



Annual Report 2013

Shining a light  
on epilepsy



*I registered for the Epilepsy Online Support Group because I was curious. I'd never made it to a face-to-face support group meeting because I don't drive due to my epilepsy. I love that I can join the online support group from the comfort of my living room without having to organise childcare or transport. I find the group is fun. It's good to talk about epilepsy with others who understand. By sharing information we can show that life with epilepsy is not just manageable, it's fulfilling.*

*Deirdre-Anne Wynne Robinson, Dublin.*

*When I was at school, all they saw was my epilepsy and not my potential and I wasn't given a chance. Being on 'Training For Success' was the first opportunity I had to be treated as a unique individual. I now intend to do a degree in Event Management and plan to set up my own business.*

*Denise O'Connell, Training for Success student.*

*After the initial shock of our daughter's epilepsy diagnosis, we reached out to Epilepsy Ireland to try to understand more about this condition and how we could support our daughter. Through our interactions with Epilepsy Ireland we have attended regular information events and equally importantly, had opportunity to engage with other parents whose children have epilepsy. We have truly benefited from the support of Epilepsy Ireland. It is a great comfort knowing that we were not alone.*

*Helen McGrath, Co. Offaly.*

*Epilepsy Ireland has been a huge benefit to the children with epilepsy attending our services, particularly in supporting families who have more unusual presentations of the condition. The new 'Living with Epilepsy' toolkit has been a very useful method of creating a greater understanding for the child family and empowering carers to provide a safer environment for the child.*

*Elaine O'Brien-Doyle, Acute Paediatric Link Nurse, Regional Hospital Portlaoise.*

*I am the mother of a fantastic young man Mark who is 18 years old and has had epilepsy for the last 10 years. I have been attending the Cork meetings since Mark was first diagnosed and through this support, we learned a lot about epilepsy and met some great people. When Mark's seizures returned after three years of freedom, Niamh was there for us. Without her we would have no one at the other end of the phone to help us.*

*Una Long, Cork*



*I was diagnosed with epilepsy when I was seven years old. It really affected my confidence. I was so nervous to do anything in case I had a seizure, but Epilepsy Ireland really helped me and my family in so many ways! Last year I went on Ryan Tubridy's radio show to raise awareness of epilepsy. Then I decided to run a horse show fundraiser because I wanted to give something back and raise awareness among the people I've been competing with for years. I was delighted when my efforts raised over €2,000 for Epilepsy Ireland's great work.*

*Laura Hall, Co Wicklow.*



*Because our non-medical staff were able to avail of Epilepsy Ireland's training in the administration of buccal midazolam, all of our children can now take an active part in everything the community has to offer, just like their mainstream peers. Without Epilepsy Ireland's training, our 21 children would be confined to the four walls of the school where they have immediate access to our nurse.*

*Denise Cole, Principal, Offaly School for Special Education.*

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## Our Vision

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

## Mission Statement

Epilepsy Ireland is committed to working for, and meeting the needs of everyone with epilepsy in Ireland and their families and carers.

## Our Objectives

- To provide support, information and advice to people with epilepsy
- To provide information and advice to health professionals in dealing with epilepsy
- To improve public understanding of epilepsy (in order to eliminate fear and prejudice) through awareness campaigns and education programmes
- To undertake, encourage and assist research into the causes of, cure for and management of epilepsy and into the social and psychological effects of the condition
- To promote legislative and civil rights for people with epilepsy and to campaign to eliminate all discriminatory practices and policies affecting them
- To provide support for people with epilepsy in the area of training and employment
- To operate as a public forum and an advocate for the condition of epilepsy
- To raise funds to support our work in an awareness-creating manner

## Governance

Epilepsy Ireland is committed to achieving and maintaining the highest standards of governance. The Board of Directors have determined that the organisation will, by the end of 2014 or as soon afterwards as possible, comply with and maintain the standards outlined in:

- The Code of Practice for Good Governance of Community, Voluntary and Charitable Organisations in Ireland (The Governance Code)
- The Statement of Guiding Principles for Fundraising

Epilepsy Ireland aims to attain PQASSO (Practical Quality Assurance System for Small Organisations) accreditation in 2014. PQASSO is the leading quality standard developed for the non-profit sector, demonstrating that sound governance practices, financial and risk management procedures, systems for measuring outcomes and paths to continuous improvement are in place.

# A MESSAGE FROM



**Mark Dowdall**  
Chairman

I am honoured to present the 2013 Annual Report of Epilepsy Ireland which showcases the progress made in the past year and marks my election as Chair of the Association.

I would like to extend my sincerest thanks to Mrs. Tessa Dagge who had chaired the Association for the previous 12 years. Tessa has been involved with the Association for over 30 years; her expertise is still available

as she remains on our Board and is a member of the key Finance and Audit sub-committee.

In 2013 we changed our name to Epilepsy Ireland which received overwhelming support from all quarters. We hope that this new name will play a key role in shining a light on epilepsy and help to change public perceptions of the condition. Sadly, as the results of the recent research undertaken for Epilepsy Ireland, much still needs to be done in this area.

The Finance and Audit sub-committee also saw a change in 2013 with the election of a new Treasurer, Michael McLoughlin, who had been a member of this sub-committee for a number of years. This sub-committee and Board continue to work tirelessly to ensure that Epilepsy Ireland has the highest standards of governance in place and have committed to implementing and maintaining the standards outlined in The Code of Practice for Good Governance of Community, Voluntary and Charitable Organisations in Ireland and The Statement of Guiding Principles for Fundraising in 2014.

Our Epilepsy Awareness sub-committee, chaired by Cathy Grieve led on the planning and implementation of awareness activities and played a key role in our rebranding and in organising European Epilepsy Day. One of the members of this sub-committee is Rick O'Shea, 2FM presenter and Patron of Epilepsy Ireland who has significantly raised the profile of epilepsy and improved public understanding of the condition.

There are numerous people I would like to thank but in particular I would like to acknowledge the unwavering support of my fellow Officers, Vincent Savino, Vice-Chair; Claire Crehan-Dowdall, Hon. Secretary and Michael McLoughlin, Hon. Treasurer as well as our Board of Directors. I would also like to acknowledge the efforts of our many volunteers who gave up their time and resources during the year in support of Epilepsy Ireland.

The ongoing work of Epilepsy Ireland is delivered by its staff who have demonstrated energy, generosity and commitment to ensuring the best possible level of service is provided by the organisation in 2013. I want to thank our CEO Mike Glynn and all the staff team for their ongoing dedication to achieving our vision of a society in which no person's life is limited by epilepsy.



**Mike Glynn**  
Chief Executive

The most significant development of 2013 was perhaps the introduction early in the year of a new name for our organisation, Epilepsy Ireland. The response from our members, supporters and the general public has been almost unanimously favourable and I firmly believe that by highlighting in our name the condition we represent, we can lead the way in resolving many of the age-old misconceptions about epilepsy.

Despite continual funding cuts, Epilepsy Ireland strives to maintain and to develop our services and in 2013 we launched the new *Living Well With Epilepsy* toolkit and oversaw the expansion of our online support group service. A proud moment for the organisation was when our Training for Success (TFS) programme was shortlisted and subsequently won the AONTAS STAR National Award.

European Epilepsy Day is firmly established as the main platform for raising awareness of the condition and in February Epilepsy Ireland chose to highlight the common myths and misunderstandings that still exist via a successful PR and advertising campaign.

Our advocacy work took centre stage for much of 2013. Despite our intensive campaign, the Government did not agree to the exemption of anti-epileptic drugs in the Health (Pricing & Supply of Medical Goods) Act. However, our work has been hugely successful in highlighting and minimising the risks of AED substitution to policy makers, health professionals and people with epilepsy. We also campaigned extensively for the opening of the Epilepsy Monitoring Units in Cork and Dublin and were rewarded in June with the re-opening of the EMU in Beaumont Hospital. The campaign to open the CUH unit unfortunately must continue.

A goal in our Strategic Plan (2012-2016) was bring about a major international epilepsy conference in Ireland; this goal was achieved when the European Forum on Epilepsy Research (EFER) took place in Dublin in May. Furthering our commitment to developing and funding Irish research, support was committed to a new project at Trinity College aiming to develop a set of educational tools people can use in disclosing the fact they have epilepsy.

Much of our work is dependent on public generosity and I want thank all our members, volunteers, supporters and donors for their continued support during 2013. Thank you also to our Board and our Committees for their invaluable support throughout the year which is deeply appreciated. Finally, I wish to take the opportunity to thank all our staff for their dedication, energy and commitment to the continued development of Epilepsy Ireland and the services we provide.

# ABOUT 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 in which the person becomes rigid, then falls to the ground and there is jerking of all four limbs. 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 & 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.

Although major strides have been made in recent times, there can still be a stigma associated with the condition, a hidden burden which discourages many people from speaking about their epilepsy and from seeking the care and support they require. The stigma of epilepsy is often highlighted as being as problematic as the seizures themselves.

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 half of which are due to a poorly understood phenomenon called Sudden Unexpected Death in Epilepsy (SUDEP).

In Ireland, The National Epilepsy Care Programme, set up in May 2010 under the leadership of Dr. Colin Doherty has brought about many much-needed improvements in services for people with epilepsy, including the development of standardised operating procedures, pathways for seizure management in the emergency department and perhaps most importantly the recruitment and training of almost 20 Advanced Nurse Practitioners. While other challenges still need to be overcome, such as addressing the management of epilepsy at primary care level and opening the Epilepsy Monitoring Unit at Cork University Hospital, people with epilepsy can for the first time in decades look to a brighter future where they are provided with the best value care, in the right place, at the right time.

## Be Seizure Aware

Epilepsy Ireland's ongoing *Seizure Aware* campaign aims to increase public awareness of epilepsy, to banish the myths that surround the condition and to ensure that everybody knows how to respond appropriately when someone has a seizure. Do you know how to respond? Follow our guide below and be *Seizure Aware*.

**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 ID.
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 behaviour)

- 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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# INFORMATION & SUPPORT

The core function of Epilepsy Ireland is to serve people with epilepsy and their families by providing support and information.

Our National Information Officer and 10 regionally based Community Resource Officers (CROs) provide a range of services to individuals including one-to-one support; telephone support and hospital & community outreach services. The CRO team also provide an array of information & education services to groups including our online and local support groups for people with epilepsy and parents of children with epilepsy; information talks, seminars and conferences and other awareness activities. We also actively engage in supporting our members through advocacy, assisting in areas of employment, entitlements, law, education and accessing mainstream services.

Our information service is available to people with epilepsy, their families, health professionals, teachers, schools, employers and the general public. The service offers a wide range of leaflets, books and information packs available in both in print and electronic format about epilepsy and its management. Supporting people in their safety needs is also important and we offer safety aids including special safety pillows and identity bracelets.

Our Specialist Nurse Helpline operates on Monday mornings throughout the year, staffed by Sinead Murphy, Clinical Nurse Specialist in Community Epilepsy Services. Epilepsy News, our quarterly magazine is circulated to all members and from 2013 is available to download. In 2013, the epilepsy.ie website registered 82,000 visits, an increase of 15% compared to 2012. A total of 53,000 unique visitors accessed our site, also an increase of 15% and a total number of 357,000 page views were recorded, an increase of 6%. The site regularly updated with news articles, hosts a large database of information resources, and a comprehensive list of our regional activities and events.

## The Year in Numbers

- **20,967:** Total contacts with all Epilepsy Ireland services for the year (including CRO support contacts, Training For Success, health professional training, events, community presentations and the Specialist Nurse Helpline).
- **13,773:** Total one-to-one contacts (not including outreach) made to Epilepsy Ireland's community resource officers and the National Information Officer.
- **640:** Total number of contacts reached through the Epilepsy Ireland Outreach services.
- **5,310:** Attendance at presentations, seminars, school talks and other events facilitated by Epilepsy Ireland staff.
- **393:** Number of new sign-ups to the Online Support Group service. The group was accessed by 238 individuals.
- **1,045:** Total number of people supported by the Epilepsy Ireland Specialist Nurse

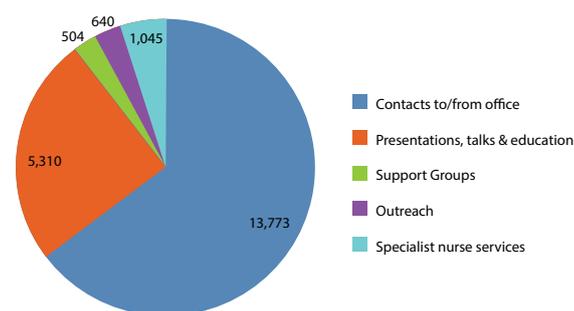
## Living Well With Epilepsy Toolkit

The Living Well with Epilepsy toolkit was launched at the National Conference in Tullamore in September. Aimed at those who are newly diagnosed with epilepsy, it provides information to adults and parents about the condition of epilepsy; supports them in its management and helps the person maximise their relationship with their medical

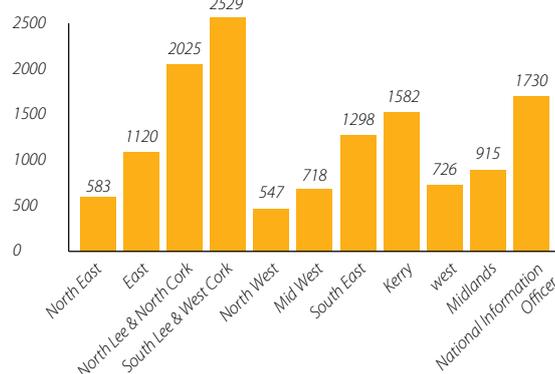
team. The toolkit is designed to aid the newly-diagnosed person with epilepsy to move from epilepsy patient to epilepsy expert. The new resource will support the work and objectives of the National Epilepsy Care Programme in delivering quality and accessible services for people with epilepsy.

Following the launch, Epilepsy Ireland's CRO team began offering Living Well with Epilepsy support sessions in all regions providing one-to-one, individually tailored sessions. The initial response has been very positive, demonstrating that the toolkit provides much needed support to people in the early stages of managing their condition.

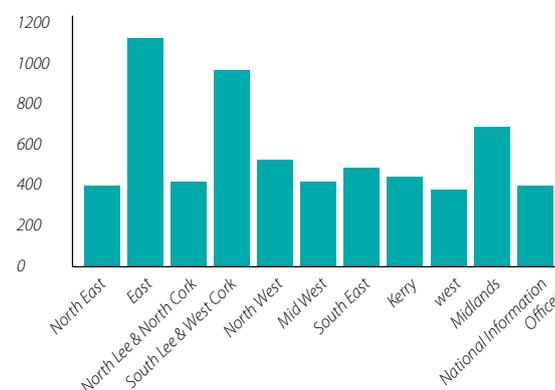
## Breakdown of support contacts, 2013.



## Total Number of contacts by region.



## Total numbers attending presentations, support groups & outreach services by region, 2013.



## Online Support Groups

First launched in October 2012, the online groups grew significantly in 2013. 50 online sessions were facilitated by our CRO team and 238 people participated. At the end of the year there were 547 people registered for the service. Following a 6-month review in March we developed theme-specific sessions including education & training and women's health and introduced sessions for specific groups such as parents and under 30s.

## National Conference

Epilepsy Ireland's national conference *Exploring Epilepsy: Health & Lifestyle Issues* was held in September in Tullamore with 180 delegates attending. Keynote speakers included Dr Peter Widdes-Walsh, consultant neurologist & epileptologist and Dr Amre Shahwan, consultant clinical neurophysiologist & epileptologist. Interactive workshops were held on memory management, epilepsy & health, disclosing epilepsy, stress management & mindfulness and epilepsy & mental health.

## Events & Programmes

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

### Information seminars

- Tullamore: 'Epilepsy, Health Issues and Mindfulness' event.
- Waterford: A seminar for people with epilepsy and parents of children with epilepsy.
- Sligo: An epilepsy awareness Q&A evening.
- Carrickmacross: The Good Emotional Health in Epilepsy event.
- Limerick: The 'Managing Stress & Anxiety through Self-Care' event hosted by Anne Buckley, RGN & Certified Stress Advisor.
- Roscommon: A supportive event for people bereaved through Sudden Unexpected Death in Epilepsy (SUDEP), providing the opportunity for families to meet and share experiences.

### Supporting Parents

- Dublin: A special seminar for parents addressed by Prof. Joan Austin, a world leading expert on epilepsy and children's mental health issues.
- Dundalk: A series of four 'Mums with Epilepsy' educational meetings were held.
- Cavan: A seminar on 'Behavioural Issues in Children with Epilepsy' was held in Virginia.

### Educational Programmes

- Limerick & Ennis: The Living Well with Epilepsy psycho-educational programme was held over two sessions in both locations with 23 attendees.
- Killarney: A four-session programme on Empowerment was held, along with some yoga activities, to support people with epilepsy to develop life skills.

### NAI wellness days

- Epilepsy Ireland participated with the Neurological Alliance of Ireland and other neurological charities to deliver educational and awareness seminars in Cork, Galway and Kilkenny.

### Working with Young People

- Limerick: A 'Parents and Teens' evening was held covering issues relating to teenagers with epilepsy, including pressures and stigma issues.
- Dublin: a new pilot discussion and social group called

*SpeakOut HangOut* was run for young people with epilepsy. Running over a 6-session period in autumn, it focused on specific areas of relevance to young people including stigma, disclosure, relationships, education and health.

- Letterkenny: A young person's support event was held featuring peer-to-peer support.

### Social Activities

In August 2013, a family day was held in the Phoenix Park and in November a family entertainment morning took place in the Planet Entertainment Centre in Cork. More informal social activities and groups were also held throughout the year in a variety of locations. The Lord Mayor of Cork, Cllr John Buttimer kindly invited the Cork parents support group along with their children to a social evening for families in City hall.



The new *Living Well With Epilepsy* toolkit, supporting people recently diagnosed with epilepsy was launched in 2013.



Organising the chaos at a family fun day in the Phoenix Park!



World renowned paediatric epilepsy expert Prof. Joan Austin spoke at a meeting for parents in October.

# AWARENESS

## Epilepsy Ireland – a new name

In February 2013, Brainwave – The Irish Epilepsy Association became Epilepsy Ireland. The goal of the rebranding was to give the organisation the best possible tools with which to meet our objective of improving public understanding of epilepsy.

The name change, identified in the Strategic Plan 2012-2016 as a key objective, was based on a conviction that the word “epilepsy” should not be hidden in the title of our organisation. It was also clear from research that very few people were aware of Brainwave and that even fewer could identify which medical condition we were associated with.

The name Epilepsy Ireland provides an opportunity to improve public understanding of what we do and of epilepsy itself. The changeover process was smooth and feedback from members and from the public has been exceptionally positive. While the old name has been consigned to history, the new branding did retain some traditional features such as the light bulb logo and the blue/ yellow colours.

## European Epilepsy Day

The 3rd annual European Epilepsy Day (EED) took place on February 11th. Epilepsy Ireland chose to highlight the common myths and misunderstandings that exist around epilepsy, while also highlighting our new name.

A series of advertisements were broadcast over 400 times on national and local radio, voiced by Rose of Tralee Nicola McEvoy and Epilepsy Ireland patron Rick O’Shea. Over €80,000 of pro-bono advertising space was donated by Irish newspapers and campaigns were also run using social media; on the DART in Dublin and via a poster campaign targeting pharmacies.

The Epilepsy Knowledge & Attitudes survey was a valuable tool in securing a huge amount of coverage in national newspapers, radio and TV and online. The findings revealed that significant misunderstanding persists among the public in relation to epilepsy. Perhaps the most telling statistic was that almost 1 in 5 people said they would not employ a person with epilepsy.

Epilepsy.ie and the Seizure Aware microsite site received an overhaul and February 11th broke the site’s busiest day record. Almost 4,000 people visited the site during the EED campaign and almost half a million people were ‘reached’ on Facebook. Events marking EED were held in Dublin, Cork, Dundalk and Tullamore.

## European Month of the Brain

The European Commission designated May 2013 as European Month of the Brain.

Across Europe, the month was devoted to raising awareness of neurological conditions and demonstrating the importance of brain research. Two major international brain conferences took place in Dublin during the month including the European Forum on Epilepsy Research (see page 11). Epilepsy Ireland joined forces with other brain charities to organise wellness days for people with neurological conditions in Kilkenny, Limerick, Cork and Galway.

## Epilepsy in the Media

Epilepsy Ireland worked with all branches of the media to keep epilepsy in the public eye throughout the year. The highest profile media event was the Late Late Show appearance of Ireland rugby head coach Joe Schmidt and Rick O’Shea to highlight the condition. Joe’s son Luke has epilepsy and both he and Rick spoke openly and honestly about their personal experiences of living with epilepsy.

For the third time, an Irish production was honoured in the International Excellence in Epilepsy Journalism awards when the Midlands 103fm documentary ‘The Parish’ produced and presented by Kieran Feeney and featuring Epilepsy Ireland members and staff scooped the top award in the radio category.

## Social Media

As a channel of communication and awareness-raising, social media continued to grow in importance and a new social media strategy was developed during the year. By the year end, our Facebook community had grown from 2,200 to 3,400 and 11,000 video views were recorded on YouTube.

## Epilepsy Awareness sub-committee

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



*Emma Boughton (aged 6) and Sadbh Mechan (aged 5) pictured with Rose of Tralee Nicola McEvoy and Peter Murphy, Deputy CEO at the launch of the new Epilepsy Ireland name.*



*Joe Schmidt and Rick O’Shea appearing with Ryan Tubridy on the Late Late Show to discuss epilepsy.*

# ADVOCACY

Epilepsy Ireland has a long history of actively advocating on behalf of the 37,000 people with epilepsy in Ireland. 2013 was a particularly busy year in this regard with a number of important issues on the agenda.

## Health (Pricing & Supply of Medical Goods) Act

The Health (Pricing & Supply of Medical Goods) Act was signed into law in May 2013, formally introducing a new system of generic substitution for medicines that are deemed interchangeable by the Irish Medicines Board (IMB).

Epilepsy Ireland campaigned to have anti-epileptic drugs (AEDs) legislatively excluded from generic substitution due to safety concerns highlighted in numerous international studies. The dangers of switching were highlighted to personally to Minister Alex White and to TDs and Senators from all parties in meetings, presentations and by phone and email contact. Epilepsy Ireland members were provided with templates to contact their own representatives, a comprehensive media campaign was launched and substantial support was built. Epilepsy Ireland's Mike Glynn and Peter Murphy along with consultant neurologist Peter Widdess-Walsh presented the case for exclusion to the Joint Oireachtas Committee on Health and Children in March.

However no exemption was granted. Epilepsy Ireland met with the IMB who confirmed that they understood the issues around AEDs and that no medications will be deemed interchangeable if there are safety concerns around doing so. Communication with the IMB remains on-going. Meanwhile, an educational campaign called 'Accept No Substitute' was launched providing people with epilepsy and their families with a simple 3-step guide to avoid inappropriate substitution.

## Epilepsy Monitoring Units

At the beginning of 2013, both of Ireland's Epilepsy Monitoring Units (EMUs) were inactive. The unit at Beaumont Hospital had been closed in 2012 for an upgrade which had been completed and the new Cork University Hospital unit had been fully equipped. However, neither could open due to the HSE's recruitment moratorium which prevented the hiring of essential nurses and technicians.

Epilepsy Ireland launched a political and media campaign to highlight the unacceptable lack of basic monitoring for people with difficult-to-diagnose epilepsy and those being considered for surgery. The issue featured prominently in the press, on radio and was covered by RTE's Primetime and TV3's Ireland AM. Politicians from all sides lent their support to the cause and finally, in May the new 4-bed EMU at Beaumont began admitting patients again. Despite Minister Reilly's promise to have the CUH unit open in quarter 3 of 2013, it remained closed at the year end. With waiting lists growing and patients being unnecessarily sent abroad for monitoring, Epilepsy Ireland's efforts are continuing in 2014.

## Neurology Services

Through our involvement with the Neurological Alliance of Ireland (NAI), Epilepsy Ireland continues to campaign for improved neurological care services in Ireland alongside almost 30 other representative groups. In 2013, we participated in an awareness day at Leinster House and in the NAI's 'Red Card for Neurological Care' campaign

highlighting the unacceptable waiting lists for neurological services and the impact of recessionary cuts.

The HSE's National Epilepsy Care Programme, led by Dr Colin Doherty continued its work to improve epilepsy services in 2013. This involves obtaining the resources on the ground to provide necessary services; effecting changes in practice to reduce variability and drive improvement; and measuring and collecting data to help drive change. Epilepsy Ireland's CEO Mike Glynn is a member of the Programme's Clinical Advisory Group.

## National and International Partnerships

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

International Bureau for Epilepsy

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

The Neurological Alliance of Ireland

[www.nai.ie](http://www.nai.ie)

Disability Federation of Ireland

[www.disability-federation.ie](http://www.disability-federation.ie)

Medical Research Charities Group

[www.mrcg.ie](http://www.mrcg.ie)

Joint Epilepsy Council of the UK and Ireland

[www.jointepilepsycouncil.org.uk](http://www.jointepilepsycouncil.org.uk)



*Gay Mitchell received the IBE/ILAE Ambassador for Epilepsy award in Montreal in 2013. Gay has been a long-time and successful advocate for the epilepsy cause in Europe.*



*Epilepsy Ireland presented to the Joint Oireachtas Committee in March on the dangers of generic substitution of AEDs.*

# TRAINING & EDUCATION

## Training For Success

Training For Success (TFS) is Epilepsy Ireland's pre-employment training programme for people with epilepsy run in partnership with the Institute of Technology Sligo and funded by Solas/ FAS.

First established in 1998, the aim of the programme is to address the needs of young adults with epilepsy in accessing meaningful employment. Even today TFS remains the only course of its kind in Europe, providing a practical and inspirational experience for young people with epilepsy who, because of their condition have experienced difficulties in progression of their educational and career aspirations. Offering FETAC Level 4 certification over a number of modules, TFS continues its original remit of developing practical, interpersonal and communication skills to help develop the individual personal confidence.

2013 was another successful year for TFS, but also one that has brought new challenges for the future. In both the 2012-2013 and 2013-2014 academic years, the yearly maximum of 14 students undertook the programme. 2013 began with the TFS being announced the winner of the 2013 AONTAS STAR Award - Nationwide Category - at a ceremony in Dublin. The STAR Awards are presented annually to acknowledge and showcase the work that communities and community based organisations make in the delivery of adult educational programmes throughout the country. Projects must show a high level of collaboration and partnership amongst participating groups; a learner-centred approach to education and clear evidence of outcomes. 115 projects were nominated in 2013, covering the four provinces and the fifth Nationwide category, of which TFS was declared the winner. The award is a much appreciated mark of recognition for the course and reward for the dedication of the TFS Programme staff and all 200 students that have completed the course to date.

However, in the latter half of the year the Institute of Technology Sligo indicated that it will significantly reduce its participation in its partnership with Epilepsy Ireland and Solas/ FAS. Whilst it is anticipated that the Institute will continue to host the programme on its extensive campus, procurement and provision of all teaching staff will become the responsibility of Epilepsy Ireland from the academic year of 2015/2016 onwards. Discussions concerning the implications of this decision will be undertaken in 2014 between all of the parties. The primary objective will be the continuation of this very successful and unique programme.

## Health Professional Training

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

The introduction of Buccalam in late 2012 saw changes being made to the original training programme in order to incorporate specific detail on the new medication.

In 2013 there was another significant increase in training days provided. 55 training sessions were delivered nationwide, compared with the 36 in 2012. In total, 554 people received the training in 2013, compared to 336 the previous year. 60% of the training provided in 2013 was 'in-house' – courses booked by organisations for relevant staff – a major shift from when the training was first introduced in 2009 when less than 10% of programmes delivered were in-house.

By the end of 2013, Epilepsy Ireland had delivered a total of 152 training days, providing this important, highly sought-after training to 1,695 health and allied health professionals.



*Students and staff from TFS accepting the AONTAS Star award: David Gillick, student; Paul Sharkey, Epilepsy Ireland; Maire Tansey, TFS Course Facilitator; Denise O'Connor, student and Honor Broderick, TFS Programme Manager.*



*TFS student Denise O'Connell accepting the AONTAS Star award.*



*Staff from Midway Services were just some of the 550 trainees who received their certificates in Epilepsy Awareness & the Administration of Buccal Midazolam in 2013.*

# RESEARCH

## Epilepsy Ireland Research Funding Scheme

Since the launch of the Epilepsy Ireland Research Funding Scheme in October 2008, over €750,000 has been invested in a total of seven projects we believe have the potential to add significantly to existing scientific knowledge of epilepsy and aid in the search for better outcomes.

Through the scheme, we fund pioneering research proposals that go through a rigorous examination process, including international peer-review, review by the Epilepsy Ireland Research Review Board and a final review by the Health Research Board (HRB). Proposals that pass all three stages are jointly funded by Epilepsy Ireland and the HRB under the HRB/ MRCG Joint Funding Scheme. 2013 saw the retirement of Prof. David Chadwick who chaired the Research Review Board since its inception. We thank him for his commitment and wish him all the best in his retirement.

## New Research Award

One new research funding award was made in 2013. Dr Naomi Elliott from the School of Nursing & Midwifery, Trinity College Dublin was granted €149,000 over three years for her study entitled 'The collaborative development of an evidence-based educational resource for self-disclosure strategies for people with epilepsy'. It will explore the concerns that adults with epilepsy have about telling others about their epilepsy and investigate what ways they find are best to tell other people about having epilepsy.

## Ongoing Projects

At the end of 2013, three research projects remained underway:

- **An evaluation of the role of the Epilepsy Specialist Nurse and the impact on patient quality of life**  
Prof. Agnes Higgins from Trinity College is assessing the role of the Epilepsy Specialist Nurse to determine if there are differences in outcomes between people who have access to an ESN and those that don't.
- **Demystify the veil of secrecy: a mixed method inquiry of parent-child dialogue about epilepsy and its associated stigma**  
Dr Veronica Lambert from DCU is examining the differences in perceptions and communications that exist between families when it comes to discussing and disclosing epilepsy.
- **A pharmacogenomic study of chronic refractory epilepsy**  
Dr. Gianpiero Cavalleri from the RCSI continued his work on the role of genes in patients' responses to epilepsy drug treatments. The team have already contributed to significant discoveries and the study will finish in 2014.

## Completed Research Projects

Two previously funded research projects were completed in 2013. Dr Yvonne Langan's study on the role of baroreflex sensitivity in people with epilepsy and its links to SUDEP found that both heart rate variability (HRV) & baroreflex sensitivity are reduced in people with epilepsy, potentially increasing the risk of sudden death. The study confirmed previous work on HRV but baroreflex sensitivity had not been studied in epilepsy previously. The study won the 2013 Kirker Prize awarded by the Irish Neurological Association.

Prof. David Henshall's study on the role of epigenetics in temporal lobe epilepsy (TLE) identified methylation changes to non-coding RNA in TLE. It identified methylation-sensitive short and long non-coding RNAs, including microRNA. This represents the first analysis of genome-wide DNA methylation changes in TLE and helps explain how gene expression is controlled in epilepsy. In 2013, Prof. Henshall was awarded an €11.5m EU grant to lead an international consortium investigating molecular mechanisms involved in epilepsy, in particular the role of microRNA.

## European Forum on Epilepsy Research

One of Epilepsy Ireland's strategic objectives for 2012-2016 was to bring a major international epilepsy conference to Ireland. In May 2013, to mark European Month of the Brain, the European Forum on Epilepsy Research took place in Dublin. Epilepsy experts as well as policy makers and politicians from around Europe gathered to discuss how the EU and its Horizon 2020 research programme can help alleviate the burden of epilepsy. Reducing epilepsy costs, tackling stigma and improving diagnosis and treatment were just some of the themes highlighted.

## Other research activities

Epilepsy Ireland is an official collaborator on the HRB-funded project being undertaken by Dr Veronica Lambert at DCU entitled "Talking about Epilepsy"; which began in 2013. We also continued our collaboration on an international study on the care of people with epilepsy and intellectual disability, which is due to report in 2014. As the year came to a close, plans were being put in place to develop an Epilepsy Deaths Register for Ireland to stimulate research on SUDEP and other epilepsy deaths.



*Prof. Emilio Perucca, Prof. Helen Cross, former Minister for European Affairs Lucinda Creighton and Epilepsy Ireland CEO Mike Glynn at the European Forum on Epilepsy Research.*



*Dr Naomi Elliott, Assistant Professor in General Nursing at Trinity College Dublin was awarded an Epilepsy Ireland research grant in 2013.*

# FUNDRAISING

Income from fundraising in 2013 was €521,908, a similar result to the previous year (€523,644). Fundraising encompasses numerous activities, campaigns and donations. In recent years, our focus has been on raising relatively small amounts from a large number of sources, for example church gate collections, the national raffle and Rose Appeals.

Supporter participation continues to be a key part of our fundraising. Last year, hundreds of people all over the country supported epilepsy by participating in events or by organising their own event. Unfortunately, just a few examples can be highlighted here, but we are hugely grateful to all our fundraising volunteers who supported our work in 2013.

## Play your part for Epilepsy

Epilepsy Ireland needs your help! There are many ways that you can support our work in providing 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
- Become a member
- Recommend us for your workplace charity of the year

**Play your part for Epilepsy:**  
What will you do?

@epilepsyireland | www.facebook.com/epilepsy.ie | www.epilepsy.ie | Email: info@epilepsy.ie

We'd love to hear from you! Call us at 01 4557500 for more information or check the fundraising section on [www.epilepsy.ie](http://www.epilepsy.ie). You can also download our new leaflet **Play your part for Epilepsy** from the site or get it from any EI office.



Emma & Julie Hogan were just two of the 150 volunteers who helped raise over €18,000 taking part in the 2013 Dublin Women's Mini Marathon.



TV Dragon Gavin Duffy, Mary Mitchell O'Connor TD and Epilepsy Ireland Patron Rick O'Shea donned their whites for the Look Who's Cooking fundraiser in Dublin in April.



DoneDeal.ie nominated Epilepsy Ireland as one of their chosen charities in 2013, donating almost €13,000 in October.



Supporting our flag day in Cork in 2013 were the students from Presentation College, one of many local schools that took to the streets to raise €3,150 on the day.



Ed Manders took on the challenge of swimming the English Channel for Epilepsy Ireland. He raised an amazing €8,650 for Epilepsy Ireland.

# 2013 FINANCIAL REPORT

Epilepsy Ireland reported a small deficit of €12,696 in 2013 (surplus of €36,316 in 2012). Income from grants and fundraising income increased by €58,298 to €1,560,515. However, expenditure also increased by €112,524 to €1,651,977 mainly as a result of strategic projects such as the development of the Living Well With Epilepsy toolkit, new research commitments and the name change to Epilepsy Ireland.

€759,000 (47% of total turnover) was received in Section 39 grants from the Health Service Executive under nine regional service level agreements. €522,000 (33%) of our funding was from public fundraising activities including donations, collections, corporate support, national campaigns, events and membership subscriptions. €215,000 (13%) was in grants from non-HSE sources and €93,000 (6%) was other income such as interest and training provided to health professionals.

Of every €1 we spent in 2013, 72c went to direct charitable objectives, 14c was spent on fundraising and 14c was spent on administration and governance. The nature of our work is highly dependent on direct staff resources, and in 2013, 61% of all expenditure was pay-related. Epilepsy Ireland employs 24 people and the average salary paid is less than €34,500. No additional payments or bonuses of any kind are paid to Epilepsy Ireland employees apart from employer pension fund contributions. A SORP table of salaries is included with the 2013 audited accounts. In 2009 staff took a 3% pay cut across the board. Salaries have remained frozen since then. Our Board members and members of our sub-committees are volunteers who donate freely their time, skills and experience.

Detailed financial information is available in our audited accounts which can be downloaded from [epilepsy.ie](http://epilepsy.ie).

## Income & Expenditure Account for the year ended 31 December 2013

	2013	2012
	€	€
Income	1,560,515	1,502,217
Expenditure	(1,651,977)	(1,539,453)
<b>Operating (deficit)/ surplus</b>	<b>(91,462)</b>	<b>(37,236)</b>
Investment Income	3,109	4,604
Interest Income	40,477	45,016
Unrealised gain/ (loss) on quoted investments	35,180	23,932
<b>(Deficit)/ Surplus on Ordinary activities before taxation</b>	<b>(12,696)</b>	<b>36,316</b>
Tax on (deficit)/ surplus on ordinary activities	-	-
<b>(Deficit)/ Surplus on ordinary activities after taxation</b>	<b>(12,696)</b>	<b>36,316</b>

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

## Brainwave - The Irish Epilepsy Association t/a Epilepsy Ireland Balance Sheet as at 31 December 2013

	2013	2012
	€	€
<b>Fixed Assets</b>		
Tangible Assets	132,483	135,579
Financial Assets	186,829	151,649
	<u>319,312</u>	<u>287,228</u>
<b>Current Assets</b>		
Debtors	35,929	29,211
Cash at Bank and in hand	1,751,201	1,811,037
	<u>1,787,130</u>	<u>1,840,248</u>
<b>Current Liabilities</b>		
Creditors (Amounts falling due within one year)	(263,659)	(271,997)
	<u>1,523,471</u>	<u>1,568,251</u>
<b>Net Current Assets</b>	<b>1,523,471</b>	<b>1,568,251</b>
<b>Net Assets</b>	<b>1,842,783</b>	<b>1,855,479</b>
<b>Capital and Reserves</b>		
Income & Expenditure Account	726,383	739,079
Special Reserves	1,116,400	1,116,400
	<u>1,842,783</u>	<u>1,855,479</u>

# OUR PEOPLE

## Board of Directors

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

\* Chair/Treasurer elected October 2013

## Finance & Audit sub-Committee

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

## Epilepsy Awareness sub-Committee

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

## Research Peer Review Board

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

† Retired May 2014

## Patron

### Rick O'Shea

Rick was diagnosed with epilepsy at the age of 16. He has been Patron of Epilepsy Ireland since 2006. Raising awareness of the condition has been a personal mission for Rick since then and he has undertaken dozens of media interviews, presented at national and international epilepsy events and taken a lead role in numerous Epilepsy Ireland awareness-raising and

## Staff

### Chief Executive

Mike Glynn

### Deputy CEO

Peter Murphy

## Services

### Director of Services

Wendy Crampton

### National Information Officer

Geraldine Dunne

### Community Resource Officers:

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

### Clinical Nurse Specialist in Community

#### Epilepsy Services

Sinead Murphy (Beaumont Hospital)

## Administration & Fundraising

### Key Fundraiser

Noeleen McDaid

### Membership & Fundraising Officer

Ashley Butler

### Fundraising Assistants

Glenna Gallagher  
Catherine Healy

\*Resigned September 2013

\*\* Appointed November 2013

### Training & Communications Manager

Paul Sharkey

### Training For Success Manager

Honor Broderick

### Training For Success Facilitator

Maire Tansey

### Accounts & Administration Manager

Elizabeth Ryan

### PA to CEO

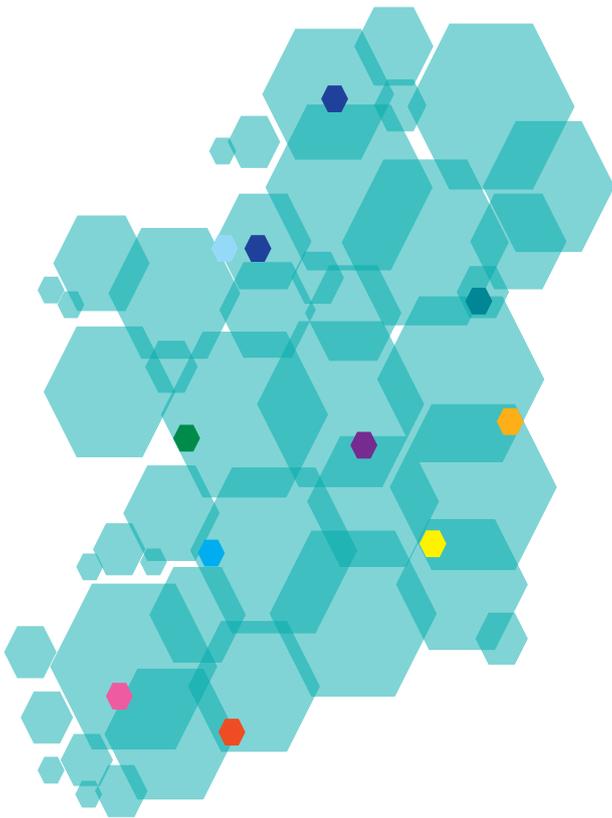
Mary Malone

### Receptionists

Madge Geoghegan  
Joan McDermott



# LOCATIONS



## Head Office

Address: 249 Crumlin Road, Dublin 12.  
Tel: 01 455 75500  
Email: [info@epilepsy.ie](mailto:info@epilepsy.ie)

## Specialist Nurse Helpline

Tel: 01 455 4133 Monday 9.30am – 1pm

## North West

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

## Letterkenny Office

Grand Central Complex, Floor 2B, Canal Road, Letterkenny,  
Co Donegal.  
Tel: 074 9168725  
Email: [amooney@epilepsy.ie](mailto:amooney@epilepsy.ie)

## Sligo Office

2C Castle House, Castle Street, Sligo  
Tel: 071 91 41858  
Email: [amooney@epilepsy.ie](mailto:amooney@epilepsy.ie)

## West

Covering: Galway, Roscommon & Mayo  
Community Resource Officer: Edel Killarney  
Westside Resource Centre, Seamus Quirke Road, Westside,  
Galway.  
Tel: 091 587640  
Email: [ekillarney@epilepsy.ie](mailto:ekillarney@epilepsy.ie)

## Mid-West

Covering: Limerick, Clare & Tipperary North  
Community Resource Officer: Anna Kelly  
Social Service Centre, Henry St., Limerick.  
Tel: 061 313773  
Email: [akelly@epilepsy.ie](mailto:akelly@epilepsy.ie)

## Kerry

Covering: Co. Kerry  
Community Resource Officer: Kathryn Foley  
9/10 The Paddocks, Ballydowney, Killarney, Co. Kerry.  
Tel: 064 6630301  
Email: [kfoley@epilepsy.ie](mailto:kfoley@epilepsy.ie)

## Cork

Community Resource Officers:  
South Lee & West Cork: Niamh Jones  
North Lee & North Cork: Mary Lawlor  
35 Washington Street, Cork.  
Tel: 021 - 4274774  
Email: [Niamh - njones@epilepsy.ie](mailto:Niamh-njones@epilepsy.ie) / [Mary - mlawlor@epilepsy.ie](mailto:Mary-mlawlor@epilepsy.ie)

## South East

Covering: Kilkenny, Wexford, Carlow, Waterford & Tipperary  
South  
Community Resource Officer: Joan Ryan  
C/o HSE, St. Joseph's, Waterford Rd, Kilkenny.  
Tel: 056 7789904  
Email: [jryan@epilepsy.ie](mailto:jryan@epilepsy.ie)

## Midlands

Covering: Offaly, Longford, Laois & Westmeath  
Community Resource Officer: Margaret Bassett  
c/o Carers Association Market Square, Tullamore, Co. Offaly.  
Tel: 057 9346790  
Email: [mbassett@epilepsy.ie](mailto:mbassett@epilepsy.ie)

## East

Covering: Dublin, Kildare & Wicklow  
Community Resource Officer: Ina Murphy  
Epilepsy Ireland National Information Officer: Geraldine Dunne  
249 Crumlin Road, Dublin 12.  
Tel: 01 - 4557500  
Email: [Geraldine: gdunne@epilepsy.ie](mailto:Geraldine:gdunne@epilepsy.ie) / [Ina: imurphy@epilepsy.ie](mailto:Ina:imurphy@epilepsy.ie)

## North East

Covering: Louth, Meath, Monaghan & Cavan  
Community Resource Officer: Noreen O'Donnell  
Unit 1a, Partnership Court,, Park St, Dundalk, Co. Louth.  
Tel: 042 - 9337585  
Email: [nodonnell@epilepsy.ie](mailto:nodonnell@epilepsy.ie)

## Training For Success

Manager: Honor Broderick  
Institute of Technology Sligo, Ballinode, Sligo.  
Tel: 071 915 5303  
Email: [Broderick.honor@itsligo.ie](mailto:Broderick.honor@itsligo.ie)

## Online

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



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[facebook.com/epilepsy.ie](https://facebook.com/epilepsy.ie)  
[youtube.com/BrainwaveEpilepsy](https://youtube.com/BrainwaveEpilepsy)  
[@epilepsyireland](https://twitter.com/epilepsyireland)

Charity Number:  
CHY 6170

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