with Epilepsy Ireland board members Cathy Grieve and Carol Saarsteiner at the Look Who's Cooking fundraiser.



The Rose of Tralee, Haley O'Sullivan took part in the Dublin Women's Mini Marathon for Epilepsy Ireland. Haley is pictured with Epilepsy Ireland fundraising team Glenna Gallagher & Ashley Butler and volunteer Katie Kelly.



Above: Volunteers from State Street International Fund Services Below - Cold but enthusiastic Rose Week volunteers from Sacred Heart School, Tullamore.



Winners of the Epilepsy Ireland/ Dublin Photography School photography competition, whose photographs were selected for the 2015 Epilepsy Ireland fundraising calendar.



Tour De Gags was just one of dozens of volunteer-led events organised for Epilepsy Ireland in 2014. Now in its fifth year, Tour De Gags has raised over €50,000 for our work and has enabled the creation of the Epilepsy Deaths Register for Ireland.

2014 FINANCIAL REPORT

Epilepsy Ireland reported net outgoing resources on unrestricted funds of €22,354 in 2014 (2013: €12,696), which was a satisfactory result given the economic challenges facing all not-for-profit organisations. In addition, the Board funded designated charitable activities during the year in accordance with our Strategic Plan, which increased total net outgoing resources to €101,804.

In order to provide more detailed information on the performance and financial position of the charity, Epilepsy Ireland has prepared our financial statements in accordance with the Charities Statement of Recommended Practice (SORP). Detailed financial information is available in our audited accounts which can be downloaded from the Publications section of epilepsy.ie.

Statement of Financial Activities for the financial year ended 31 December 2014

	Restricted Funds 2014 €	Unrestricted Funds 2014 €	Designated Funds 2014 €	Total Funds 2014 €	Total Funds 2013 €
Incoming Resources					
HSE Grants	750,545	-	-	750,545	827,291
IT Sligo	93,600	-	-	93,600	93,600
Research grants	62,920	-	-	62,920	53,553
Fundraising & Other Income	-	602,827	-	602,827	586,071
Investment Income	-	3,132	-	3,132	3,109
Interest Income	-	32,386	-	32,386	40,477
Total Incoming Resources	907,065	638,345	-	1,545,410	1,604,101
Resources Expended					
Charitable Activities	901,223	396,004	198,957	1,496,184	1,552,691
Governance Costs	5,842	5,843	-	11,685	11,570
Direct Fundraising Costs	-	157,976	-	157,976	87,716
Total Resources Expended	907,065	559,823	198,957	1,665,845	1,651,977
	-	78,522	(198,957)	(120,435)	(47,876)
Unrealised gain on investments	-	18,631	-	18,631	35,180
Net Outgoing Resources	-	97,153	(198,957)	(101,804)	(12,696)
Taxation	-	-	-	-	-
Net Outgoing Resources after tax	-	97,153	(198,957)	(101,804)	(12,696)
Transfer between funds	-	(119,507)	119,507	-	-
Net Outgoing Resources for financial year	-	(22,354)	(79,450)	(101,804)	(12,696)
Total funds brought forward 1/1/2014	-	726,383	1,116,400	1,842,783	739,079
Total funds brought forward 31/12/2014	-	704,029	1,036,950	1,740,979	1,842,783

Balance Sheet as at 31 December 2014

	2014 €	2013 €
Fixed Assets		
Tangible Assets	169,430	132,483
Financial Assets	205,460	186,829
	<u>374,890</u>	<u>319,312</u>
Current Assets		
Stock	19,827	-
Debtors	53,012	35,929
Cash at Bank and in hand	1,625,749	1,751,201
	<u>1,698,588</u>	<u>1,787,130</u>
Current Liabilities		
Creditors (Amounts falling due within one year)	(332,499)	(263,659)
Net Current Assets	<u>1,366,089</u>	<u>1,523,471</u>
Net Assets	1,740,979	1,842,783
Represented By		
Restricted funds	-	-
Unrestricted funds	704,029	726,383
Designated funds	1,036,850	1,116,400
Total Funds	1,740,979	1,842,783

OUR PEOPLE

Board of Directors

Mr Mark Dowdall (Chairman)
Mr Vincent Savino (Vice-Chairman)
Mr Michael McLoughlin (Treasurer)
Ms Claire Crehan-Dowdall (Secretary)
Mrs Tessa Dagge
Prof Norman Delanty
Mr Derry Gray *
Ms Cathy Grieve *
Dr Michael Hennessy
Dr Christine Linehan *
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
* Elected October 2014
** Resigned October 2014

Finance & Audit sub-Committee

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

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

Patron

Rick O'Shea

2FM presenter Rick was diagnosed with epilepsy at the age of 16. In March 2006, he became Epilepsy Ireland's Patron. Since then, Rick has been instrumental in helping to raise awareness of epilepsy, taking part in dozens of media interviews, speaking at national and

Staff

Chief Executive
Mike Glynn

Deputy CEO
Peter Murphy

Services
Director of Services
Wendy Crampton

National Information Officer
Geraldine Dunne

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

Clinical Nurse Specialist in Community Epilepsy Services
Sinead Murphy (Beaumont Hospital)

Administration & Fundraising

Key Fundraiser
Noeleen McDaid*

Membership & Fundraising Officer
Ashley Butler

Fundraising Assistants
Glenna Gallagher
Catherine Healy
Barbara Doyle**

* Retired December 2014
† Retired July 2014
§ Appointed July 2014
** Appointed July 2014

Training & Communications Manager
Paul Sharkey

Training For Success Manager
Honor Broderick

Training For Success Facilitator
Maire Tansey

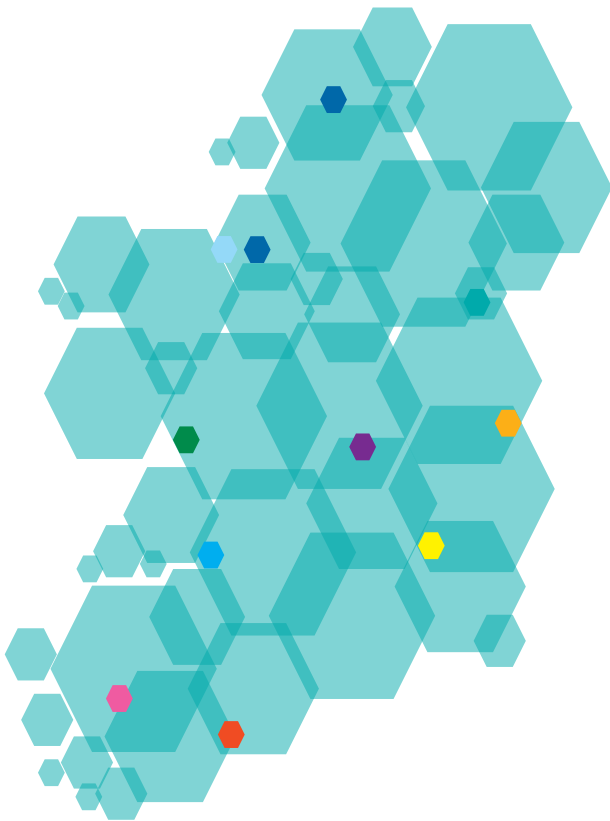
Accounts & Administration Manager
Elizabeth Ryan†, David Scott §

PA to CEO
Mary Malone

Receptionists
Madge Geoghegan
Joan McDermott



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
Email: amooney@epilepsy.ie

Letterkenny Office

Grand Central Complex, Floor 2B, Canal Road, Letterkenny,
Co Donegal.
Tel: 074 916 8725

Sligo Office

Model & Niland Arts Gallery, The Mall, Sligo
Tel: 071 91 41858

West

Covering: Galway, Roscommon & Mayo
Community Resource Officer: Edel Killarney
Westside Resource Centre, Seamus Quirke Road, Westside,
Galway.
Tel: 091 587 640
Email: ekillarney@epilepsy.ie

Mid-West

Covering: Limerick, Clare & Tipperary North
Community Resource Officer: Anna Kelly
Social Service Centre, Henry St., Limerick.
Tel: 061 313 773
Email: akelly@epilepsy.ie

Kerry

Covering: Co. Kerry
Community Resource Officer: Kathryn Foley
Glenwood, Park Road, Killarney, Co. Kerry
Tel: 064 663 0301
Email: kfoley@epilepsy.ie

Cork

Community Resource Officers:
South Lee & West Cork: Contact: Niamh Jones
North Lee & North Cork: Mary Lawlor/Loretta Kennedy
35 Washington Street, Cork.
Tel: 021 - 427 4774
Email: njones@epilepsy.ie (Niamh);
mlawlor@epilepsy.ie (Mary/ Loretta)

South East

Covering: Kilkenny, Wexford, Carlow, Waterford & Tipperary
South
Community Resource Officer: Joan Ryan
C/o HSE, St. Joseph's, Waterford Rd, Kilkenny.
Tel: 056 778 9904
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: 057 934 6790
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 - 455 7500
Email: Geraldine: gduenne@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 - 933 7585
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](https://twitter.com/epilepsyireland)
Youtube: youtube.com/BrainwaveEpilepsy
Instagram: [epilepsy_ireland](https://instagram.com/epilepsy_ireland)



Epilepsy Ireland
249 Crumlin Road
Dublin 12
Tel: 01 455 7500
Fax: 01 455 7013
info@epilepsy.ie
www.epilepsy.ie

 facebook.com/epilepsy.ie

 BrainwaveEpilepsy

 @epilepsyireland

 epilepsy_ireland

Charity Number:
CHY 6170

Brainwave The Irish Epilepsy Association t/a Epilepsy Ireland is a Company Limited by Guarantee. Registered in Dublin, company registration number 77588

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

