



Celebrating 50 years in 2016

## Annual Report 2015

**Shining a light on epilepsy since 1966**



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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 January 2015, the organisation was awarded the Practical Quality Assurance System for Small Organisations (PQASSO) Quality Mark Level 1. 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. Epilepsy Ireland has implemented Charities SORP (Statement of Recommended Practice) in our Financial Statements and is in the process of achieving full compliance with the Governance Code and the Statement of Guiding Principles for Fundraising.



# A Message from



**Mark Dowdall**  
Chairman

It is my pleasure to present Epilepsy Ireland's Annual Report for 2015. In this short review, we outline just some of the achievements of the year across our key areas of work including support services, training, research, awareness-raising and advocacy.

Our primary objective is to meet the needs of the 37,000 people with epilepsy and their families in Ireland, and I believe that as an organisation, we continue to deliver on this

objective, not just in terms of what we are doing, but also how we are doing it.

In 2015, we were awarded the Practical Quality Assurance System for Small Organisations (PQASSO) Quality Mark Level 1 by the UK-based Charities Evaluation Service. PQASSO is the leading quality assurance system 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, paths to continuous improvement and more. In these difficult times for the non-profit sector, it is imperative that we continue to ensure best practice in how we manage and govern our organisation.

It is a privilege to be entrusted with the chairmanship of our organisation on behalf of the epilepsy community and I would like to thank all those who continue to support our work. I would also like to take this opportunity to thank our board and sub-committee members who give voluntarily of their time to further the cause. To our outstanding staff team, thank you for your professionalism and commitment in responding to ever-increasing demand for our services and our resources.

I want to pay a special tribute to Mike Glynn, who retires as Epilepsy Ireland CEO in 2016, having led the Association so expertly and passionately for 21 years. Mike has always championed our core value that the wellbeing of the person with epilepsy must be at the heart of everything we do. This was evident in his many achievements such as the establishment of our nationwide services network; his passion for furthering the cause of SUDEP and his role in raising the profile of epilepsy on national and international stages. On behalf of everyone connected to Epilepsy Ireland, we thank Mike for his two decades of dedication and we wish him a happy retirement.

Finally, I want to welcome Peter Murphy as our new CEO. Peter has been part of the senior management team at Epilepsy Ireland for eight years and his commitment to the mission and vision of the organisation is well renowned. We look forward to many more successful years under Peter's leadership.



**Peter Murphy**  
Chief Executive

As the incoming CEO of Epilepsy Ireland, it is my pleasure to report on another successful year, though one which also presented challenges in meeting and resourcing increased demand for services.

In 2015, there were almost 18,000 individual contacts with our services, a 21% increase from 2014. This included almost 9,000 individual contacts made to our nationwide network of Community Resource Officers, an increase of 35%. New programmes like the STEPS self-management programme and the Living Well With Epilepsy programme continue to grow and develop in new directions.

Our services team also organised dozens of regional information events, family fun days, youth events and outreaches in addition to over a hundred support groups and online support groups. Our health professional training programme also experienced growing demand. 117 training sessions were delivered nationwide compared with 87 in 2014 and over 1,100 people were trained.

We also invested in epilepsy awareness objectives, marking the first ever International Epilepsy Day with a major TV, radio, press and online campaign fronted by Ireland rugby head coach, Joe Schmidt. The 'TEAM' campaign brought much needed attention to epilepsy and market research has shown significant increases in knowledge of seizure first-aid as a result.

Four Irish epilepsy research projects continued to receive Epilepsy Ireland funding and a new call for proposals resulted in the highest number of applications since 2009. We also launched the Epilepsy Deaths Register for Ireland, an initiative we hope will stimulate research on SUDEP and its causes.

While we can be pleased with these and other achievements, we must also recognise the need to continue to develop our work to meet the needs of people with epilepsy. We must also seek to increase our funding and fundraising to ensure that our work is sustainable. With that in mind, we began the development of a new Strategic Plan for 2017-2021, a process which will continue into 2016 and involve consultation with all organisational stakeholders.

I want to pay tribute to our small, but outstanding staff team at Epilepsy Ireland whose on-going hard work, expertise and passion has been critical to our success over the years. Finally, none of what you read about in this report would be possible but for the legions of supporters, volunteers and donors who believe in our vision of a society in which no person's life is limited by epilepsy. We are very grateful for your support in 2015 and look forward to your continued support in the years to come.

# 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 and social functioning, self-esteem and independent living.

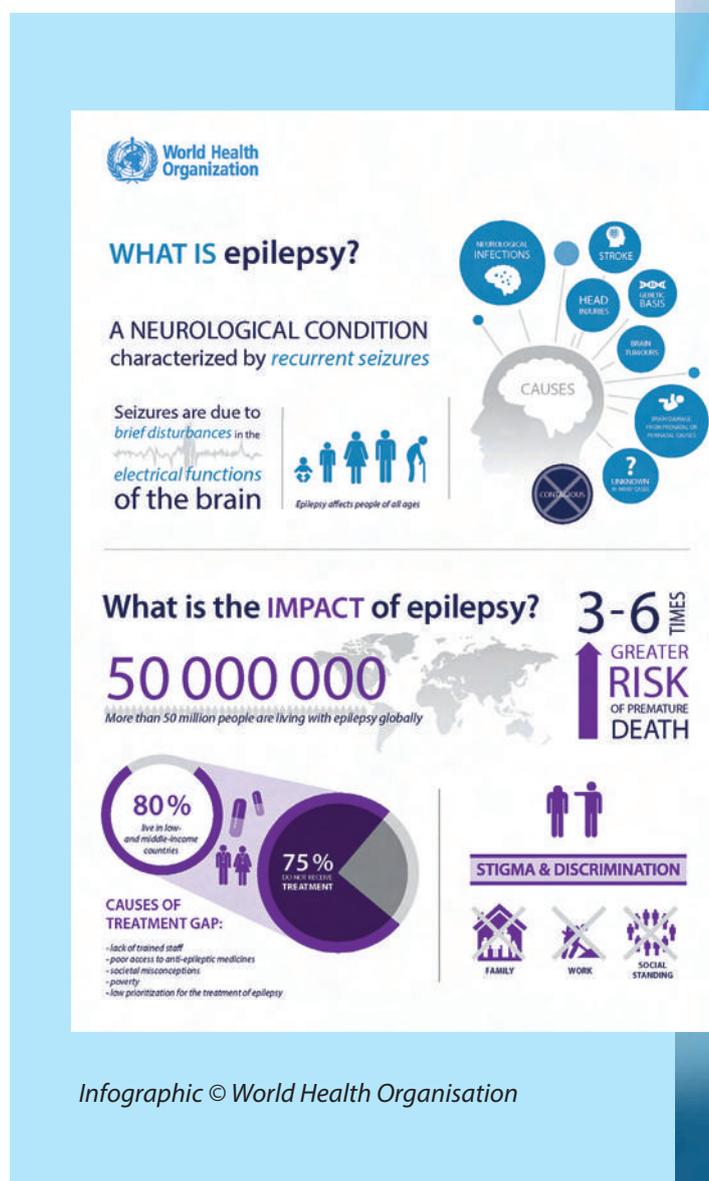
People with epilepsy must also cope with the physical impact of seizures, the side-effects of medications, and for many, the social stigma that can be associated with it. In addition to the impact that epilepsy can have on the person with epilepsy, it can also cause serious psychological, social and 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.



# Support and Information

Our services team had a great year and responded to 17,846 total contacts across all activities that we operate. This represents a 21% increase from 2014. The demand for our services is increasing and we continued to provide a wide spectrum of services based on a person-centred approach to supporting people with epilepsy, parents, carers, families, healthcare professionals and teachers. Our committed and experienced Community Resource Officer team delivered a variety of interventions and programmes from one-to-one outreach to self-management; from support groups to seminars; and from the individual with epilepsy to the professionals in healthcare and teachers.

We offer a combination of individual supportive educational interventions through telephone, email, online contact and meetings in person through all our regional offices across the country. Our Community Resource Officers dealt with 8,887 contacts with 3,157 unique individuals during the year in our one-to-one setting. We had 2,081 new service users who were welcomed into our services for the first time, consisting of adults with epilepsy (497); parents and family members (724); Professionals (492) and others (398).

We work to ensure that our services are integrated into the local community and are accessible and available in both one-to-one and group settings. Our very successful STEPS self-management programme was run in 11 venues and catered for 78 attendees in 2015. The outcomes for this programme have been documented in an evaluation report and show significant benefits being reported by participants relating to their knowledge, skills and confidence in managing their epilepsy.

Our Epilepsy Nurse Specialist provides a helpline and delivers sessions across the country for adults with epilepsy. She also operates a clinic in Beaumont hospital and in other hospitals in Dublin. In 2015, she dealt with 1154 contacts and gave 12 public talks to 270 individuals nationally.

## The Year in Numbers

- **17,846:** 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).
- **8,887:** Total one-to-one contacts made to Epilepsy Ireland's community resource officers and the National Information Officer.

- **505:** Total number of contacts reached through the Epilepsy Ireland Outreach services.
- **4,044:** People who attended school and organisational talks
- **174** attendees of STEPS and Parents STEPS programmes
- **518** Living well with epilepsy toolkits delivered to people newly diagnosed with epilepsy
- **45:** Number of Online Support Group run during 2015. The group was accessed by 117 individuals.
- **1,154:** Total number of people supported by the Epilepsy Ireland Specialist Nurse

## Supporting People with Self-Management

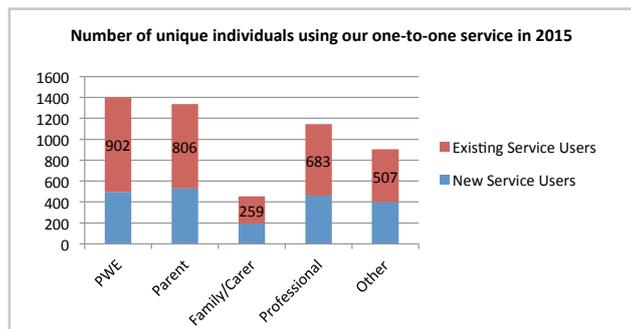
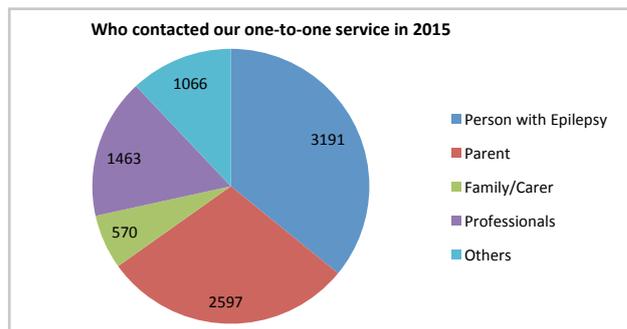
Living Well with Epilepsy – our resource toolkit offered to newly diagnosed adults with epilepsy and parents of children with epilepsy – has continued to be in demand, with 518 toolkits being delivered. In 2014 and 2015, our new toolkit has reached 851 individuals. They have all received at least one support and education session with the toolkit, and for some up to three sessions have been provided. The opportunity to learn all the important aspects of epilepsy management shortly after diagnosis, is an invaluable support to the individual.

## STEPS Self-Management Programme for People with Epilepsy

The STEPS programme introduced in 2014 has again led to some very favourable outcomes. The evaluations from course participants indicate its value in supporting self-management activity; in providing opportunities for people to work as a group and meet others with epilepsy and gain peer support and learning; and also in improving people's confidence in their lives. The feedback indicated



El member Orla Ellison with her daughter Lacey and friend Brooke try out the new colouring book for kids



that further skills in managing moods, stress and developing wellbeing and mindfulness approaches are an important future development and we will continue to ensure that we develop courses which support people to become empowered in their epilepsy self-management. In our second year of this programme, we ran 11 programmes in regional locations with 78 attendees.

### **NEW Parents STEPS Epilepsy Management Programme**

An exciting new programme was developed in 2015 and delivered nationally in 13 locations for parents of children with epilepsy. This course covered a wide variety of topics, including understanding epilepsy; managing medications and healthcare; education; managing behaviours; talking about epilepsy with children and other relevant topics. Many of the country's top experts in the field provided the content for this programme and we were delighted to deliver it to 96 parents in 2015.

### **National Conference**

Our 2015 National Conference was held in the Malton Hotel in Killarney, and 180 delegates joined us on our topic of 'Embracing Epilepsy: Current Issues for Adults, Parents & Families'. We were delighted that the speakers gave of their time and expertise so willingly, and we heard presentations from Dr. Joan Austin, distinguished Professor Emerita, Indiana University School of Nursing USA and Dr. Sophia Varadkar, Consultant Paediatric Neurologist, Great Ormond Street Hospital, London.

### **Epilepsy Ireland Smartphone App**

The Epilepsy Ireland Smartphone app was launched in 2015 and is available on both iPhone and Android free of charge. The app, which has been made possible with the support of Hewlett Packard, will help people with epilepsy to track and record their seizures, as well identify potential trigger factors and seizure patterns. A key feature of the app is the ability for parents or family members to quickly capture and link videos to a person's seizure record.

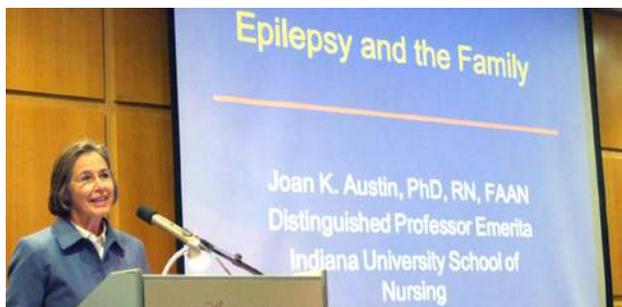
### **Support Groups and Online Support Groups**

We ran 56 local support groups at various locations for parents and families. 423 people attended the groups. We also delivered 45 online support sessions to 117 attendees.

### **Family Events**

Each year we provide fun activity events for families who have children with epilepsy or parents who have epilepsy. These really important events provide social opportunities for children and parents and valuable peer support opportunities. In 2015, we held the following events:

- Visiting the Zoo family event in Dublin in July with 93 attendees
- Wicklow bowling family event in October with 24 attendees
- Family Fun Day in November in Cork with 55 attendees



*Joan Austin speaking at last year's National Conference*

### **New Resources**

In 2015 we developed three new important new educational resources. 'Talking about Epilepsy' is for families to explore how to talk to children about epilepsy and how to disclose epilepsy to others. 'Epilepsy and School' is a new resource providing information for parents about the school going child and epilepsy, and 'When Mummy Gets Dizzy' is a poetry and colouring book made especially for children whose parents have epilepsy. It provides an educational resource for adults to talk to their children about their own epilepsy.

### **Events & Programmes**

In every region across Ireland, information events and seminars are run on a regular basis. In 2015, a variety of events and activities were delivered to a broad variety of audiences. The following is a selection of our activities:

- Teachers Seminars in Mayo, Galway, Cashel, Clonmel, Carlow, Kilkenny and Tullamore with over 200 teachers in attendance
- Health & Wellness seminars in Letterkenny and Rosnakill, Co. Donegal
- International Epilepsy Day information event in Co. Sligo
- Health and Wellbeing Seminar, and workshop days on seizures and safety in Waterford
- Teenager Seminar in Killarney
- Seminar in Drogheda with Dr. Gillian Fortune for parents, carers and educators
- Stress Management Days in Limerick and in Galway
- Memory Information sessions and young adults sessions in Galway
- Information sessions in Galway, Tullamore, Cork, Donegal, Kilkenny, Carlow
- Women and Epilepsy Information session in Galway



# Awareness and Advocacy

## International Epilepsy Day

On February 9th, the first ever International Epilepsy Day took place. In Ireland, a big effort was made to take advantage of the awareness opportunity and thanks to the support of Ireland rugby head coach, Joe Schmidt, a TV, radio and press advertising campaign was launched. This was the first ever TV ad campaign highlighting epilepsy awareness in Ireland and the ad was shown almost 1,000 times on Irish TV. Focusing on seizure first-aid, the ad was seen by an estimated 60% of all adults. The TV campaign was complemented by additional radio, press and online advertising.

Social Media played a huge role in International Epilepsy Day. People across the country uploaded their #epilepsyday photos, which had #epilepsyday trending on twitter in Ireland for much of the day. Facebook was also a hive of activity and saw the campaign reach almost 500,000 people in the week before February 9th. The Be Seizure Aware video, a short video on how to respond to seizures reached over 32,000 views on YouTube. The campaign led to a five-fold increase in traffic to the epilepsy.ie website, where people were able to find out more about epilepsy and first aid, read and view personal stories and download educational resources.

Epilepsy Ireland offices around the country organised a range of events including coffee mornings, outreach days and seminars. Epilepsy nurses turned out in force with information stands in hospitals around the country, while groups of volunteers come together to organise their own events at work, in school and in the community. The biggest event was in Castlebar where over 250 cyclists took part in the inaugural Saddle Up for Epilepsy cycle.

There was great support from Irish MEPs at the European Parliament launch of International Epilepsy Day in Strasbourg, organised and hosted by Brian Hayes MEP who chairs the European Advocates for Epilepsy Group of MEPs. Former Minister for Health Leo Varadkar attended the Strasbourg event.

Dozens of Epilepsy Ireland volunteers stepped forward to share their experiences of living with epilepsy in local and national newspapers, on radio, TV and online. Irish Paralympian and gold medallist, Michael McKillop was just one person who spoke out about how he will not be held back by epilepsy. The campaign was covered by TV3 News; The Pat Kenny Show; Irish Times; Irish Independent;



Joe Schmidt urges everyone to be part of the TEAM for epilepsy on #epilepsyday

Irish Examiner; Irish Mirror; Sunday Independent; Journal.ie; Her.ie and numerous regional outlets. Other features of the campaign included a Tell Your TD online widget and first aid posters on both tonic-clonic and complex partial seizures.

Following the campaign, market research conducted by Amarach Research found significant increases in knowledge of seizure first-aid among the public when compared to similar findings from 2014.

## Epilepsy & Sport

Epilepsy Ireland worked to highlight the relationship between people with epilepsy and participation in sport during 2015. To support the message that having epilepsy is not a barrier for the majority of people's ability to undertake sports and physical activities, we undertook a survey of over 200 people with epilepsy. Over three-quarters of respondents reported that they took part in sports or physical activities on a weekly basis, a very encouraging finding that helped dispel an enduring epilepsy 'myth'. However some worrying trends were also present, including the fact that one in five respondents said they had been excluded by a club/ school from a sport or activity as a result of their epilepsy, highlighting the need for more public information and education in this area.

## Online and Social Media

In 2015, epilepsy.ie received 98,000 visits, an increase of 14% compared to 2014. There were 65,000 unique visitors, an increase of 13%. 85% of all visits were from Ireland, up from 82% in 2014. 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.

During 2015, Facebook connections increased from 6,200 to 9,200, while on Twitter, there were over 650 new followers and almost 500,000 tweet impressions. On YouTube, Epilepsy Ireland videos were watched 46,000 times, an increase of 24%.

## SUDEP Awareness Day

Epilepsy Ireland participated in International SUDEP Awareness Day in October 2015. SUDEP is when a person with epilepsy dies suddenly and prematurely and no other cause of death is found. The day is aimed at encouraging people with epilepsy to learn about SUDEP and their



One of the hundreds of #epilepsyday selfies from Ireland

individual risk, raising awareness of SUDEP amongst the general public and highlighting the need for more research. Using traditional and new media, Epilepsy Ireland highlighted key Irish SUDEP statistics, risk factors for SUDEP, how to manage risk and positive actions that can be taken to reduce risk.

### #iseebeyond

In 2015, Epilepsy Ireland and Headway, the acquired brain injury organisation came together to develop an innovative public awareness campaign highlighting hidden disabilities. At the year end, plans for a month long campaign in February 2016 were at an advanced stage. The campaign aims to stimulate greater understanding and empathy for people living with hidden disabilities, and raise awareness of the wide variety of unseen challenges faced by those with conditions like epilepsy or an acquired brain injury.

### Epilepsy & Pregnancy

One of the most important advocacy issues in 2015 was the issue of epilepsy drugs, particularly sodium valproate, in pregnancy. In late 2014, the European Medicines Agency issued a ruling to strengthen warnings on the use of valproate in women and girls. Epilepsy Ireland joined forces with the Migraine Association of Ireland, Disability Federation Ireland, Genetic and Rare Diseases Organisation, SHINE, Medical Research Charities Group, and the Organisation for Anti-Convulsant Syndromes Ireland to form the FACS (Fetal Anti-Convulsant Syndrome) Forum Ireland.

Throughout the year the Forum worked with a range of stakeholders including HSE, the Health Products Regulatory Authority, The Epilepsy & Pregnancy Register and the National Clinical Care Programme for Epilepsy to ensure that information on the risks was distributed to healthcare professionals and to patients. In April 2015, Epilepsy Ireland conducted a survey of women taking sodium valproate which found that there was low awareness of the risks in pregnancy and that few women reported having discussed the issue with their medical teams. Little improvement was reported later in the year even after information materials were published and this remained an active issue at the year end.

The FACS Forum is also highlighting the need to develop new clinical pathways within the health services for families potentially affected by FACS and is seeking an audit of to determine the numbers affected and whether or not their needs are being met.

### Epilepsy Lighthouse Project

The Epilepsy Lighthouse Project is being delivered by eHealth Ireland in collaboration with Royal College of Surgeons in Ireland, Epilepsy Ireland and Beaumont Hospital. It aims to build upon the success of the epilepsy electronic patient record to develop a new paradigm of healthcare delivery for Ireland, which will include genomic sequencing, the introduction of Patient Reported Outcomes and improved clinical analysis. During 2015, work continued with a view to launching the project in 2016.

### Other advocacy issues

Access to education support is another key issue for many young people with epilepsy and in 2015, we highlighted

the issue of reasonable accommodations in state exams, calling for an overhaul of the current system and the types of accommodations available to bring Ireland into line with other countries.

A long standing advocacy issue were the closed Epilepsy Monitoring Units. In early 2015, the Unit in CUH was finally opened, although both that unit and the one in Beaumont experienced operational issues throughout the year.

During the year we contributed to a number of consultation processes such as that on whether to make prescription-only emergency medicines more widely available; and the process on the future of the Clinical Genetics Service in Ireland. We also engaged with the Road Safety Authority and the National Driver Licencing Service on resolving administrative issues which prevented a number of people with epilepsy from acquiring licences despite meeting the criteria. We also engaged with the Primary Care Reimbursement Service on ensuring that all epilepsy medications were reimbursable under the Long Term illness Scheme, and we monitored and communicated on drug shortages that arose throughout the year.

On the international stage, years of campaigning by the International Bureau for Epilepsy, led in recent years by Epilepsy Ireland CEO Mike Glynn resulted in the World Health Organization approving a resolution in support of improving epilepsy care and research worldwide. The resolution is a landmark step forward in securing an international commitment to tackle epilepsy.

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

The Neurological Alliance of Ireland  
[www.nai.ie](http://www.nai.ie)

Disability Federation of Ireland  
[www.disability-federation.ie](http://www.disability-federation.ie)

Medical Research Charities Group  
[www.mrcg.ie](http://www.mrcg.ie)

Epilepsy Ireland is also represented on the Clinical Advisory Group of the HSE's National Epilepsy Care Programme, led by Dr Colin Doherty.



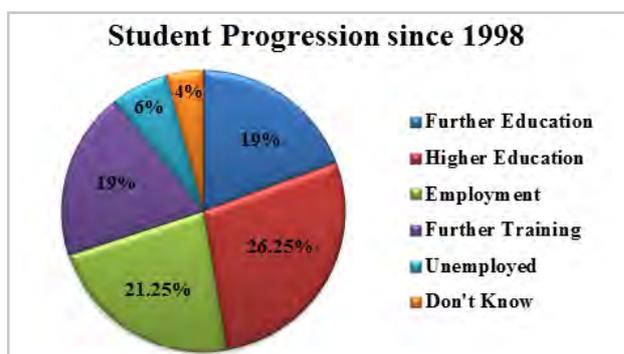
Former Minister for Health, Leo Varadkar with MEP Sean Kelly at the launch of International Epilepsy Day

# Training and 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.

2015 was another successful year for our pre-employment training programme. In both the 2014-2015 and 2015-2016 academic years, 10 students successfully completed the programme. Figures collated by Epilepsy Ireland have also revealed the positive impact of TFS since it began 18 years ago, with 85% of graduates finding a job or upskilling after they complete the programme.



\*Stats collated from Epilepsy Ireland Outcome Data 1998 - 2016

The programme, located in the Institute of Technology Sligo, and funded by the Mayo, Sligo and Leitrim Education and Training Board offers FETAC Level 4 Certification over a number of modules which include:

- Epilepsy Management
- Career Planning
- Communications
- Information Technology Skills
- Personal Effectiveness
- Mathematics
- Team Working
- Understanding Interculturalism
- Work Place Safety
- Work Experience

TFS continues its original remit of developing practical, interpersonal and communication skills to help develop the individual's personal confidence.

## 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 knowledge of epilepsy in general, understand the role of the emergency



A selection of TFS graduates since 1998. 85% found a job or upskilled after they completed TFS in 2015.

rescue medications and receive instruction in the correct administration of BM.

Commitment to providing expert training in the administration of emergency medication continued in 2015. This witnessed a further increase in training days provided. 117 training sessions were delivered nationwide, compared with the 87 in 2014, in total 1,102 people received the training in 2015 as compared with the previous year's 856, an increase of 22%. At the end of 2015, Epilepsy Ireland has delivered a total of 356 training days, providing this important training to 3,653 people.



Kolbe Special School Portlaoise who completed training on Epilepsy Awareness and BM.

## Schools Education Programme in 2015

2015 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. Our integrated approach at community level means that we are often asked to speak in schools and organisations about epilepsy. This helps to break the stigma and misunderstandings about the condition, and educates as many people as possible about how to support and include people with epilepsy in services, schools and communities. We attended 167 schools and spoke with 3,074 teachers and students and we attended 62 community and healthcare services and organisations with 970 people attending.

In 2015, we commenced our Teachers Seminars – a new approach to ensuring that teachers are educated about epilepsy and how to support children in their classrooms. We delivered seminars in 6 regions across Ireland and plan to extend this programme nationally in 2016.

# Research

## Research Funding Scheme

Since the establishment of our Research Funding Scheme in 2009 Epilepsy Ireland has invested €780,000 into crucial research. To date, eight studies have been supported ranging from genetic and molecular research to health services research and psychosocial issues like disclosure and stigma.

Four projects were ongoing throughout the year:

- **MicroRNA Biofluid Profiles as Molecular Diagnostics for Response to the Antiepileptic Drug Levetiracetam (2014-2016)\***  
Dr Sinead Heavin from RCSI is aiming to determine if a patient's miRNA profile can help predict whether they will be a responder to the AED Levetiracetam (Keppra).
  - **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, impact and cost-effectiveness of the Epilepsy Specialist Nurse role in Ireland
  - **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 around discussing and disclosing epilepsy.
  - **The collaborative development of an evidence-based educational resource for self-disclosure strategies for people with epilepsy (2014-2016)\*\***  
In the 'How to Tell' study, 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.
- \* Funded jointly between Epilepsy Ireland and the Irish Research Council under the Enterprise Partnership Scheme
- \*\* Funded jointly between Epilepsy Ireland and the Health Research Board under the MRCG Joint Funding Scheme

## Dissemination in 2015

Two papers by the DCU team were published in *Epilepsy & Behaviour* in 2015 and more findings are due to be published in 2016. Both Dr Elliott and Prof Higgins presented findings at the 2015 ILAE/IBE International Epilepsy Congress in Istanbul. Prof Henshall's lab at RCSI published important new results in *Brain* to help understand what controls gene activity in epilepsy. This study was funded by Epilepsy Ireland from 2012-2013.

## New Funding Round

A new funding proposal was issued in September 2015 where 11 applications for funding were received by the December deadline, the highest number since 2009. All proposals will undergo a detailed review process in 2016, after which the Epilepsy Ireland Research Review Committee will make recommendations for funding to the Board. We hope to fund two new projects from these applications in 2016.

## Epilepsy Death Register for Ireland

Epilepsy mortality has been a research priority for Epilepsy Ireland and in 2015, the Epilepsy Deaths Register for Ireland was launched as a partnership between Epilepsy Ireland, UK charity SUDEP Action, University College Cork and Sheffield University. The Register is funded by Epilepsy Ireland and is based on the UK Epilepsy Deaths Register which was launched in 2013. It provides a single-point for reporting epilepsy deaths in Ireland and will produce reports on information gathered offering support for researchers working in the area of epilepsy deaths. Additionally it will improve public awareness of these issues and, in conjunction with international efforts, help us to better understand the causes behind SUDEP.

## Research Communications

As well as providing financial support, Epilepsy Ireland plays a key role in helping to disseminate research findings and inform the epilepsy community on the latest developments. In April, Epilepsy Ireland and The Royal College of Surgeons in Ireland came together to organise the "Epilepsy Research Explained: Recent Discoveries and Future Directions" event in Dublin. Featuring leading Irish epilepsy researchers, the event was aimed at a non-medical audience and was fully booked for weeks in advance. It is hoped to organise similar research-themed events in 2016 and beyond. In November, the RTE documentary "10 Things to Know about the Brain" included a feature on Prof David Henshall's research on DNA methylation at RCSI which was funded by Epilepsy Ireland.

## Research Volunteers

Recruiting study participants is one of the most difficult aspects for researchers and in 2015, Epilepsy Ireland worked with a number of research teams to recruit participants, including:

- Dr Sinead Heavin's Keppra study at RCSI
- Dr Neil Powell's work on seizure dogs at QUB
- Prof. Norman Delanty, Dr. Colin Doherty and Dr. Gianpiero Cavalleri's work on epilepsy genetics
- Teachers' Knowledge of and Attitudes Towards Students with Epilepsy study at UCD

We also agreed in 2015 to support upcoming studies on epilepsy such as the European Study on the Burden and Care of Epilepsy (ESBACE) and the Epilepsy Partnership in Care (EPIC) study on patient-centred care, being led by the HSE, Maynooth University and RCSI.



*Speakers at the 2015 Epilepsy Research Explained conference in Dublin (l-r) Mike Glynn, Epilepsy Ireland CEO; Dr Gianpiero Cavalleri, RCSI; Prof Mary King, Temple St Children's Hospital; Prof Norman Delanty, Beaumont Hospital/RCSI; Prof David Henshall, RCSI.*

# Fundraising

Fundraising is an essential part of Epilepsy Ireland and the Irish public has continued to support our work in so many different ways. The goodwill of those who undertake fundraising and donate to Epilepsy Ireland is vital for the continuation of our services. Fundraising encompasses annual campaigns such as Rose appeals, the members' raffle, text-to-donate, Womens Mini Marathon 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. Income from fundraising in 2015 was €652,546.

Volunteer-led events also continue to be a key part of our fundraising. Hundreds of people all over the country yet again supported Epilepsy Ireland by participating in events or by organising their own events. Epilepsy Ireland extends our deepest gratitude to all our fundraising volunteers and donors who supported our work in 2015 and we are delighted to highlight some examples here.



Amanada Malone from Wexford was one of many who raised awareness on International Epilepsy Day and raised some funds for Epilepsy Ireland by organising a coffee morning and selling our roses.

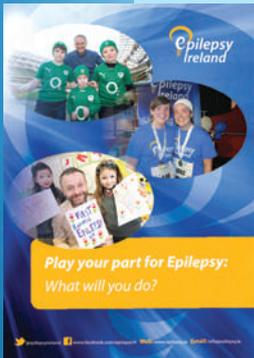


Cycle for Epilepsy Ireland. Lil Histon from Cork put her best foot forward to raise funds for Epilepsy Ireland.

## 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](http://epilepsy.ie) or call us at 01 4557500. We'd love to hear from you.



Bernard Hughes, Volunteer with Epilepsy Ireland and Peader Collins celebrated the 20th anniversary of the Irish Tree Centre who organised a fantastic family Day and also made Epilepsy Ireland their beneficiary charity.



Taoiseach Enda Kenny pictured after the 2015 Saddle Up For Epilepsy in Castlebar, Co Mayo.



A big thanks to Frank Kenny, Darren Cahill, John McNamara & Davy Conroy who took part in the punishing Croghan Hill Challenge in Offaly. They raised a fantastic €1,000 for us.



Chefs pose for a photo after 'The Coddle Cook Off' where restaurants in Temple Bar raised funds for Epilepsy Ireland.

# 2015 Financial Report

Epilepsy Ireland reported net outgoing resources of €243,692 in 2015 (2014: €120,434). This was a satisfactory performance in light of increased activity in areas such as services, awareness, training and research combined with the economic challenges facing all not-for-profit organisations. 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 2015) and FRS102.

The full financial statements are available from from the Publications section of [epilepsy.ie](http://epilepsy.ie) or from [info@epilepsy.ie](mailto:info@epilepsy.ie)

## Statement of Financial Activities for the financial year ended 31 December 2015

	<b>Restricted Funds 2015</b>	<b>Unrestricted Funds 2015</b>	<b>Total Funds 2015</b>	<b>Total Funds 2014</b>
	<b>€</b>	<b>€</b>	<b>€</b>	<b>€</b>
<b>Income From:</b>				
Donations & Legacies	-	310,742	310,742	375,596
Charitable Activities	947,432	83,512	1,030,944	958,199
Other Trading Activities	86,500	168,162	254,662	175,710
Investment Income	-	21,873	21,873	35,535
Other Income	-	3,630	3,630	370
<b>Total Income</b>	<b>1,033,932</b>	<b>587,919</b>	<b>1,621,851</b>	<b>1,545,410</b>
<b>Expenditure On:</b>				
Charitable Activities	980,738	353,585	1,334,323	1,209,165
Raising Funds	50,536	259,027	309,563	307,889
Other	-	221,657	221,657	148,790
<b>Total Expenditure</b>	<b>1,031,274</b>	<b>834,269</b>	<b>1,865,543</b>	<b>1,665,844</b>
<b>Net Income/ (Expenditure)</b>	<b>2,658</b>	<b>(246,350)</b>	<b>(243,692)</b>	<b>(120,434)</b>
Unrealised gain on quoted investments	-	28,782	28,782	18,630
Taxation	-	-	-	-
<b>Net Movement in Funds for financial year</b>	<b>2,658</b>	<b>(217,568)</b>	<b>(214,910)</b>	<b>(101,804)</b>
<b>Total funds brought forward 1/1/2015</b>	<b>-</b>	<b>1,740,979</b>	<b>1,740,979</b>	<b>1,842,783</b>
<b>Total funds carried forward 31/12/2015</b>	<b>2,658</b>	<b>1,523,411</b>	<b>1,526,069</b>	<b>1,740,979</b>

## Balance Sheet as at 31 December 2015

	<b>2015</b>	<b>2014</b>
	<b>€</b>	<b>€</b>
<b>Fixed Assets</b>		
Tangible Assets	163,690	169,430
Financial Assets	234,242	205,460
	<b>397,932</b>	<b>374,890</b>
<b>Current Assets</b>		
Stock	7,718	19,827
Debtors	42,636	53,012
Cash at Bank and in hand	1,367,534	1,625,749
	<b>1,417,888</b>	<b>1,698,588</b>
<b>Current Liabilities</b>		
Creditors (Amounts falling due within one year)	(289,751)	(332,499)
<b>Net Current Assets</b>	<b>1,128,137</b>	<b>1,366,089</b>
<b>Total Net Assets</b>	<b>1,526,069</b>	<b>1,740,979</b>
<b>Funds of the Charity</b>		
Restricted funds	2,658	-
Unrestricted funds	596,745	704,029
Designated funds	926,666	1,036,950
<b>Total Funds</b>	<b>1,526,069</b>	<b>1,740,979</b>

# 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  
Dr Brian McNamara  
Ms Norma Mitchell  
Ms Carol Saarseiner  
Dr Joyce Senior  
Dr Brian Sweeney  
Dr David Webb

## Finance & Audit Committee

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

## 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

## 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/Carina Fitzgerald (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)

### Community Epilepsy Specialist Nurse

Sinead Murphy (Beaumont Hospital)

## Fundraising & Administration

### Membership & Fundraising Officer

Ashley Butler

### Finance Manager

David Scott \*

### Churchgate Collections

Barbara Doyle

### Fundraising Assistants

Glenna Gallagher  
Catherine Healy

### Training & Communications Manager

Paul Sharkey

### Training For Success Manager

Honor Broderick

### Training For Success Facilitator

Maire Tansey

### PA to CEO

Mary Malone

### Receptionists

Madge Geoghegan  
Joan McDermott

\* Resigned September 2015

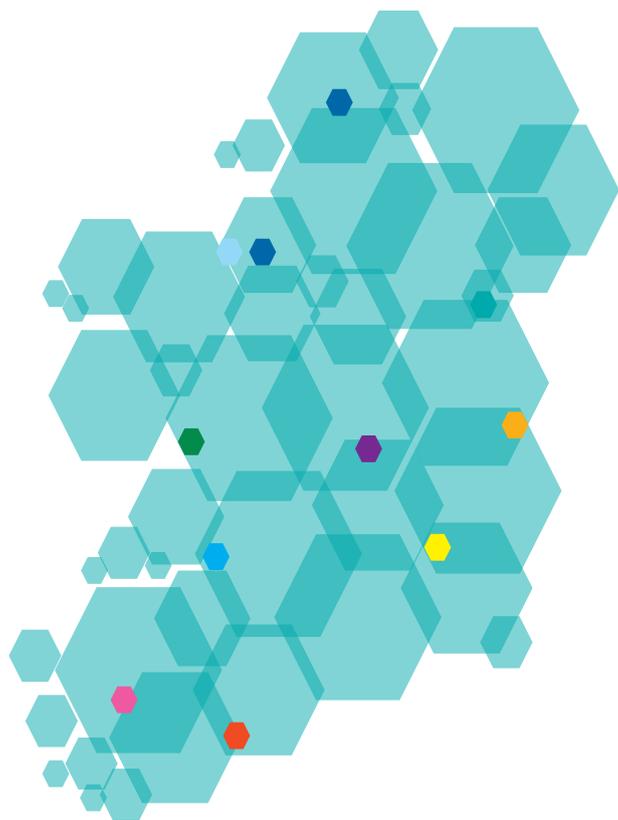
## Patron

### Rick O'Shea

2FM presenter Rick was diagnosed with epilepsy at the age of 16 and has been our charity Patron for nearly ten years. During this time, he has been active in raising awareness through media interviews, speaking at national and international epilepsy events and taking a lead role in many Epilepsy Ireland fundraising events. "It's a pleasure to help Epilepsy Ireland in shining a little light on the condition and why it shouldn't prevent you from leading a full, successful life", says Rick.



# Locations



## 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 The Charleville Ctr. Church Ave, Tullamore, Co. Offaly.  
Tel: 057 934 6790  
Email: mbassett@epilepsy.ie

## East

Covering: Dublin, Kildare & Wicklow  
Community Resource Officer: Ina Murphy/Carina Fitzgerald  
Epilepsy Ireland National Information Officer: Geraldine Dunne  
249 Crumlin Road, Dublin 12.  
Tel: 01 - 455 7500  
Email: Geraldine: gdunne@epilepsy.ie / Ina: imurphy@epilepsy.ie / Carina: cfitzgerald@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

## 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

## Online

Web: [epilepsy.ie](http://epilepsy.ie)  
Online Support Group: [support.epilepsy.ie](http://support.epilepsy.ie)  
Facebook: [facebook.com/epilepsy.ie](https://facebook.com/epilepsy.ie)  
Twitter: @epilepsyireland  
Youtube: [youtube.com/BrainwaveEpilepsy](https://youtube.com/BrainwaveEpilepsy)  
Instagram: [epilepsy\\_ireland](https://instagram.com/epilepsy_ireland)



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 BrainwaveEpilepsy  
 @epilepsyireland  
 epilepsy\_ireland

Charity Number: 20010553  
CHY Number: 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

