



Celebrating 50 years in 2016

Annual Report 2016

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 Strategic Aims

- Providing support and information services
- Communicating, raising awareness and advocating about epilepsy
- Providing training and education
- Undertaking and supporting epilepsy research
- Raising the necessary funds for our work
- Operating a stable, transparent and accountable organisation meeting best practice standards

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.



Epilepsy Ireland in 2016

Epilepsy Ireland supports and represents approximately 37,000 people with the condition through our offices in Dublin, Cork, Dundalk, Galway, Kerry, Kilkenny, Letterkenny, Limerick and Tullamore as well as our Training For Success course based in IT Sligo.

Service Users

2,129
new service users



Services



We dealt with
19,460
contacts representing a
10% increase
on 2015

National Conference

Our National Conference was attended by **250 members** from all areas around the country



Research

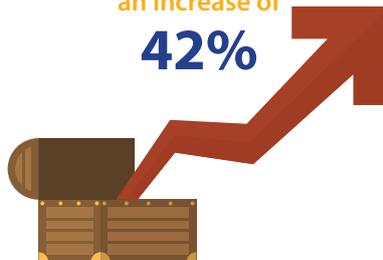


Since 2009, Epilepsy Ireland has invested over
€920,000
into nine Irish research projects

Training

1,571
people received training in 2016 as compared with the previous year's

1,102,
an increase of
42%



Communications



Over
13,000
followers
on Epilepsy Ireland's social media pages



www.facebook.com/epilepsy.ie [@epilepsyireland](https://twitter.com/epilepsyireland)
www.epilepsy.ie Email: info@epilepsy.ie

A Message from



Mark Dowdall
Chairman

I am delighted to present Epilepsy Ireland's Annual Report for 2016 which highlights our work and achievements as we endeavour to meet the needs of the 37,000 people with epilepsy and their families in Ireland.

2016 marked the 50th anniversary of the organisation, a landmark which allowed us to briefly look back over our history. The past 50 years has seen Epilepsy Ireland develop into an organisation that today

operates nationally providing a wide range of services and engaging in an increasing array of activities to promote our mission.

However, the year was not about looking back, but preparing for the future. In March, the board appointed Peter Murphy as the new Chief Executive, following the retirement of Mike Glynn, who had served Epilepsy Ireland for over 20 years. Peter had previously been part of the management team since 2008. In December, we published a new Strategic Plan for 2017-2021, renewing our vision and redefining our organisational objectives to best meet the needs of the 37,000 people with epilepsy.

Over the next five years, we aim to maintain existing services and activities, while also developing in new directions across the key areas of Support & Information, Training, Epilepsy Awareness, Advocacy and Research. This report outlines our work and our successes in 2016 under these same headings.

As we look to the future, we are particularly aware of the importance of maintaining a sustainable organisation, not just in terms of raising the funds needed to implement our plans, but also ensuring that the organisation maintains the highest standards of governance, quality and financial stability. These are issues that the board continued to focus on in 2016 and I want to thank my fellow voluntary board members and Officers for their continuing time, expertise and passion for our work. Thank you also to the members of our sub-committees including the Finance & Audit sub-committee and the Research Review board for their invaluable contributions.

I also want to highlight the dedication and professionalism of our excellent team of staff at head office and around the country, who continue to dedicate themselves to our vision of a society in which no person's life is limited by epilepsy. Finally, thank you to all our supporters who donated to the cause of epilepsy in 2016, whether financially or by investing their time and skills. While the charity employs a small staff team, our volunteers are our lifeblood who enable the work that you see highlighted here to take place.



Peter Murphy
Chief Executive

Epilepsy is a complex condition that affects 37,000 people in Ireland, including at least 10,000 people whose seizures cannot be controlled by available treatments and for whom the diagnosis can have significant and long-lasting consequences. It can affect a person's education, employment, psychological and social functioning and independent living. People with epilepsy must also navigate complex systems in areas like health, education and social protection and function in a world that often does not understand epilepsy and what living with the condition entails.

This is a simplistic account of living with a complex condition but it serves to outline why Epilepsy Ireland exists and also why we categorise our work into five key pillars – Support & Information; Training & Education; Awareness; Advocacy and Research. Within each of these areas, much progress was made in 2016.

There were 19,460 individual contacts with our services (an increase from 17,846 in 2015). We supported over 3,300 unique individuals, including over 2,000 new service users. In order to meet the increasing demand, additional resource hours were allocated (via fundraising) to two regions. Much of the increased demand is a result of the growth and success of programmes like the Living Well With Epilepsy programme and the STEPS programme, in addition to renewed efforts to reach out to groups such as teachers and teenagers with epilepsy.

Our training programme in Epilepsy Awareness & the Administration of Buccal Midazolam also continued to grow in 2016. 152 training days were provided (2015: 117) and 1571 people attended the courses, an increase of 42%. Our awareness-raising activities focused on campaigns such as International Epilepsy Day and the 'I See Beyond' campaign, a hugely successful joint initiative with the brain-injury charity Headway focusing on hidden disability. One new research project was funded in 2016 and the grant of over €140,000 to RCSI takes our investment since 2009 to over €900,000.

In 2016, we report a surplus of €61,000, which was the first surplus since 2012, and which would not have been possible was it not for a single large donation of over €140,000.

Implementing our new strategic plan will require an ongoing focus on raising funds and I want to thank all those who supported our work and our vision in 2016 and who continue to do so. Finally, I am indebted to our outstanding team here at Epilepsy Ireland who continue year on year to meet all expectations and reach new standards.

In my new role as CEO of Epilepsy Ireland, I very much look forward to working alongside our staff, board, volunteers, supporters and funders as we continue to work to meet the needs of people with epilepsy and their families.

What is Epilepsy?

Epilepsy affects more than 6 million people in Europe and about 50 million people worldwide. Research conducted by Epilepsy Ireland in 2009 found that there are almost 37,000 people over the age of five with epilepsy in Ireland. This makes epilepsy one of the most common neurological conditions but despite its prevalence it remains a much misunderstood and often stigmatised disability.

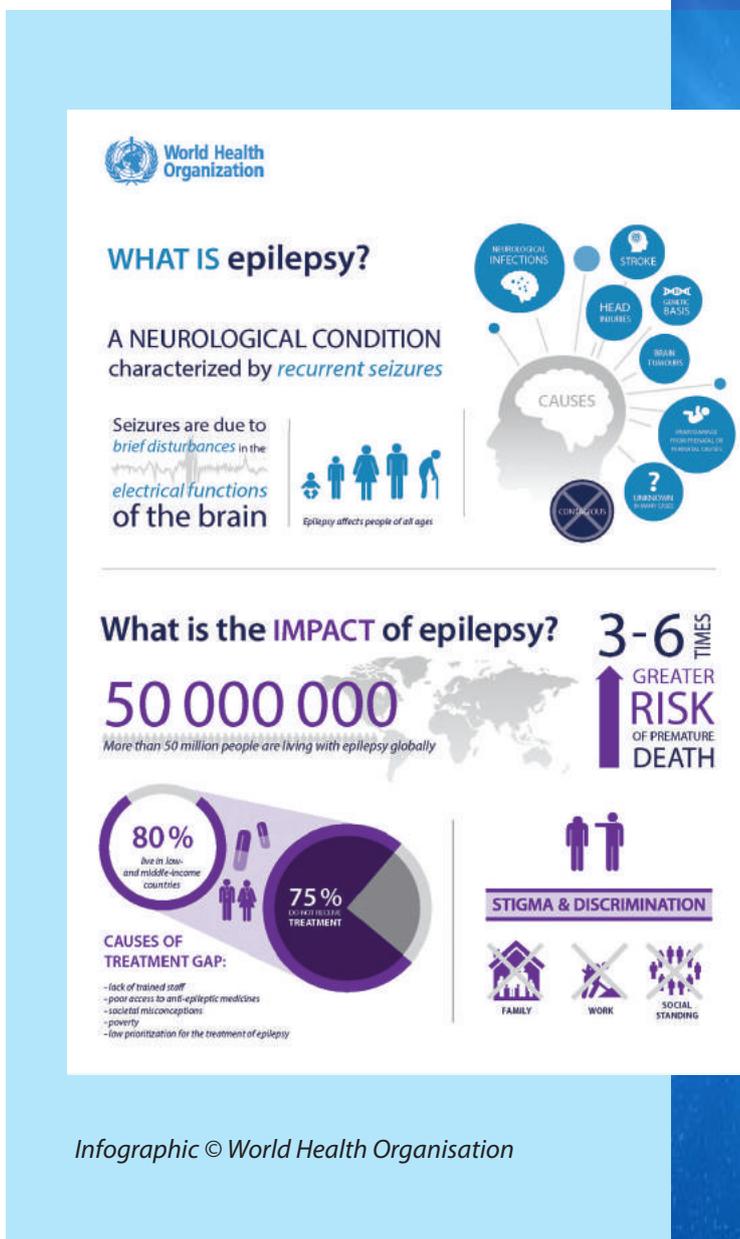
The term 'epilepsy' is used to describe a group of disorders, all of which are characterised by recurrent unprovoked seizures involving abnormal electrical activity in the brain. Seizures can take many forms depending on which part of the brain is affected. Partial seizures initially affect only one 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. All generalised seizures involve the loss of consciousness including the most well-known type of seizure, the tonic-clonic seizure. About 1 in every 20 people will have a seizure at some time during their lives. Epilepsy affects people of all ages, but is more prevalent in children, adolescents and the elderly. It is also more common in people with an intellectual disability. In about 60% of cases, no specific cause can be identified. In the remaining 40% of people, common causes include head injuries, strokes, brain infections, birth defects and genetic conditions like tuberous sclerosis.

Today, epilepsy is very much a treatable condition and thanks to advances in medications and surgical techniques, up to 70% of people can become seizure free. However, Epilepsy Ireland estimates that a minimum of 10,000 people still have uncontrolled epilepsy in Ireland. For this group in particular, the condition can be a source of major long-term, yet often hidden disability. A diagnosis will involve learning to cope with the physical impact of seizures, the medications prescribed to control them and impaired psychological and social functioning. Loss of one's driver's license, employment, education and relationship problems, loss of independence and low self-esteem are all potential challenges that may need to be overcome. In addition to the impact that epilepsy can have on the person living with the condition, it can also cause serious psychological, social and economic consequences for their families and carers.

While often erroneously thought of as benign, studies have shown that people with epilepsy have a higher risk of mortality than the general population. There are an estimated 130 epilepsy-related deaths in Ireland each year, about 40 of which are due to a poorly understood phenomenon called Sudden Unexpected Death in Epilepsy (SUDEP).

Epilepsy health services have historically been neglected in Ireland, a situation which has changed in recent years due to the work of the National Epilepsy Clinical Care Programme.

The Programme launched its Model Of Care in 2016 outlining a framework that 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 16 new Advanced Nurse Practitioner positions dedicated to epilepsy care.



Infographic © World Health Organisation

Support and Information

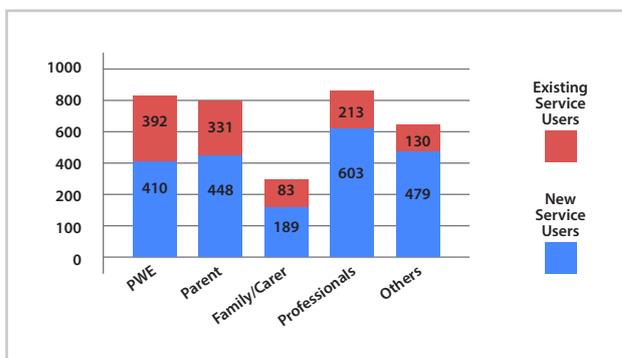
Each year our services team deal with many thousands of contacts in our individual work, group programmes, training courses and through our seminars and events. In 2016 we dealt with 19,460 contacts representing a 10% increase on 2015. Epilepsy Ireland's referrals from medical and community settings are increasing, and our services focused on those newly diagnosed and people seeking to improve their self-management (with our STEPS and Parents STEPS programmes). In 2016, we continued to add new and innovative services, offering activities for children with epilepsy (e.g. our Puppet Workshops) and seminars for teachers. Additionally we met the needs of healthcare and teaching professionals with talks and seminars, as well as providing a range of services for those affected by epilepsy.

One-to-One Services

Our one-to-one work in 2016 was managed by our expert team of Community Resource Officers, who dealt with 8,577 contacts. We worked with 3,302 individual service users of which, new referrals accounted for 2,129 individuals.

As a community based service, Epilepsy Ireland ensures that we reach people close to their homes, via our community and hospital outreach work. These sessions offer individual support, advice and information about living with the condition and are a crucial component of our service.

Number of Unique individuals using our one-to-one services in 2016



Supporting people with Self-Management Educational Tools and Programmes

In recent years, we introduced a number of self-management programmes and tools. Our Living Well With Epilepsy toolkit and education sessions have been increasingly successful with 397 toolkits delivered nationally in 2016. Since the launch of the toolkit programme in 2014 we have delivered 1,248 support sessions nationally to newly diagnosed adults and parents of children who have been newly diagnosed.

In 2016, our self-management services also continued successfully. We ran 11 STEPS programmes with 70 attendees for people with epilepsy seeking to learn about

their condition and life management as well as eight Parents STEPS Programmes with 56 attendees. People attending our STEPS programmes consistently report positive outcomes across a range of knowledge, skills and wellbeing parameters. The purpose of STEPS is for people to learn about managing their epilepsy and broader health issues as well as meeting other people with the condition to share experiences.

Epilepsy Specialist Nurse Services

Our Epilepsy Specialist Nurse (ESN) continued to deliver our helpline on Monday mornings, and provide support services across the country for adults with epilepsy through events and outreaches. The ESN operates clinics in a number of Dublin hospitals and provides specialised support to women in the capital's maternity hospitals. In 2016 in total the ESN dealt with over 1,000 contacts.

Transition Nurse Specialised Services

During 2016 we were successful in the delivery of a new programme in conjunction with Temple Street National Children's Hospital to create and develop a new pathway for transitional services for teenagers with epilepsy moving from children's to adult's services. Epilepsy Ireland were delighted to recruit a new Epilepsy Specialist Nurse for Transitional Care who provides a helpline service on Monday afternoons for parents and teenagers. Additionally, she is creating best practice responses and procedures on transitional care within the Dublin Adult and Paediatric Hospitals.

Regional Statistics

Our services could not be delivered without the dedication of the team working in our regional offices. During 2016, 19,460 contacts were facilitated by our 11 regional officers and our Information Officer, Training Manager and Epilepsy Specialist Nurse. The breakdown of contacts made by region is as follows:

2016	one-to-one	group	total contacts
North-West	612	579	1191
Mid-West	1028	574	1602
South (Killarney)	689	730	1419
South (Cork)	979	1865	2844
South - East	285	716	1001
Midlands	405	492	897
North - East	589	706	1295
West	839	1007	1846
East	3151	4214	7365
Total	8577	10883	19460

Events and Activities for children and families

Our family fun events are an important way for parents and children to meet and support each other. They provide important social activities for kids and are always well received by the families. Our main family event was held in Tayto Park in July with over 100 attendees.



The Couch family had a great time at the Family Fun Day hosted by Epilepsy Ireland in Tayto Park. They were even lucky enough to meet Mr Tayto himself!

New in 2016 - Puppet Workshops for children

In 2016, Epilepsy Ireland ran six workshops for children with epilepsy in Dublin, Cork and Galway, catering for children aged 4 – 7 and 8 -11 years old. These were run in partnership with Helium Arts, a creative organisation for children and were very successful with 56 children attending. The workshops were evaluated and proved to be an exceptional tool for helping children to talk about and be comfortable with their condition. Some comments included:

"It was lovely to hear the puppet at the start talk about feeling unwell as it had a seizure in the morning. Good to hear epilepsy being talked about" Mum, Galway

"The puppet had epilepsy and it was the first time my child got to say the word, and in such a fun way, it took the fear out of it for her" Mum, Cork



Children making puppets

Support Groups and Online Support Groups

We continued to run groups in various regions for parents and adults with epilepsy. 46 on-site groups were run with 182 people attending. Our online support group ran 46 groups with 203 attendees.

National Conference

Each year, Epilepsy Ireland organises a conference as an opportunity for our service users to learn more about the condition as well as getting a chance to meet other people in the epilepsy community and share their experiences. In 2016, as it was the 50th anniversary of the organisation, we ran a special extended two day conference held in the Alexander Hotel, Dublin which was titled 'Latest Developments in Epilepsy'. The event was attended by 250 service users across the country and had a very distinguished panel of twelve local and international speakers who discussed issues such as childrens' epilepsy, medicinal cannabis for epilepsy and the ketogenic diet (see page 8 for more).

Seminars for Teachers

Epilepsy Ireland reached a further 3,890 people through our school and community awareness work in 2016. We delivered 192 talks in total to both classrooms and community organisations. In addition, we developed and ran Teachers Seminars in many locations during 2016, a new approach to the school education work. In total, we had 17 Teachers seminars with 394 teachers attending.

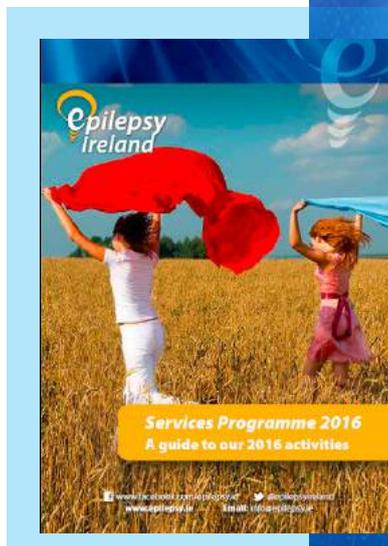
Other Events and Programmes

Our key awareness campaigns for International Epilepsy Day, National Epilepsy Week and Brain Awareness Week included activities in our regions. In 2016, a selection of our activities included:

- Epilepsy Open Talks in Tullamore, Sligo, Dundalk, Kilkenny, Cork
- Epilepsy Information Stands in Kerry, Cork, Dublin, Galway, Drogheda, Athlone, Waterford and Letterkenny
- Health & Wellness day, Letterkenny
- Epilepsy & Autism information day, Galway
- Parents and children's days in Killarney
- Women and Epilepsy talk, Limerick

NEW RESOURCE - Services Programme

In 2016, we produced a new resource with all our services activities located in one booklet (pictured right). This allows us to highlight our full range of dates, locations from the start of the year and has been a well utilised resource for organising as well as promoting our services.



Awareness and Advocacy

International Epilepsy Day

To mark International Epilepsy Day and to highlight new research and developments in the field of epilepsy, Epilepsy Ireland and the RCSI joined forces on February 8th to organise the 2nd Epilepsy Research Explained public seminar at RCSI in Dublin. A full house attended and heard keynote speaker Dr Tracy Dixon-Salazar from the CURE organisation in the US discuss her own inspirational personal story and explain how genetic testing and personalised medicine may well hold the key to finding epilepsy cures in the future. Richard Corbridge, HSE's Chief Information Officer, discussed recent and upcoming e-health developments in Ireland including the HSE's Epilepsy Lighthouse Project. Other speakers included cANP Yvonne Owen from Beaumont hospital, Dr Veronica Lambert from DCU and Trinity College researchers Prof Agnes Higgins and Dr Naomi Elliott.

Lighthouse project

Also on International Epilepsy Day, the Epilepsy Lighthouse project was launched. This project is being delivered by eHealth Ireland which is part of the HSE, in collaboration with RCSI, Epilepsy Ireland and Beaumont Hospital. It will build on the success of the existing epilepsy electronic patient record (EPR) and aims to deliver an efficient, personalised pathway for managing epilepsy using technology-based solutions.

Investment in the project in 2016 focused on three main areas: genomic sequencing of a cohort of patients with epilepsy and intellectual disability to determine the impact on care; developing an interactive patient portal to the EPR; improving clinical data analysis to better inform future care.

Epilepsy Ireland – 50th anniversary

As mentioned on page 7, Epilepsy Ireland held a two-day National Epilepsy Conference with twelve nationally and internationally renowned speakers in the Alexander Hotel, Dublin. The conference included a number of world class academics and medical experts, including Dr. David Goldstein, Director of Institute for Genomic Medicine in Columbia University. For the first time Volunteer Awards were given to Bernard Hughes, Theresa O'Brien and Ann Kinahan for their many years of loyal volunteering for Epilepsy Ireland.



Prof Norman Delanty, Dr JP Leech, Dr David Goldstein and Dr Gavin Quigley at the National Epilepsy Conference

Ahead of the event Epilepsy Ireland CEO Peter Murphy and Charity Patron Rick O'Shea spoke on RTE Radio One and Ireland AM about the condition and the history of the charity from its genesis in 1966 at a meeting in the Royal College of Physicians Of Ireland. Epilepsy News also featured two articles reflecting on the history and achievements of the organisation.

#iseebeyond

In February, Epilepsy Ireland and Headway, the acquired brain injury charity, joined forces to launch a new public awareness campaign called I See Beyond (www.iseebeyond.ie). The campaign focuses on raising awareness of hidden disabilities and the challenges these conditions can present in day to day life. It was officially launched by the then Minister For Health, Leo Varadkar TD. One of the stories being told as part of the campaign was that of Katie Cooke, who lives with multiple seizures each day, and who achieved her goal of completing the Dublin marathon. Katie's story received a hugely positive response and she has already proven to be an inspiration to many. Other videos in the campaign focus on the misunderstanding of complex partial seizures and on epilepsy stigma. All six of the videos reflect real stories and illustrate how all might not be how it seems in the day to day life of the person living with epilepsy or a brain injury. They aim to challenge those watching to think twice about what the person might be going through and to be more compassionate and understanding.

Amárach research showed that the campaign helped raise awareness since it was launched. For example, there have been significant increases in the number of people who feel comfortable telling their employer if they had a hidden disability and also the percentage of employees who felt their workplace is more knowledgeable about the issue.

Online and social media

Epilepsy Ireland's website received over 81,000 visits during 2016 with 54,000 unique visitors. In 2016 our Facebook 'likes' increased from 9,000 to over 10,000 while our Twitter followers also grew past 3,000. As the power of images on social media increases, the Epilepsy Ireland Instagram page also moved past the 1,000 mark.



Taoiseach Leo Varadkar, El Patron Rick O'Shea and Headway Volunteer, Yvonne Kelly

International SUDEP Awareness Day

To mark International SUDEP Awareness Day (October 23rd) new data from the International Epilepsy Deaths Register, which includes the recently established Epilepsy Deaths Register for Ireland, revealed that over half of the families who have lost a loved one to epilepsy were not aware that epilepsy can be fatal.

International SUDEP Awareness Day is dedicated to raising awareness of Sudden Unexpected Death in Epilepsy and other epilepsy deaths across the world. SUDEP is when a person with epilepsy dies suddenly and prematurely and no other cause of death is found. Epilepsy Ireland used the day to reach out to members, service users and the public to inform about SUDEP and also managing epilepsy risk.

Reasonable Accommodations at the Certificate Examinations (RACE) scheme

Epilepsy Ireland welcomed the changes to the Reasonable Accommodations at the Certificate Examinations (RACE) scheme announced by the State Examinations Commission (SEC) in 2016 but believes the reforms fail to address the barriers faced by students with epilepsy. During 2016 Epilepsy Ireland continued to campaign on the issue. Epilepsy Ireland estimates that each year there will be 500-600 students with the condition sitting the Leaving Cert exams. We feel it is necessary to expand on the RACE scheme to include a range of practices which are commonplace for students with epilepsy abroad:

- Repeat Leaving Cert exams for students who experience medical emergencies such as seizures
- An option to sit exams over two combined years
- An option to space out exams over a greater time period

Epilepsy and Pregnancy

Epilepsy Ireland continued to campaign on the issue of epilepsy drugs in 2016, particularly on the use and risk of sodium valproate in pregnancy. We estimate that up to 400 children could have been born in Ireland with a range of physical and developmental disabilities following in-utero exposure to the drug over the past four decades.

Ireland collaborated 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 (OACS) – a collective group known as the FACS (Fetal Anti-Convulsant Syndrome) Forum Ireland.

In 2016 the Forum campaigned for greater awareness and communication between mothers with epilepsy and health professionals to help reduce risk. The Forum also engaged with the HSE, the Health Products Regulatory Authority, The Epilepsy and Pregnancy Register and the National Clinical Care Programme for Epilepsy regarding warnings on valproate boxes as well as more detailed information on the drug for patients and professionals. Epilepsy Ireland was also involved with the HSE on producing information materials and promoting the need for greater research on FACS. We also conducted surveys of women with epilepsy taking valproate and discovered while communications were improving that only 56% say doctors have discussed risk with them.

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 and the Medical Research Charities Group.

Epilepsy Ireland is also represented on the Clinical Advisory Group of the HSE's National Epilepsy Care Programme.

Strategic Plan 2017-2021

Officially launched by Ireland Rugby Head Coach Joe Schmidt in the Royal College of Physicians of Ireland, the Plan was developed over an 18-month period with input from a wide range of stakeholders, including Epilepsy Ireland members, service users, volunteers, health professionals and staff.

We have identified six Strategic Aims which together form the framework for the Plan. These are: Providing support and information services; Communicating, raising awareness and advocating about epilepsy; Providing training and education; Undertaking and supporting epilepsy research; Raising the necessary funds for our work; Operating a stable, transparent and accountable organisation meeting best practice standards.

Built into the six Strategic Aims are 21 Strategic Objectives that we will endeavour to meet during the five year period of the plan, subject to suitable funding streams becoming available and being maintained.



Epilepsy Ireland, CEO Peter Murphy, Ireland Rugby Head Coach Joe Schmidt, Epilepsy Ireland Chairman Mark Dowdall and Epilepsy Ireland Patron Rick O'Shea

Training and Education

Health Professional Training

For over six years Epilepsy Ireland has offered a training programme in epilepsy awareness and the administration of Buccal Midazolam (BM) to health professionals. The health initiative is unique in Ireland and follows the Joint Epilepsy Council guidelines on training standards for the administration of BM. The purpose of the programme is for participants to gain a greater awareness of epilepsy in general, understand the role of emergency rescue medication and receive tuition in correct use of BM.

2016 witnessed an increase in demand for training days. 152 training sessions were delivered nationwide, compared with the 117 in 2015. In total 1,571 people received the training in 2016 as compared with the previous year's 1,102, an increase of 42%. At the end of 2016, Epilepsy Ireland had presented a total of 508 training days, providing this important training to 5,224 people since 2010.

Feedback of the programme and in particular the extent to which participants awareness has improved or increased as a result of the course show that an average of 96% strongly agree/ agree that the programme has improved their ability to deal with the emergency response involving the administration of BM.

Training For Success

An analysis of data from 1998 to 2015 showed encouraging statistics on Training For Success (TFS), Epilepsy Ireland's pre-employment training programme, based in Institute of Technology, Sligo. Since its inception in 1998, 85% of graduates have found a job or upskilled after they completed the programme. Over 250 students have graduated since the course began and it remains the only programme of its kind in Europe. TFS continues to offer a career path for young people with epilepsy who, because of their condition, have experienced challenges in both education and the workplace.

The outcome for the 2015-2016 and 2016-2017 academic years is that 19 students will have successfully completed the programme. TFS continues its original aim of developing practical, interpersonal and communication skills to help foster confidence.



Attendees with their certs of attendance at a BM training day in Dundalk



Michael Scanlon following his recent graduation from TFS

The programme is funded by the Mayo, Sligo and Leitrim Education and Training Board and offers FETAC Level 4 Certification over a number of modules.

Schools Education Programme

2016 was another popular year for the Schools Education Programme, which aims to raise awareness of epilepsy for those with the responsibility for ensuring a safe education environment. In 2016 2,820 teachers, SNAs and students attended 125 Epilepsy Awareness presentations nationwide.

Epilepsy Awareness

Epilepsy Ireland continued to provide awareness presentations to other organisations which include employers, training organisations and support organisations. A total of 67 presentations were delivered nationwide in 2016 with 1,041 people in attendance.



TFS students on a trip to the Sligo Races

Research

New Research Funding

In 2016, Epilepsy Ireland approved funding for one new study under our Research Funding Scheme. Prof David Henshall from RCSI was awarded €144,484 for his three-year study entitled "MicroRNAs in the mechanism of ketogenic diet therapies and as biomarkers in paediatric epilepsy". The study is co-funded by Epilepsy Ireland and the Health Research Board. The research aims to find out more about the ketogenic diet, a special diet that helps to control seizures in children.

Since 2009, Epilepsy Ireland has now invested over €920,000 into nine Irish research projects. This funding has led to important discoveries in gene activity; progressed understanding of epilepsy deaths; assisted researchers in attracting larger EU funding for continued research; influenced how health services are delivered and generated valuable information to assist people with epilepsy in their daily lives.

Ongoing Research Projects

The following projects were active during 2016:

- **MicroRNA Biofluid Profiles as Molecular Diagnostics for Response to the Antiepileptic Drug Levetiracetam¹**

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 life²**

Prof Agnes Higgins from Trinity College is assessing the role, impact and cost-effectiveness of the Epilepsy Specialist Nurse role in Ireland. Work had almost been completed by the end of 2016 and the launch of the final report was being planned for February 2017.

- **Demystify the veil of secrecy: a mixed method inquiry of parent-child dialogue about epilepsy and its associated stigma²**

Dr Veronica Lambert from DCU is examining the differences in perceptions and communications that exist between families around discussing and disclosing epilepsy. One very practical outcome which we hope will leave a lasting legacy was the development of a Community of Practice of Irish health professionals with a shared passion for resolving the challenges faced by children and parents in communicating about epilepsy. The team also published findings in *Epilepsy & Behaviour* in 2016.

- **The collaborative development of an evidence-based educational resource for self-disclosure strategies for people with epilepsy²**

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. The study is due to finish in 2017, and we look forward to the publication of important information resources including a website and an app to assist people in disclosing their epilepsy.

Epilepsy Death Register for Ireland

In 2015, Epilepsy Ireland and UK charity SUDEP Action launched the Epilepsy Deaths Register for Ireland (EDRI) to learn more about epilepsy mortality, drive research into the issue and to gather data to assist those at the most risk of SUDEP. In 2016, data was released from the International Epilepsy Deaths Register which includes the new Irish Register. It was the first time that Irish figures had been included alongside information from the British and American Registers.



Dr Tracy Dixon Salazar gave an inspiring presentation at the Epilepsy Research Explained event, organised by Epilepsy Ireland and the RCSI to highlight the latest developments in Irish and International research into epilepsy

Non-financial support

During the year, Epilepsy Ireland provided non-financial assistance to a range of epilepsy studies, including:

- The EPIC study, a collaboration by HSE, RCSI and Maynooth University aiming to understand how epilepsy services in Ireland can become more patient-centred.
- Dr Neil Powell's work at Queens University investigating if untrained pet dogs can predict seizures
- A study on epilepsy terminology by Liverpool University
- Irish aspects of the European Study on the Burden and Care of Epilepsy (ESBACE) at UCD
- A UCD study on the role of stress in epilepsy.
- A UCC study on medication adherence in young adults with epilepsy

We are also partnering on the HSE's pioneering Epilepsy Lighthouse Project which aims to develop e-health in epilepsy, through the expansion of the Epilepsy Electronic Patient Record and study of the benefits of genomic testing.



Epilepsy Ireland awarded a grant of €144,484 to Prof David Henshall, RCSI for his study on the ketogenic diet

1. Funded jointly between Epilepsy Ireland and the Irish Research Council under the Enterprise Partnership Scheme
2. Funded jointly between Epilepsy Ireland and the Health Research Board under the MRCG Joint Funding Scheme

Fundraising

Epilepsy Ireland strives to improve the health and quality of life for people with epilepsy and we rely on voluntary contributions to fund much of our work. All fundraising no matter how large or small has a worthwhile impact on our ability to deliver services and programmes.

Our Fundraising includes annual campaigns such as Rose appeals, the members' raffle, text-to-donate, Women's Mini Marathon and the Christmas appeal. Church-gate collections continue to be an important source of funding with volunteers helping across the country.

Individual donations, corporate support and event fundraising again provided significant funds during the calendar year. We partnered with Dublin Chamber of Commerce who chose Epilepsy Ireland as one of their chosen charities for 2016/2017. Income from fundraising in 2016 was €705,000, an increase of 28% from 2015.

Volunteer-led events such as Saddle Up For Epilepsy also continue to be an integral part of our fundraising. Hundreds of people all over the country yet again supported Epilepsy Ireland by participating in or by organising their own events. We extend our deepest gratitude to all our fundraising volunteers and donors who supported our work in 2016 and we are delighted to highlight some examples here.

To see more photos, make sure to follow Epilepsy Ireland on Facebook, Twitter and Instagram where we post great photos on a regular basis.

In 2016 Epilepsy Ireland continued to operate to the highest standards of transparency and accountability in accordance with best governance practice. In July 2017, we signed up to the Statement of Guiding Principles for Fundraising. For more information go to <http://www.epilepsy.ie/index.cfm/spKey/about.governance.html>



Ross and Joey O'Dea presenting a €20,000 cheque to Epilepsy Ireland CEO after they raised money through a beard growing challenge



Cyclists pictured in Mayo for the 2016 Saddle Up For Epilepsy where over €24,000 was raised



Dublin Chamber of Commerce raised over €33,000 for Epilepsy Ireland and Father Peter McVerry Trust. Dicom Managing Director Greg Clarke; Dublin Chamber of Commerce CEO Mary Rose Burke; Epilepsy Ireland Communications Officer Conor and Father Peter McVerry National Director Of Services, Brian Friel



Graeme McQueen, Public Relations Manager with Dublin Chamber of Commerce, Lorcan Colclough, Audit & Assurance Partner with Mazars Ireland, Stephen O'Leary, Media Analyst with Olytico and Derry Gray, Partner with BDO at the Chamber Golf Day 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
- Leave Epilepsy Ireland a legacy gift with mylegacy.ie

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.

2016 Financial Report

In 2016, Epilepsy Ireland reported net incoming resources of €61,166 (2015: net outgoing resources €214,910), which surpassed budgeted expectations. The figure includes an unforeseen donation of €141,319 received during the year, and is inclusive of expenditure on strategic projects such as research grants and funding for the new Transition Epilepsy Nurse Specialist position.

In order to provide more detailed information on the performance and financial position of the charity, Epilepsy Ireland prepares our financial statements in accordance with the Charities Statement of Recommended Practice (SORP 2015) and FRS102. The full financial statements are available from the Publications section of epilepsy.ie or from info@epilepsy.ie.

Statement of Financial Activities for the financial year ended 31 December 2016

	Restricted Funds 2016	Unrestricted Funds 2016	Total Funds 2016	Total Funds 2015
	€	€	€	€
Income From:				
Donations & Legacies	-	484,080	484,080	310,742
Charitable Activities	912,730	128,951	1,041,681	1,030,944
Other Trading Activities	85,246	133,713	218,959	254,662
Investment Income	-	823	823	21,873
Other Income	-	18,732	18,732	3,630
Total Income	997,976	766,299	1,764,275	1,621,851
Expenditure On:				
Charitable Activities	934,243	330,906	1,265,149	1,334,323
Raising Funds	48,590	207,535	256,125	309,563
Other	156,185	15,156	171,341	221,657
Total Expenditure	1,139,018	553,597	1,692,615	1,865,543
Net Income/ (Expenditure)	(141,042)	212,702	71,660	(243,692)
Unrealised gain on quoted investments	-	(10,494)	(10,494)	28,782
Taxation	-	-	-	-
Transfers between funds	155,753	(155,753)	-	-
Net Movement in Funds for financial year	14,711	46,455	61,166	(214,910)
Total funds brought forward 1/1/2016	2,658	1,523,411	1,526,069	1,740,979
Total funds carried forward 31/12/2016	17,369	1,569,866	1,587,235	1,526,069

Balance Sheet as at 31 December 2016

	2016	2015
	€	€
Fixed Assets		
Tangible Assets	150,830	163,690
Financial Assets	223,748	234,242
	374,578	397,932
Current Assets		
Stock	3,935	7,718
Debtors	42,977	42,636
Cash at Bank and in hand	1,455,703	1,367,534
	1,502,615	1,417,888
Current Liabilities		
Creditors (Amounts falling due within one year)	(289,958)	(289,751)
Net Current Assets	1,212,657	1,128,137
Total Net Assets	1,587,235	1,526,069
Funds of the Charity		
Restricted funds	17,369	2,658
Unrestricted funds	700,826	596,745
Designated funds	869,040	926,666
Total Funds	1,587,235	1,526,069

Our People

Board of Directors

(as at 31 December 2016)

Mr Mark Dowdall (Chairman)
Mr Vincent Savino (Vice-Chairman)
Mr Michael McLoughlin (Treasurer)
Ms Cathy Grieve (Secretary)
Mrs Tessa Dagge
Prof Norman Delanty
Mr Derry Gray
Dr Michael Hennessy
Dr Christine Linehan
Dr Bryan Lynch
Dr Brian McNamara
Ms Norma Mitchell
Ms Carol Saarsteiner
Dr Joyce Senior
Dr Brian Sweeney
Dr David Webb

Finance & Audit Committee

Mr Michael Sheehy (Chairman)
Mrs Tessa Dagge
Mr Mark Dowdall
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

(as at 31 December 2016)

Chief Executive

Peter Murphy

Services

Director of Services

Wendy Crampton

National Information Officer

Geraldine Dunne

Community Resource Officers:

Ina Murphy (Eastern Region)
Carina Fitzgerald (Eastern Region)
Cliona Molloy (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)
Mary Baker (North East Region)

Community Epilepsy Specialist Nurse

Sinead Murphy (Beaumont Hospital)
Yvonne Owen (Transition Nurse)

Fundraising & Administration

Fundraising & Communications Manager

Michael Carty

Communications Officer

Conor Culkin

Membership & Fundraising Officer

Ashley Butler

Churchgate Collections

Barbara Doyle

Fundraising Assistants

John Ryan
Judith Kelleher

Training & Communications Manager

Paul Sharkey

Training For Success Manager

Honor Broderick

Training For Success Facilitator

Maire Tansey

Finance Manager

Siobhan Carter

Executive Assistant

Cathy Powell

Receptionists

Madge Geoghegan
Joan McDermott

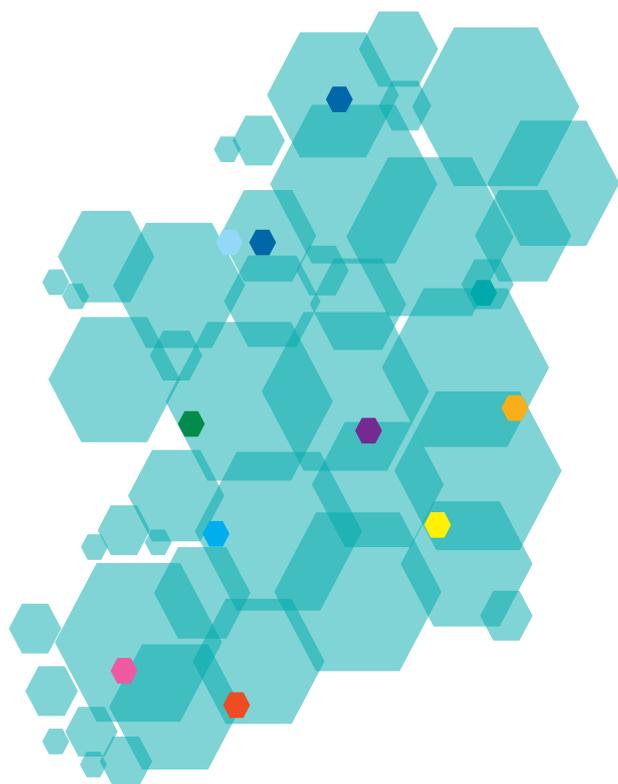
Patron

Rick O'Shea

Broadcaster Rick was diagnosed with epilepsy at the age of 16. In March 2006, he answered Epilepsy Ireland's call to become the Patron of the charity. For over 11 years Rick has been active in helping to raise awareness of the condition, taking part in dozens of media interviews, speaking at national and international epilepsy events and taking a lead role in numerous Epilepsy Ireland fundraising events. "It is an honour to be able to help Epilepsy Ireland in shedding a little light on epilepsy and why it doesn't have to stop you from leading a full, successful life", says Rick.



Locations



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: Loretta Kennedy
35 Washington Street, Cork.
Tel: 021 - 427 4774
Email: lkennedy@epilepsy.ie (Loretta)
njones@epilepsy.ie (Niamh)

South East

Covering: Kilkenny, Wexford, Carlow, Waterford & Tipperary South
Community Resource Officer: Miriam Gray
C/o HSE, St. Joseph's, Waterford Rd, Kilkenny.
Tel: 056 778 9904
Email: mgray@epilepsy.ie

Midlands

Covering: Offaly, Longford, Laois & Westmeath
Community Resource Officer: Cliona Molloy
c/o The Charleville Ctr. Church Ave, Tullamore, Co. Offaly.
Tel: 057 934 6790
Email: cmolloy@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: Mary Baker
Unit 1a, Partnership Court, Park St, Dundalk, Co. Louth.
Tel: 042 - 933 7585
Email: mbaker@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 and Transitional 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: Veronica Bon
Social Service Centre, Henry St., Limerick.
Tel: 061 313 773
Email: vbon@epilepsy.ie

Online

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

