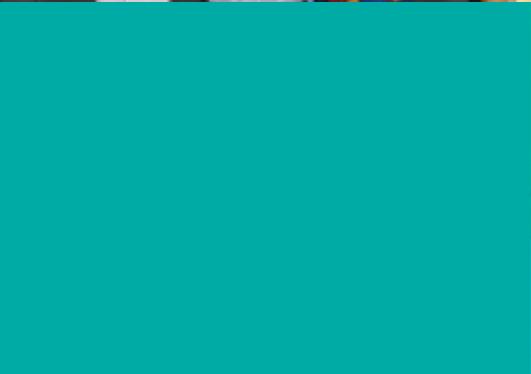
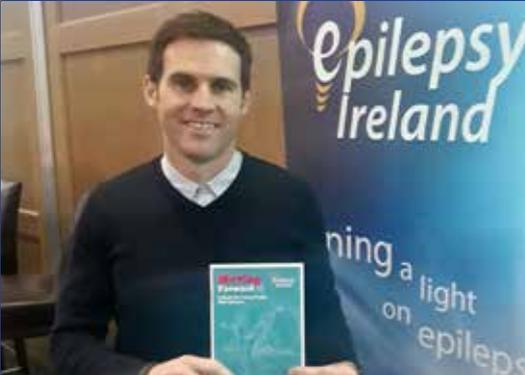




2018



ANNUAL REPORT



EPILEPSY IRELAND IN 2018

Epilepsy Ireland supports and represents the 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 at IT Sligo.

Service Users

2,449
new service users
compared to 2,132
in 2017



Services



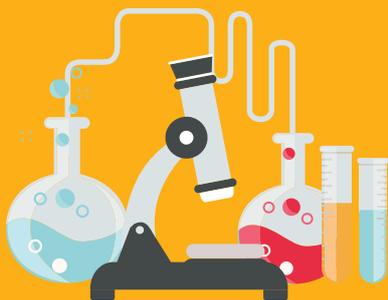
There were
19,447
individual contacts
in 2018

National Conference

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



Research



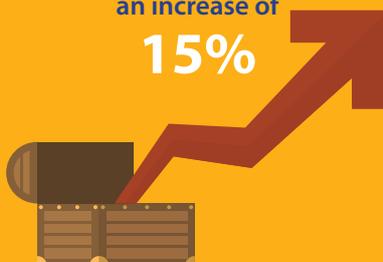
Since 2009, Epilepsy Ireland
has invested over

€1 million
into 13 Irish research
projects

Training

2,146
people received training in
2017 as compared with the
previous year's

1,863,
an increase of
15%



Communications



Epilepsy Ireland's
social media channels
increased to nearly

20,000
followers.

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

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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**

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We confirm that Epilepsy Ireland complies with The Governance Code for the Community, Voluntary and Charitable Sector in Ireland. As a charity seeking donations from the public, we aim to comply with the Guidelines for Charitable Organisations on Fundraising from the Public.



Best Practice in Transparency and Accountability

A MESSAGE FROM

**Mark Dowdall,
Chairman**



I am delighted to welcome you to this report on Epilepsy Ireland's services and activities in 2018. I hope you will see that it was a productive and successful year across the different areas of our work that exist to support and represent the 37,000 people with epilepsy in Ireland.

Important objectives for Epilepsy Ireland are to ensure that our work is effective, that we utilise all our resources efficiently and that we operate in accordance with best-practice governance standards for charities. With this in mind, in 2018 we became one of only circa 70 Irish charities who have attained the 'Triple Lock' standard awarded by Charities Institute Ireland (you can read more about this on page 13).

In addition, we attained - for the second time - the Practical Quality Assurance System for Small Organisations (PQASSO) quality mark, the leading quality assurance system developed for the non-profit sector. While some high profile negative events of recent years have damaged public confidence in the voluntary sector, I firmly believe that with these standards in place all our stakeholders can have confidence in Epilepsy Ireland, not just in the work we do but also in how we do it.

None of the achievements outlined in this report would have been possible without the dedication of the staff, volunteers and supporters who work so hard to make a difference to the lives of people affected by epilepsy in Ireland. I would like to thank everybody around the country who has supported our work in any way, whether by making donations, engaging in fundraising or raising awareness about epilepsy and Epilepsy Ireland. This also includes my fellow board and sub-committee members who voluntarily give of their time and expertise to guide, govern and support the work of the organisation.

While we anticipate some challenging times ahead, especially in resourcing all the new ideas and initiatives we have planned in our ambitious Strategic Plan 2017-2021, we will never lose sight of our vision which is of a society where no person's life is limited by epilepsy. As directors of the only national epilepsy support and representative organisation, we take our responsibilities to our members, service users and the general public very seriously. Through our services, training, research, advocacy and awareness-raising work, supported by a strong governance framework, we will continue to strive towards realising this vision in 2019 and years to come. We appreciate your continued support towards achieving this goal.



**Peter Murphy,
CEO**

Thank you for taking the time to read about the work of Epilepsy Ireland in 2018. There are many successes and achievements to celebrate at the end of another busy and challenging, yet very exciting year.

Demand for our key services remained high after several years of growth. It was notable that we worked with a greater number of new service users than in previous years while feedback also indicates that we are increasingly working on more complex support and advocacy issues than ever before.

Our training for health and allied health professionals increased by 15% in 2018 with over 2,000 trainees completing the one-day programme. Our outreach services, including our work with schools was also extremely busy, as were our self-management and educational programmes.

We also relaunched the epilepsy.ie website, developed a range of new information resources, revamped our membership offering, ran successful campaigns for International Epilepsy Day and Purple Day, and funded two exciting new epilepsy research projects. We have now invested over €1m in Irish research over the past decade. Our advocacy agenda was dominated by the sodium valproate campaign which resulted in the implementation of important risk reduction measures for women with epilepsy.

It was a very positive year financially with our income exceeding €2m for the first time. This was mainly due to a small number of one-off donations including an incredible €160,000 received through the Permanent TSB charity of the year partnership. Thank you to all the staff of PTSB as well as all our members and supporters across the country for the donations and thousands of volunteering hours that went in to supporting our work. We were in a strong position to meet significant HSE shortfalls, something which is extremely welcome in a competitive fundraising environment and an era of static government funding.

We have an exceptional staff team at Epilepsy Ireland. From our services and training team who have redoubled their efforts in recent years to meet growing demands to the fundraising and administration personnel who diligently support our front-line work, there is a great passion and enthusiasm for what we do at the charity. Many of our team are part-time and all operate within challenging budgetary constraints in fulfilling their roles. I want to thank all our staff wholeheartedly for their continuing support as we look forward to 2019 and beyond.

WHAT IS EPILEPSY?

Derived from the Greek 'epilepsia' which means 'to seize', 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.

Epilepsy affects an estimated 50 million people worldwide. In Ireland, there are 37,000 people (over the age of five) living with epilepsy and there are an estimated 1,300 – 2,100 new diagnoses each year. It is therefore one of the most common neurological conditions.

Seizures can take many forms depending on which part of the brain is affected. For example, generalised seizures such as tonic-clonic seizures or absence seizures involve networks on both sides of the brain at onset and involve loss of consciousness. Focal (partial) seizures initially affect only one part of the brain and depending on the area, may result in symptoms such as twitching, jerking, automatic movements or changes in sensation, emotions or thinking.

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 acquired causes include head injury, stroke, brain infections and birth defects.

Genetics also plays an important role. Some types of epilepsy are due to a single gene defect and over 200 genes have now been implicated in epilepsy. More commonly, epilepsy is associated with interactions between multiple genes and environmental factors.

Epilepsy is very much a treatable condition and thanks to advances in medications, surgical techniques and dietary treatments such as the ketogenic diet, up to 70% of people can become seizure-free. However, there are still 10,000-15,000 people with uncontrolled epilepsy in Ireland today.

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 often significant medication side-effects and impaired psychological functioning. Epilepsy can affect the person's employment, education and relationships and can lead to the loss of independence and self-esteem. Stigma is also commonly experienced by many people and public misunderstanding can occasionally lead to discrimination. Epilepsy can also have serious psychological, social and economic consequences for 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. Deaths may be as a result of the underlying cause of the seizures, trauma, prolonged seizures or Sudden Unexpected Death in Epilepsy (SUDEP).

Epilepsy and neurological health services have historically been neglected in Ireland. This has improved in the past decade thanks to the work of the National Epilepsy Clinical Care Programme, e-health initiatives and the appointment of new consultant and specialist-nursing posts. However, additional resources are still required to ensure equality of access across the country and to deliver optimal medical care to specific groups such as patients with intellectual disability and women of childbearing potential. There is also a critical need to expand both the epilepsy surgery and ketogenic diet services.

First Aid For Tonic Clonic Seizures

Convulsive seizures where the body stiffens (tonic phase) followed by general muscle jerking (clonic phase)



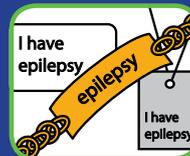
1. DO time the seizure



2. DO remove any harmful objects



3. DO cushion the head



4. DO look for Epilepsy I.D.



5. DON'T put anything in the person's mouth



6. DON'T restrain the person or move unless in danger



7. DO turn the person on side (into recovery position) when seizure stops



8. DO stay with the person until the seizure ends and offer assistance



When to call an ambulance

- If the seizure is longer than 5 minutes
- If one seizure follows another without stopping
- If you know it is the person's first seizure
- If the person is injured
- If you are in any doubt

Complex Partial Seizures
(Non-convulsive seizures with confusion, wandering, unusual behaviours)

- Stay with the person
- Time the seizure
- Guide away from any danger
- Speak gently and calmly to reassure the person
- DON'T restrain the person unless in danger



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www.epilepsy.ie facebook.com/epilepsy.ie @epilepsyireland

SUPPORT AND INFORMATION

Overview

Epilepsy Ireland provides a range of support services including one-to-one support, outreach services, support groups, educational programmes, individual group-based self-management programmes and a nurse-led helpline. Our staff team also develop and coordinate a range of seminars and events in addition to producing a range of resources and publications. Our services are provided by a team of 11 Community Resource Officers (CROs) based in Dublin, Cork, Galway, Limerick, Kilkenny, Killarney, Tullamore, Letterkenny/Sligo and Dundalk. In addition, services are provided by the National Information Officer, Community Epilepsy Specialist Nurse and Transition Nurse Coordinator.

During 2018, the demand for services remained steady with an increase in the frequency of contacts and the complexity of issues arising for service users. There were 19,447 individual contacts with our services in 2018 (2017: 20,156). One-to-one contacts with our CROs, Information Officer, Training Manager and Epilepsy Nurses totalled 9,794 in 2018 (2017: 9,750). Contact with individuals in group settings including educational / awareness sessions, group self-management and training programmes totalled 9,653 in 2018 (2017: 10,406).

Number of new service users in 2018

Person with epilepsy	582
Parent of child	618
Family/carer	230
Professional	526
Other	493
Total	2,449

Regional Statistics 2018

	Total	Individual	Group
North-West	1,577	683	894
Mid-West	1,493	709	784
South (Killarney)	1,706	722	984
South (Cork)	2,240	957	1,283
South-East	1,907	800	1,107
Midlands + North East	1,943	1,023	920
West	900	335	565
East	7,681	4,565	3,116
Total	19,447	9,794	9,653

Alongside our core one-to-one supports we encourage individuals to undertake our Living Well with the Epilepsy 'Toolkit' Programme. This programme was specially designed for people with a new diagnosis of epilepsy and can also be beneficial for parents of children who have been newly diagnosed. In 2018, 545 people completed the programme (2017: 488). Since 2014 over 2,000 service users have availed of this core service programme.

Our team of CROs facilitate a number of self-management programmes for adults with epilepsy and for parents of children with epilepsy. These group-based programmes include Support and Training in Epilepsy Self-management (STEPS) and Parents STEPS. These programmes enable individuals to learn more about epilepsy and gives them the tools and knowledge to become experts in managing their own epilepsy. Programmes are typically delivered in a group setting over six sessions.

An advanced self-management programme called Innerwise was developed in 2017. This programme focuses on improving mental health and wellbeing, managing stress and developing life management skills through tools that include mindfulness and meditation. The small size of these group based programmes allow for in-depth peer learning and mutual support which have been one of the key benefits to those who participate.

Self-Management Programmes 2018

Course	No. of Courses	No. of Participants
STEPS	6	40
Parent STEPS	4	19
Innerwise	4	27
Parents Innerwise	6	44

Since these programmes were introduced in 2015, 57 Self-Management courses have been delivered with almost 340 participants.

Regional support groups are facilitated by CROs across the country. These support groups offer individuals an informal opportunity to share information, offer and receive mutual support. Where required, external inputs are organised on issues of interest and relevance to the group. In 2018 there were 51 support group events with 553 people attending across the regions.

In 2018, we continued to provide support to hospital-based epilepsy services and through our outreach services. We also accepted referrals from many of the country's Epilepsy

Specialist Nurses (ESNs), Neurologists and Paediatric Neurologists. Our joint education sessions delivered by CROs and ESNs continue to be an important service delivered on-site at epilepsy clinics. There were 68 sessions held in hospital settings in 2018 with 413 individuals availing of this support.

Epilepsy Specialist Nurses

In 2018 we continued to fund two Epilepsy Specialist Nurse positions, the Candidate Advanced Nurse Practitioner post at Beaumont Hospital and the Epilepsy Transition Coordinator with the Children's Hospital Group. As part of their service, both nurses continued to offer a confidential helpline every Monday for both adults and teenagers/parents. The service provides epilepsy advice and support and the nurses signpost people to appropriate services. These are full-time HSE posts which are funded by Epilepsy Ireland.

Working with Younger People, Families and Siblings

In 2018, the annual family fun day took place in July at Clara Lara, Co. Wicklow with regional family events taking place in Kerry and Limerick. In Galway, an event specifically for teens was hosted and in Cork, a specific STEPS programme was held with a group of teenagers. Both events were well attended and positively received.

The 'Electric Feathers' project in association with Helium Arts brought together 16 children and teens in 2018.



Electric Feathers Art Project

Three art workshops took place in early 2018 with 16 young people. The young people worked with various different art forms through the workshops, such as animation; plaster of Paris, clay, fabric and painting of all types. They developed and created their own avatars / superheroes and through this process they got to discuss elements of themselves and similarities between them and their avatar! There were also opportunities to discuss their own epilepsy while they were working on their art.

Mags Cummins and Una Long (Cork Parents Support Group) pictured with Community Resource Officer Niamh Jones at the National Conference with their Volunteer Of The Year Award.



2018 National Epilepsy Conference

The 2018 National Epilepsy Conference took place in Dublin in September with over 200 people attending to learn about the latest developments in epilepsy care, research and services. Speakers included the inspirational Donna Kennedy who spoke about 'Life Beyond Epilepsy'. Dr. Colin Doherty gave an input on medicinal cannabis for epilepsy and discussed the latest developments in epilepsy research. A video interview was broadcast on the day with Prof. Orrin Devinsky, one of the world's leading experts in medicinal cannabis.



Our National Conference was attended by over 200 members from all areas around the country.

Information provision

We continually review and update our epilepsy information materials and we now have available a wide range of resources that are available in hard copy or download from our website. In 2018, new resources published by Epilepsy Ireland included our new 'Education Information Pack' which aims to inform staff across education settings about the particular needs of students with epilepsy. Epilepsy Ireland has also updated our Smartphone app which now comes with a wider range of features to support people with epilepsy and parents of children with the condition.

Workshops and Seminars

Epilepsy Ireland strives to listen to feedback from individuals and family members on the areas that they would like more information and support. This led us to organise and deliver a number of seminars on different topics across the country in 2018 including two '**Heads Up**' seminars in November in Dublin and Athlone.

The 'Heads Up' seminars were the first events organised by Epilepsy Ireland specifically looking at issues around memory, cognition and mental wellbeing for adults with epilepsy.

In November 2018, Limerick hosted a seminar entitled '**Supporting Families to Manage Epilepsy**'. This seminar covered a range of issues to support families to manage epilepsy and included inputs on 'Epilepsy and Intellectual Disability'.

New membership plan

In 2018 we completed a full review of our membership, aimed at both growing membership and improving the benefits of membership. Other issues that were addressed included the membership fees and the need to present better choice to members. Epilepsy Ireland now offers an improved package with five, three and one year options.

TRAINING AND EDUCATION

Health Professional Training

Epilepsy Ireland has provided a training programme in Epilepsy Awareness and the administration of Buccal Midazolam (BM) to health and allied health professionals since 2009. This is the only programme of its kind in Ireland and adheres to the guidelines and training standards developed by the Joint Epilepsy Council of the UK and Ireland.

The programme's aim is for participants to expand their knowledge of epilepsy in general, understand the role of the emergency rescue medication BM and receive instruction in the correct administration of BM.

Demand for the service has been increasing year on year and this continued in 2018. 199 sessions were delivered in 2018 compared to 191 in 2017. The number of people that attended the training programme also increased from 1,863 people in 2017 to 2,146 people in 2018; an increase of 15%. These courses are delivered by Epilepsy Ireland's Training Manager and team of Community Resource Officers around the country. All our staff have received 'train the trainer' training and undertake bi-annual refreshers from Quarriers UK.

Epilepsy Ireland has many long standing clients who regularly access the training service while new organisations we work with include a large number of those involved in the delivery of home care services.

The programme is particularly successful in developing participants' knowledge and skills of understanding epilepsy and responding to seizures appropriately. Course evaluation data has shown a high degree of satisfaction with the programme. For example, 96% of participants Strongly Agree or Agree that the programme has improved their ability to deal with the emergency response involving the administration of BM for prolonged/ serial seizures.

Following discussions with Quarriers and Crumlin Children's Hospital, 2018 saw the full training programme (with some modifications) opened to pre-school staff.

We also introduced demonstration evenings for parents and carers – 10 events were held nationwide with 128 people in attendance. These sessions proved very successful and further sessions will be offered in 2019.

Training for Success

Training for Success (TFS) is a programme developed by Epilepsy Ireland for people with epilepsy as a way of making education more easily accessible. This unique one-year course was first established in 1998 as a pre-employment qualification and this element has continued to be an integral component of the course.

TFS also provides practical and inspirational experiences for people with epilepsy who, due to their condition have experienced difficulties in the progression of their educational and career aspirations.



Over 2,100 people participated in our training programme on Epilepsy Awareness and the administration of Buccal Midazolam in 2018.

Students from Training For Success with Epilepsy Ireland's Communications Officer Conor Culkin at IT Sligo.



TFS is based in the Institute of Technology Sligo and funded by the Mayo, Sligo and Leitrim Education and Training Board (MSLETB). In 2017, the programme was upgraded from a QQI Level 4 Award to a QQI Level 5 Award. This change meant that the course was regraded from a pre-employment course to a full access programme, while the course content has also been updated, including the addition of a maths module.

The outcome for the 2017-2018 term was that seven graduates completed the term and the 2018-2019 class started with seven students. The variety of employment, training and education options in recent years has brought challenges for recruitment and during 2018, we worked with TFS partners to put new recruitment and sustainability measures in place. We thank MSLETB and IT Sligo for their ongoing commitment to supporting people with epilepsy through TFS.

Schools Education Programme

2018 was another busy year for our Schools Programme. This programme aims to raise awareness of epilepsy among those with the responsibility for ensuring a safe education environment. A typical session provides an introduction to epilepsy, a brief classification of seizure activity; and most importantly the basic best practice do's and don'ts of seizure management. The sessions aim to dispel the myths and misunderstanding that can surround epilepsy and address any issues that are relevant to the specific setting. School presentations may also include student colleagues of the child/ student with epilepsy.



Tom Byrne, Brian Faughnan and Jennifer Omereye Jimoh pictured at the 2018 Training For Success graduation day.

In 2018, over 3,000 students, teachers and SNAs attended 146 Epilepsy Awareness presentations on-site nationwide.

Our dedicated seminars for teachers and SNAs saw 16 sessions provided nationwide and 426 people attended these evening programmes.

3,000

students, teachers and SNAs attended 146 Epilepsy Awareness presentations on-site nationwide.

Awareness Raising Presentations

The work of Epilepsy Ireland reaches further than those immediately affected by the condition. We provide awareness raising presentations to a broad range of community organisations, training bodies and employers. These presentations cover the broad range of issues that may affect a person with epilepsy including driving, safety and employment rights. There were a total of 62 presentations delivered in 2018, attended by 1,050 people.



Ciara McGrath, Mikaela McSkeane, Lorraine Lally and Community Resource Officer, Edel Killarney at an Epilepsy Awareness evening in Galway.

2,146

trainees completed our one-day course on epilepsy awareness and the administration of Buccal Midazolam in 2018

AWARENESS AND ADVOCACY

International Epilepsy Day 2018

International Epilepsy Day (#EpilepsyDay) is celebrated around the world to help promote better public understanding of the condition.

Historically, epilepsy has not been well understood and many people report experiencing stigma and discrimination, often leading to a reluctance to disclose or discuss the subject.

International campaigns such as this have helped bring about major changes in this regard and in 2018, #EpilepsyDay was one of the most high-profile days in recent years.

Epilepsy Ireland used the day to focus on the top five things to know about the condition, as voted upon by Epilepsy Ireland service users:

- How to respond to a seizure
- Not every seizure is a tonic-clonic seizure
- Epilepsy can be life threatening
- Epilepsy in most cases does not affect your career
- Epilepsy doesn't define who you are.

Some of the highlights in 2018 included Rick O'Shea's appearance on Claire Byrne Live, talking about his epilepsy diagnosis as well as multiple interviews on national and local radio. There were also over 4,000 Irish tweets on February 12th and #EpilepsyDay was the most talked about topic on Twitter in Ireland.

National Epilepsy Week

To mark National Epilepsy Week in May, we announced results of a survey conducted among young people aged 16-21 on their experience of living with the condition. The results showed that:

- 65% of respondents have concerns about lifestyle issues such as drinking alcohol, socialising, sport and travel
- 56% were worried about employment
- 64% said they were concerned about anxiety issues
- 56% have confidence and self-esteem worries

These and other important challenges facing young people were addressed in a new printed and online information resource called Moving Forward – a Guide for Young People with Epilepsy. The guide contains resources for teens and parents and aims to support teenagers as they make the often difficult transition from paediatric to adult care.



Epilepsy Ireland and other neurological charities at Leinster House as part in the NAI's 'Invest in Neurology' campaign 2018.

Epilepsy Ireland Patron Rick O'Shea discussed his condition on Claire Byrne Live on International Epilepsy Day.



Brain Awareness Week

Epilepsy Ireland together with 10 other member organisations of the Neurological Alliance of Ireland, launched a campaign in March calling on the Government to prioritise investment in neurology services. The "Invest in Neurology" campaign called on the Government to take immediate action to tackle staffing deficits in services across the country as well as longer term investment to develop specialist services for specific neurological conditions, including the National Epilepsy Clinical Care programme. The campaign engaged with key political figures during the year including the Minister for Health and the Chair of the Oireachtas Health Committee.

Social Media

Social media is one of our most powerful communication tools and in 2018 our Facebook 'likes' increased from 12,000 to nearly 14,000 while our Twitter followers also grew past 4,000. As the power of images on social media continues, the Epilepsy Ireland Instagram page also increased its followers to 1,500.

Purple Day

For the second year running, Epilepsy Ireland participated in Purple Day, an international grassroots effort dedicated to increasing awareness about epilepsy on March 26th. On Purple Day, people in countries around the world are invited to wear purple and host purple themed events in support of the condition. Over 30 well-known Irish buildings such as The National Convention Centre and The Mansion House turned purple for the evening. Many people also supported the cause on social media as hundreds of Epilepsy Ireland supporters shared their purple themed images online or took part in purple-related fundraising efforts.

SUDEP Action Day

SUDEP Action Day in October is dedicated to raising awareness of Sudden Unexpected Death in Epilepsy and other epilepsy deaths across the world. Epilepsy Ireland used the day to reach out to members, service users and the public to inform about SUDEP and also on the critical issue of managing epilepsy risks.

Mark Earley wrote a moving piece for the Journal.ie about his late wife Liane who died in April 2017 from a nocturnal seizure and was also interviewed on RTE Radio One by Ryan Tubridy. Mark has also incredibly raised over €55,000 for Epilepsy Ireland through numerous events, including the inaugural Liane Deasy Memorial Swim, quizzes, music gigs and comedy nights.

Epilepsy Ireland also participated in the Prevent21 Summit on Tackling Epilepsy Deaths in the UK which was attended by a wide spectrum of clinicians, policy makers, epilepsy organisations and medical professionals.

New Website

Epilepsy Ireland relaunched our website (epilepsy.ie) in September to reflect the importance of modern day communication for our service users. The new website is intended to be a trustworthy resource for people with epilepsy, their families and carers as well as professionals and the general public. The site aims for simplicity and an interface that is intuitive and easily navigable for the user.

The site features an innovative and modern design and is optimised for mobile devices. It now contains a greater depth of information and features new sections for specific audiences e.g. parents, women, children and teenagers. Almost 80,000 site sessions were recorded in 2018.

Sodium Valproate Campaign

The most significant advocacy issue of 2018 continued to be the ongoing Sodium Valproate (Epilim) campaign. Epilepsy Ireland and other organisations in the FACS (Foetal Anti Convulsant Syndrome) Forum continued to advocate for the implementation of new measures to reduce the risks of children being affected by in-utero exposure to the drug and for better supports for families affected by FACS.

In February, following intensive campaigning work in 2017, we welcomed the European Medicine Agency's (EMA) new measures to reduce risks in women and girls. Throughout the year, we worked closely with the HSE, the Health Products Regulatory Authority (HPRA), the Pharmaceutical Society of Ireland (PSI) and other stakeholders to ensure that the EMA's measures were fully implemented in Ireland.

We also met with Minister Simon Harris to discuss the response needed to address the needs of patients on valproate and families who have been affected by FACS. The meeting led to the establishment of a HSE Valproate Response team, which alongside Epilepsy Ireland and OACS Ireland worked on implementing a detailed action plan throughout 2018. This included direct communications with GPs and patients taking valproate, the establishment of a nurse-led helpline, a HSE report on the potential scale of

FACS in Ireland, the development of a diagnostic pathway for FACS to include a new consultant geneticist, the approval of a new women's health in epilepsy programme, additional funding for epilepsy specialist nurses and resources for the Epilepsy Pregnancy Register. The Epilepsy Ireland funded Transition Nurse Co-ordinator was seconded to HSE for four months to manage the valproate helpline.

Other successes for the campaign included HPRA-approved on-box and blister-pack warnings, new information resources for professionals and patients, a commitment to end the dispensing of Epilim in plastic bags and clear guidance for pharmacists issued by the PSI.

As the year ended, plans were in place for a national conference on valproate in 2019 and a plan for a range of disability and support services for those affected was under consideration with the HSE.

The FACS Forum also secured an Oireachtas Health Committee hearing on the issue, attended by the HSE, HPRA and the FACS Forum including Epilepsy Ireland CEO Peter Murphy. The Committee later published a report detailing 12 specific recommendations to the government on the issue, many of which reflected the FACS Forum key demands.

While 2018 was a very productive year in terms of reducing future risks, and securing services for those affected by FACS, work still needs to be progressed on another FACS Forum demand that an inquiry is needed to examine the historical use of valproate and whether valproate-related disabilities could have been prevented.



Epilepsy Ireland CEO, Peter Murphy speaking about Sodium Valproate at the Oireachtas Health Committee.

Working with other organisations

Epilepsy Ireland is also an active member of the following national and international organisations through which we advocate on behalf of people with epilepsy:

- Neurological Alliance of Ireland
- International Bureau for Epilepsy
- Disability Federation of Ireland
- Medical Research Charities Group
- Irish Platform for Patient Organisations, Science & Industry

We also work closely with medical professionals through the HSE's National Epilepsy Care Programme, the Epilepsy Electronic Patient Record steering group, the Irish Epilepsy League and the Irish Epilepsy Nurses Group.

RESEARCH

€1million

has been invested since the Epilepsy Ireland Research Funding Scheme began in 2009

13

Irish epilepsy projects have received funding from Epilepsy Ireland in the past decade

2017/ 2018 Research Funding Scheme Call

The Epilepsy Ireland Research Funding Scheme was set up in 2009 to provide epilepsy researchers in Ireland with an avenue to access funding for quality, high-impact research.

In October 2017, the sixth call for funding proposals under the Scheme was announced. We invited applications on a number of priority topics for research projects of up to a three-year duration to a maximum of €50,000 p.a.

A record 15 pre-applications were received; the application involved both a shortlisting process and a full international peer review process which was undertaken by the Research Review Committee in 2018. This intensive review process ultimately resulted in one application (below) being funded from September 2018 under the Joint Funding Scheme operated by the Health Research Board and the Medical Research Charities Group.

Over €1 million has been invested since the Epilepsy Ireland Research Funding Scheme began in 2009.

New Grants Awarded 2018

A grant of €148,998 over three years was awarded under the HRB/MRCG Joint Funding Scheme to the RCSI to investigate possible links between auto-immune epilepsy and bacteria found in the gut. 50% of the funding is made available by the Health Research Board while Epilepsy Ireland will fund the other 50% through fundraising efforts and designated research reserves. The study will be led by Prof. Gianpiero Cavalleri of the new FutureNeuro Research Centre. The study represents a new, important and potentially highly significant opportunity to understand the causes of and potential treatments for autoimmune epilepsy, a rare form of drug-resistant epilepsy that is currently poorly understood.

Also in 2018, we agreed to co-fund a major new piece of research being undertaken at RCSI on the role of new technologies in improving epilepsy health services.

Entitled “Co-Producing Health and Well-Being in Partnership with Patients, Families and Communities: The Role of the Epilepsy Patient Portal”, the study will measure patient, carer and healthcare professional perspectives on the usability and usefulness of the epilepsy e-Portal. The e-Portal is a recent addition to the National Epilepsy Electronic Patient Record system which allows epilepsy patients to access and interact with their own health records online. The e-portal offers potential to improve patient empowerment, enable the development of stronger partnerships between healthcare professionals and patients and better co-ordinate the patient’s care. The project is funded by the Health Research Board under the Applied Partnership Awards 2018. €20,000 is provided in co-funding by Epilepsy Ireland as a knowledge-user.



The new FutureNeuro Centre at RCSI is developing new technologies and solutions for the diagnosis and treatment of epilepsy.

The €1 million milestone reached

The latest research grants awarded mean that Epilepsy Ireland has now invested over €1 million since 2009 under our Research Funding Scheme. In total, 13 projects have been funded in that time, covering a wide range of relevant research questions including epilepsy genetics, molecular mechanisms of epilepsy, sudden unexpected death in epilepsy, stigma, family communications, epilepsy specialist nurses, biomarkers, seizure dogs and e-health. Eight of the 13 studies have been co-funded by the Health Research Board and the HRB/MRCG Joint Funding Scheme remains integral to Epilepsy Ireland's ability to support Irish research. The impact of our funding can be measured not just in terms of the volume of publications in leading medical journals such as *Epilepsia*, *Nature Genetics*, *The Lancet* and *Brain* but also through successes such as:

- Enabling Irish research teams and patients to participate in large scale international studies
- Seeding for larger national and international research grants such as the Future Neuro Research Centre.
- Contributing to international efforts to better understand SUDEP through the Epilepsy Deaths Register for Ireland
- New support services for people with epilepsy for example, the resources developed through the How2Tell study on disclosing epilepsy
- Shaping advocacy on the provision of epilepsy health services e.g. The Prevalence of Epilepsy in Ireland study and the SENSE study on epilepsy nurses.
- Ensuring that State research funds are allocated to epilepsy, one of the most common brain conditions
- Supporting young scientists and clinicians in developing expertise in epilepsy

Ongoing research projects

Prof David Henshall's three-year study at RCSI entitled "MicroRNAs in the mechanism of ketogenic diet therapies and as biomarkers in paediatric epilepsy" continued throughout 2018 and is due to be completed in 2019. The study is investigating whether microRNA levels in blood samples or other body fluids (urine, saliva) can predict which children will benefit most on the diet and shed new light on how the diet works.

The Epilepsy Deaths Register for Ireland, a partnership with UK charity SUDEP Action, University College Cork and Sheffield University, also continued in 2018. The Register aims to drive research and learn more about epilepsy deaths and how they might be prevented. To date, details of 74 Irish deaths are recorded on the register.

Other Research Activities 2018

- Our Community Resource Officers took part in a participatory action research study on intersectoral collaboration in epilepsy care in Ireland, and data was presented at the 2018 National Conference (the EPIC study).
- We are collaborating with Dublin City University on the PPI Ignite project, an initiative which aims to help researchers involve the public and patients at the centre of the health research process.
- We are collaborating on a HRB-funded two-year study into the effectiveness of risk minimisation measures to prevent harm from teratogenic medicines in pregnancy. This important RCSI-led study was approved for funding in 2018 and focuses on the anti-epileptic drug sodium valproate.
- Epilepsy Ireland also provided non-financial support for projects at University College Cork and at the University of Liverpool in 2018.



Epilepsy Ireland is funding a new project on the relationship between epilepsy and the microbiome led by Prof. Gianpiero Cavalleri of RCSI.



A record 15 funding applications were received in the latest round of Epilepsy Ireland's Research Funding Scheme.



Ketogenic diet therapies are being researched by Prof David Henshall.

FUNDRAISING

Epilepsy Ireland can only continue to make a difference thanks to the generosity of individuals and companies throughout Ireland who contribute to our fundraising efforts.

Our wide range of fundraising activities supplement our HSE-supported service delivery, and fund our advocacy, awareness-raising and research-funding efforts.

Annual fundraising events include national church gate collections, the Rose Week Appeal, the annual fundraising lunch, our members raffle and the Time for a Break monthly draw. Our supporters take part in events like the Women's Mini Marathon and other events and challenges around the country, while others generously make donations or invest their time and skill in organising their own events. Just two of the many notable volunteer-led events in 2018 included the inaugural Liane Deasy Memorial Swim and the annual Tour de Gagg cycle.

In 2018, Purple Day was a platform from which we ran a new fundraising event and this proved a popular initiative, which we aim to build upon in the coming years. Corporate partnerships are an increasingly important part of our fundraising efforts and in 2018, we were delighted to have been chosen by Permanent TSB as their Charity of the Year. Their outstanding work on our behalf through staff fundraising and engagement opportunities resulted in a donation of over €160,000.

Corporate donations, alongside a significant legacy received during the year meant that income from Fundraising in 2018 was €946,000 compared to €636,000 in 2017.

This was an outstanding result in an uncertain and competitive fundraising environment, and meant that we were able to meet HSE deficits from current year income, while recording a rare operational surplus. However, we also recognise that these results are highly unlikely to recur in subsequent years, and we need to redouble our efforts to maintain and develop our income from fundraising.

We would like to thank all our donors and volunteers around the country who have helped to support our work in so many different ways. On this page, we feature just a few of the wonderful fundraising activities from 2018. To see more, make sure to follow us on social media, and please consider making a donation or getting involved in our fundraising efforts in 2019.

Visit epilepsy.ie for more information or to make a secure donation. If you'd like more information please contact us at fundraising@epilepsy.ie.



Mark Earley (right) has raised over €55,000 for Epilepsy Ireland in memory of his wife Liane.



Stephen Teeling Lynch from GoTri Triathlon Club Shannon who organised a 5km Run/Walk/Jog for the month of January.



Staff from Airtel supporting Purple Day 2018.



Mia Shepherd from the Hospital Saturday Fund presenting Epilepsy Ireland's Michael Carty with a grant to develop our information resources.



Joe Molloy, Damien Duff, Kevin Kilbane and Brian Kerr pictured at the Epilepsy Ireland charity lunch.

GOVERNANCE

In 2018, we were awarded 'Triple Lock' status by the Charities Institute Ireland (CII). Triple Lock status is awarded to charities that uphold the highest standards in transparent reporting, ethical fundraising and strong governance structures. This recognition is the gold standard for Irish charities.

To achieve the Triple Lock, we:

- Adopted and maintain compliance with the Charity Regulator's Guidelines for Charitable Organisations on Fundraising from the Public.
- Prepare our annual financial statements in compliance with the Charity SORP (Statement of Recommended Practice under FRS102) accounting standard.
- Completed the full implementation of the Governance Code for the Community and Voluntary Sector. The Code comprises a set of recommended practices for the boards

of Irish charities and was adopted in full by the Epilepsy Ireland Board in July 2018.

We have also committed to keeping our compliance under ongoing review, and we look forward to fully meeting the requirements of the Regulator's new Charities Governance Code in 2019 or early 2020.

In 2018, we were also re-certified by the NCVO in the UK for a further three years with the PQASSO Quality Standard for Charities (Level 1). The quality system comprises 12 specific standards and almost 100 individual indicators which must be met in order to receive certification. PQASSO offers our stakeholders an additional level of assurance of how we do our work and our commitment to quality across all parts of the organisation.

Board of Director Meetings 2018	Feb 5th	April 3rd	May 29th	July 24th	Sept 3rd	Oct 23rd	Dec 3rd
Mr. Mark Dowdall	✓	✓	✓	✓	✓	✓	✓
Ms. Cathy Grieve	✓	✓	✓	✓	✓	✓	✓
Mr. Michael McLoughlin	✓	✓	X	✓	✓	X	✓
Mr. Vincent Savino	✓	✓	✓	X	X	X	X
Mrs. Tessa Dagge	✓	✓	X	✓	X	✓	✓
Mr. Derry Gray	✓	X	✓	X	✓	✓	X
Dr. Christine Linehan	✓	✓	✓	✓	✓	✓	✓
Ms. Carol Saarsteiner	✓	X	✓	X	X	X	✓
Dr. Joyce Senior	✓	X	X	X	X	X	X
Mr. Tony Caravousanos	✓	✓	✓	✓	X	✓	✓
Ms. Clare O'Dea	✓	✓	✓	X	✓	X	X
Mr. Paul Kehoe					✓	✓	✓
Ms. Mary Fitzsimons	Not a member				✓	✓	X
Mr. Ambrose Kealy					✓	✓	✓

Dr. Michael Hennessy, Dr. Bryan Lynch, Dr. Brian McNamara, Dr. Brian Sweeney, Dr. David Webb and Prof. Norman Delanty did not attend board meetings in 2018.

Finance & Audit sub-committee

The role of the Finance & Audit Sub-Committee is to assist, support and advise the Board in the management and monitoring of the organisation's finances, business activities and strategic direction. In particular, it advises the board on matters relating to budgeting; monitoring of income and expenditure; financial audit; strategic planning; financial procedures and controls; risk; and utilisation of reserves. In 2018, the sub-committee met on seven occasions.

Other sub-committees

The Governance & Nominations sub-committee advises the board on matters of corporate governance including board composition, structure and board recruitment. The Quality & Safety sub-committee oversees the development and implementation of a quality and safety programme across Epilepsy Ireland services. The Remuneration sub-committee has responsibility for setting the CEO's objectives and evaluating CEO performance.

Finance & Audit sub-committee meetings 2018	Mar 5th	Mar 27th	May 15th	July 10th	Aug 28th	Oct 16th	Nov 26th
Mr. Michael Sheehy	✓	✓	✓	✓	✓	✓	✓
Ms. Mark Dowdall	X	✓	✓	✓	✓	✓	X
Mr. Michael McLoughlin	X	X	✓	X	X	✓	n/a
Mr. Paul Kehoe	✓	✓	✓	✓	✓	✓	✓
Ms. Tessa Dagge	X	✓	✓	✓	✓	✓	✓
Mr. Tony Rhatigan	✓	X	✓	✓	X	✓	X
Mr. Declan Service						✓	✓
Mr. Derek Heffernan	Not a member					✓	✓

FINANCIAL REPORT 2018

In 2018, Epilepsy Ireland reported net incoming resources of €137,562 (2017: net outgoing resources, €274,118).

Income increased to €2.04m in 2018 from €1.67m in 2017, mainly as a result of one-off unrestricted income from legacies and a one-year corporate partnership.

Expenditure was broadly in line with both 2017 actual expenditure and with 2018 expectations, totalling €1.91m (2017: €1.95m). €150,975 of unrestricted income was utilised to offset deficits in HSE-funded services (2017: €175,154).

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) and FRS102.

The full financial statements are available from epilepsy.ie (from July 2019) or from info@epilepsy.ie.

Brainwave - The Irish Epilepsy Association T/A Epilepsy Ireland

Statement of Financial Activities (Incorporating Income and Expenditure Account) for the Financial Year Ended 31 December 2018.

	Restricted Funds 2018 €	Unrestricted Funds 2018 €	Total Funds 2018 €	Restricted Funds 2017 €	Unrestricted Funds 2017 €	Total Funds 2017 €
INCOME FROM:						
Donations and Legacies	17,970	680,984	698,954	40,164	304,396	344,560
Charitable Activities	896,298	159,069	1,055,367	886,013	137,853	1,023,866
Other Trading Activities	46,287	201,267	247,554	57,435	234,543	291,978
Investment Income		881	881	-	2,207	2,207
Other Income		43,293	43,293	-	13,938	13,938
Total	960,555	1,085,494	2,046,049	983,612	692,937	1,676,549
EXPENDITURE ON:						
Charitable activities	902,854	499,351	1,402,205	953,226	463,264	1,416,490
Raising funds	18,515	293,606	312,121	23,089	303,452	326,541
Other	174,610	19,551	194,161	168,264	39,372	207,636
Total	1,095,979	812,508	1,908,487	1,144,579	806,088	1,950,667
Net (expenditure)/income before movement on investments and taxation	(135,424)	272,986	137,562	(160,967)	(113,151)	(274,118)
Unrealised gain on quoted investments	-	-	-	-	-	-
Taxation	-	-	-	-	-	-
Transfers between funds	150,975	(150,975)		175,154	(175,154)	-
Net movement in funds	15,551	122,011	137,562	14,187	(288,305)	(274,118)
Total funds brought forward at 1 January 2018	31,556	1,281,561	1,313,117	17,369	1,569,866	1,587,235
Total funds carried forward at 31 December 2018	47,107	1,403,572	1,450,679	31,556	1,281,561	1,313,117

FINANCIAL REPORT 2018

Brainwave - The Irish Epilepsy Association T/A Epilepsy Ireland

Balance Sheet As at 31 December 2018

	2018	2017
	€	€
Fixed Assets		
Tangible assets	132,764	145,211
	<u>132,764</u>	<u>145,211</u>
Current Assets		
Stock	10,137	6,425
Debtors	101,579	103,475
Cash at bank and in hand	1,459,045	1,413,218
	<u>1,570,761</u>	<u>1,523,118</u>
Current Liabilities		
Creditors: Amounts falling due within one year	<u>(252,846)</u>	<u>(355,212)</u>
Net Current Assets	<u>1,317,915</u>	<u>1,167,906</u>
TOTAL NET ASSETS	<u>1,450,679</u>	<u>1,313,117</u>
FUNDS OF THE CHARITY:		
Restricted funds	47,107	31,556
Unrestricted Funds		
- General funds	762,323	577,085
- Designated funds	641,249	704,476
TOTAL FUNDS	<u>1,450,679</u>	<u>1,313,117</u>

OUR PEOPLE

Board of Directors

(as at 31 December 2018)

Mr Mark Dowdall (Chairman)
Mr Vincent Savino (Vice-Chairman)
Mr Paul Kehoe (Treasurer)
Mr Michael McLoughlin (Treasurer)
Ms Cathy Grieve (Secretary)
Mr Tony Caravousanos
Mrs Tessa Dagge
Prof. Norman Delanty
Ms Mary Fitzsimons
Mr Derry Gray
Dr Michael Hennessy
Mr Ambrose Kealy
Mr Michael McLoughlin
Dr Bryan Lynch
Dr Brian McNamara
Ms Clare O'Dea
Ms Carol Saarsteiner
Dr Joyce Senior
Dr Brian Sweeney

Finance & Audit sub-committee

Mr Michael Sheehy (Chairman)
Mrs Tessa Dagge
Mr Mark Dowdall
Mr Derek Heffernan
Mr Paul Kehoe
Mr Tony Rhatigan
Mr Declan Service

Research Peer Review Board

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

Quality & Safety sub-committee:

Mark Dowdall
Michael McLoughlin
Peter Murphy
Tara Smith

Governance & Nominations sub-committee:

Cathy Grieve
Mark Dowdall
Ambrose Kealy

Remuneration sub-committee

Mark Dowdall
Derry Gray
Cathy Grieve

Staff (as at 31 December 2018)

Chief Executive

Peter Murphy

Services

Director of Services

Tara Smith

National Information Officer

Geraldine Dunne

Community Resource Officers:

Carina Fitzgerald (Eastern Region)
Edel Curran (Eastern Region)
Cliona Molloy (Midlands Region)
Miriam Gray (South East Region)
Loretta Kennedy (Southern Region, Cork)
Niamh Jones (Southern Region, Cork)
Kathryn Foley (Southern Region, Kerry)
Veronica Bon (Mid West Region)
Edel Killarney (West Region)
Agnes Mooney (North West Region)
Mary Baker (North East Region)

Epilepsy Specialist Nurses

Sinead Murphy, cANP (Beaumont Hospital)
Yvonne Owen, ANP (Transition Nurse)

Fundraising, Communications and Administration

Fundraising & Communications Manager

Michael Carty

Communications Officer

Conor Culkin

Membership & Fundraising Officer

Ashley Butler

Churchgate Collections

Barbara Doyle

Fundraising Assistants

Luke Meany
Judith Kelleher

Training Manager

Paul Sharkey

Training For Success Manager

Honor Broderick

Training For Success Facilitator

Maire Tansey

Finance Manager

Andrew O'Dwyer

Executive Assistant

Cathy Powell

Receptionists

Madge Geoghegan
Joan McDermott

Community Employment Scheme

Kelly Burke

OUR LOCATIONS

Head Office

249 Crumlin Road, Dublin 12.

Tel: 01 455 7500

Email: info@epilepsy.ie

Epilepsy Ireland National Information Officer: Geraldine Dunne

Email: Geraldine: gdunne@epilepsy.ie

Specialist Nurse and Transitional Nurse Helpline

Tel: 01 455 4133 Monday 9.30am

- 1.30pm. Tel: 01 455 4133 Monday

2.00pm - 5.00pm

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 9168725

Sligo Office

2c Castle House, Castle Street, Sligo.

Tel: 071 91 41858

West

Covering: Galway, Roscommon & Mayo.

Westside Resource Centre, Seamus

Quirke Road, Westside, Galway.

Tel: 091 587 640

Community Resource Officer:

Edel Killarney

Email: ekillarney@epilepsy.ie

Midwest

Covering Limerick, Clare, Tipperary North.

Social Service Centre, Henry St., Limerick.

Tel: 061 313 773

Community Resource Officer:

Veronica Bon

Email: vbon@epilepsy.ie

Kerry

Covering Co.. Kerry

9/10 the Paddocks, Ballydowney,

Killarney, Co. Kerry

Tel: 064 663 0301

Community Resource Officer:

Kathryn Foley

Email: kfoley@epilepsy.ie

Cork

83 Beech Road, Muskerry Estate,

Ballincollig, Co. Cork

Tel: 021 427 4774

Community Resource Officers:

South Lee & West Cork:

Niamh Jones

North Lee & North Cork:

Loretta Kennedy

Email: lkenedy@epilepsy.ie

njones@epilepsy.ie

South East

Covering: Kilkenny, Wexford,

Carlow, Waterford & Tipperary South.

C/o HSE, St. Joseph's, Waterford Road,

Kilkenny.

Tel: 056 778 9904

Community Resource Officer:

Miriam Gray

Email: mgray@epilepsy.ie

Midlands

Covering Offaly, Longford, Laoish and Westmeath.

c/o The Charleville Centre, Church Ave,

Tullamore, Co. Offaly.

Tel: 057 934 6790

Community Resource Officer:

Cliona Molloy

Email: cmolloy@epilepsy.ie

East

Covering: Dublin, Kildare & Wicklow.

249 Crumlin Road, Dublin 12.

Tel: 01 455 7500

Community Resource Officers:

Edel Curran, Carina Fitzgerald.

Edel: ecurran@epilepsy.ie

Carina: cftzgerald@epilepsy.ie

North East

Covering: Louth, Meath, Monaghan & Cavan.

Unit 1a, Partnership Court, Park St,

Dundalk, Co. Louth.

Tel: 042 933 7585

Community Resource Officer:

Mary Baker

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

Online

Web:

epilepsy.ie

Facebook:

facebook.com/epilepsy.ie

Twitter:

[@epilepsyireland](https://twitter.com/epilepsyireland)

Youtube:

youtube.com/BrainwaveEpilepsy

Instagram: [epilepsy_ireland](https://instagram.com/epilepsy_ireland)

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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
Chartered Accountants
Deloitte & Touche House
Earlsfort Terrace
Dublin 2



Best Practice in Transparency and Accountability

