



Epilepsy News

Shining a light on epilepsy

Epilepsy Ireland Issue 72 Spring 2016



I See Beyond campaign:
Minister Leo Varadkar, Rick O'Shea
and Yvonne Kelly at the launch
of the Epilepsy Ireland/ Headway
awareness campaign on hidden
disability.

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NOTE FROM THE EDITOR

Welcome to the first issue of Epilepsy News for 2016. Already proving another busy year, this is also a very special year for the association. 2016 marks the fiftieth anniversary of the founding of The Irish Epilepsy Association. Our principal purpose as then continues to be to provide information and support for people with epilepsy, their family and carers. With your continued support we will continue this work.

In the current climate of operation transformation you might find Noel Gavin's story (page 11) of interest and perhaps inspiring. For those with young children the Helium Project (see inside back cover) might prove interesting. A service programme schedule for 2016 is now available (see page 13) and all events will continue to be posted on www.epilepsy.ie so be sure to check what is happening in your area.

Happy reading

TRAINING FOR SUCCESS 2016

RECRUITMENT UNDERWAY



The poster features a young girl in a blue shirt looking thoughtful. Text includes: 'HAS EPILEPSY LEFT YOU FEELING ADRIFT?', 'Core subjects include: Career Planning, Communications, Epilepsy Management, Information Technology Skills, Mathematics, Personal Effectiveness, Understanding Interculturalism, Team Working, Work Experience, Work Place Safety', 'Training For Success', 'No leaving Certificate required', 'All eligible students receive a MSLTE training allowance and an accommodation allowance', 'Medical services on campus', 'Campus accommodation', 'Qualification Options: FETAC Level 4', 'For further information Tel: 071 915 5303', and logos for Sligo, Epilepsy Ireland, and ctb.

Training For Success (TFS), Epilepsy Ireland's pre-employment training programme is currently recruiting students for its 2016-17 term. Places are limited to 14 people. If you are or know a person with epilepsy and also capable of independent living this might just be the opportunity to improve career/ educational prospects.

Based in the Institute of Technology, Sligo TFS is a FETAC Level 4 Accredited Programme which provides training to improve career seeking skills and personal development. First established in 1998 the programme has helped many young adults improve their employment chances and also go on to third level education.

If you are interested in finding out more about this unique training experience, the only one of its kind in Europe then please contact **Honor or Maire at 071 9155303**

EPILEPSY NEWS WANTS TO HEAR YOUR STORY.

One of the most popular features of Epilepsy News is the personal story. Over the years many people have submitted their personal experiences of living and dealing with epilepsy. These stories have proved to be heart rendering, thought provoking, entertaining and most importantly inspiring.

If you have a story and would like to share it with others then we want to hear from you. Please contact us through info@epilepsy.ie all submissions will be treated confidentially and will not go to print without your final permission.

If you have a story then send it to us, if you think you would like to share your experiences but haven't yet put it on paper then let us know and we will help you prepare it for publication.



The image shows the cover of Epilepsy News magazine. It features three women standing in front of a building. Text on the cover includes: 'Epilepsy News', 'Shining a light on epilepsy', 'Issue 71', 'National Conference 2015', 'Keynote Speakers: Prof Jean K Austin; Dr Sophia Varadkar; Dr Helena Moore', and 'IN THIS ISSUE: National Conference 2015, Staying Safe for Christmas, Hanneke De Boer - an appreciation'.



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Neurology audit highlights widespread deficits



The first National Audit of Neurology Services, published in February by the Neurological Alliance of Ireland and the Neurology Clinical Care Programme, has highlighted widespread deficits. The audit found that the recommended ratio of one neurologist for every 70,000 people is exceeded in each hospital group area with the Mid West coming out worst with a ratio of 1:200,000. Only six of the 11 neurology centres in the country have dedicated neurology beds and even these are “under constant pressure from other departments”. Waiting times for routine MRI scanning exceed 12 months in seven of the 11 centres, while 10 centres reported very limited or no access to community neurorehabilitation services. Speaking at the launch of the report, NAI’s Magdalen Rogers (pictured) said “We now have clear evidence for what clinicians and people with neurological conditions have been saying for years... that we are failing to provide the level and type of care needed for 800,000 Irish people with neurological conditions that is taken for granted in other European countries.”

[GO bit.ly/1nfhgk6](https://bit.ly/1nfhgk6)

No progress in preventing epilepsy in 40 years

A Finnish study of over 100,000 epilepsy diagnoses published in *JAMA Neurology* has found that there has been no change in the incidence of epilepsy in people younger than 65 over the past 40 years and an increased incidence among older patients. Antiepileptic drugs can block seizures but they do not prevent epilepsy occurring. The current primary prevention methods are by reducing the risk for traumatic brain injury, stroke and dementia. The authors said they were surprised by the lack of change among younger patients due to the decline in road traffic accidents. However, they said the increase among older patients

was not unexpected due to an ageing population and the fact that conditions like dementia and stroke are leading causes of new-onset epilepsy.

[GO bit.ly/1QSexow](https://bit.ly/1QSexow)

Biofeedback for epilepsy



An interesting abstract at the American Epilepsy Society Annual Meeting in December suggests that biofeedback, a technique using the mind to control physiologic responses such as heart rate and respiration, can reduce seizure frequency. Dr Yoko Nagai, from the University of Sussex has developed an intervention called electrodermal (EDA) biofeedback which has been described as similar to playing a video game. The approach consists of both physiological and psychological components and over time, patients learn to anticipate and perceive seizure triggers and to respond to them. Trials have showed that 60% of 18 patients receiving the biofeedback reduced their seizure frequency by more than 50% after 12 45-minute sessions. A more recent study found an average reduction in seizure frequency of 40%. Dr Nagai now plans to develop a digital version of the therapy that can be more widely disseminated.

[GO wb.md/1L7vpeJ](https://wb.md/1L7vpeJ)

Seizure detection technology reviewed

A new study by the Cornwall Partnership NHS Foundation Trust in the UK published in the journal *Seizure* has reviewed over 40 existing studies of seizure detection devices designed for everyday use in a domestic setting. Most devices focused on changes in movement or physiological patterns. None of the devices were able to detect all seizures and false positives were a problem. Calling for studies involving more patients, the researchers concluded: “Seizure detection devices are at a relatively early stage of development... Nevertheless, the development of seizure detection devices offers great potential in

the management of epilepsy.” Meanwhile, a number of new studies were presented at the American Epilepsy Society’s Annual Meeting in December, including one of a device called the Brain Sentinel Seizure Detection and Warning System which claims to detect tonic-clonic seizures with the same success rate as an epileptologist reviewing video EEG recordings. In trials, the device sent an alert on average 14 seconds after seizure onset with 100% accuracy.

[GO bit.ly/1NMilpN](https://bit.ly/1NMilpN)

Migraine with aura and epilepsy share genetic link

A new study in *Epilepsia* has found that a strong family history of epilepsy is associated with higher incidences of migraine with aura. It has already been found that epilepsy patients have a twice as high a risk of having migraine. Until now, a shared genetic cause was never established. Using data from the Epilepsy Phenome/ Genome Project, lead author Dr. Melodie Winawer and colleagues studied 730 participants with epilepsy and 501 families with a prevalence of migraine with aura. The study concludes that the rate of migraine is increased in people who have close (rather than distant) relatives with epilepsy and only when three or more family members are affected.

[GO bit.ly/1L7u6wo](https://bit.ly/1L7u6wo)

www.brainsentinel.com | bit.ly/1RtlfSj

Vitamin D monitoring important in children with epilepsy

A new study from South Korea has found that children with epilepsy may be more likely to have a vitamin D deficiency. The study involved 198 children with epilepsy who were taking antiepileptic drugs. 124 (63%) were shown to have a vitamin D deficiency. It was more common during the winter and spring months, and in those aged over 12 years. Of the 57 subjects who were not vitamin D deficient at the time of initial testing, 47 became deficient during the five year follow-up period. The largest declines in vitamin D levels were linked to a longer period of medication, decreased mobility and underlying brain abnormalities. Vitamin D deficiency can cause fatigue, aches and pains, and frequent infections.

[GO 1.usa.gov/21O7aGt](https://1.usa.gov/21O7aGt)

EPILEPSY IRELAND AND HEADWAY JOIN FORCES

FOR #ISEEBEYOND CAMPAIGN



Have you got your personalised #iseebeyond social media profile pic yet?

Hundreds of thousands of people in Ireland are affected by hidden disabilities including 37,000 people with epilepsy and 30,000 people with an acquired brain injury (ABI).

In February, Epilepsy Ireland and Headway, the ABI charity joined forces to launch a new public awareness campaign called **I See Beyond** (www.iseebeyond.ie). The campaign focuses on raising awareness of hidden disabilities and the challenges these conditions can present in day to day life. It was officially launched on February 3rd by the Minister for Health, Leo Varadkar TD.



Epilepsy Ireland Patron Rick O'Shea with Headway volunteers Yvonne Kelly and Derek Cummins at the launch of #iseebeyond

Speaking at the launch, the Minister called on members of the public and businesses in Ireland to get behind the campaign. "I am very happy to support the 'I See Beyond' message. I think it's a very important one. It's time for all of us to take a long overdue step towards a more

inclusive society, and the best way to do that is through education... The stories being told as part of the I See Beyond campaign should touch the public consciousness and help to bring about a more compassionate response... It doesn't cost anything, and it only takes a few seconds of your time to show support on social media. But the difference you can make is invaluable."



Minister Varadkar officially launched the campaign on February 3rd

One of the stories being told as part of the campaign is that of Katie Cooke, who lives with multiple seizures each day, and who last year achieved her goal of completing the Dublin marathon. Katie's story has received a hugely positive response and she has already proven to be an inspiration to many. Other videos in the campaign focus on the misunderstanding of complex partial seizures and on epilepsy stigma.

All six of the videos used reflect real stories and illustrate how all might not be how it seems in the day to day life of the person living with epilepsy or a brain injury. They aim to challenge those watching to think twice about what the person might be going through and to be more compassionate and understanding... to See Beyond.

Epilepsy Ireland Patron Rick O'Shea also helped launch #iseebeyond. He said "I strongly believe hidden conditions such as epilepsy should get the awareness they deserve, and #iseebeyond will definitely shine a light where it's needed. From personal experience, I can say it's so important for people to understand

what living with something as hidden as epilepsy can mean and entail. Once the fear is gone, so too will the stigma around it and feelings of exclusion... We should all do our bit to get the discussion going."

Despite the prevalence of hidden disability, a national survey conducted recently by Amárach Research revealed an overwhelming lack of awareness of hidden disabilities. Seven out of 10 respondents admitted they did not know the meaning of 'hidden disability', while a similar number said they would not feel comfortable telling their employer that they had a hidden disability.

Businesses have also been invited to take part in #iseebeyond and plenty have signed up including Flogas, BDO, Energia, JustEat and Munster Rugby.



Katie Cooke's video is one of the highlights of the campaign. See it at www.iseebeyond.ie.

Support the Campaign:

- Watch and share the six short videos at iseebeyond.ie, using #iseebeyond
- Upload a selfie to generate your own #iseebeyond personalised social media icon to show your support
- Share your own personal story on the website and explain how it is to live with an illness or disability that can't easily be seen.
- Encourage your employer or other businesses you know to support #iseebeyond too!

 www.iseebeyond.ie



Every case is different. For some people, epilepsy is controlled or rare and therefore causes little or no actual disability. But for the rest of us, it's a condition with difficulties. Epilepsy News columnist Maria Carty-Mole argues that having a secret condition is definitely to our advantage...and definitely not.

The #iseebeyond campaign was launched last month, and its touching videos make the viewer think more about the fact that epilepsy is a hidden disability, one that cannot be seen at first glance. At the times when we're not staring absently into space or foaming at the mouth, we have no visible cues to indicate the condition. Our walk is stable, our physical reflexes are 'normal', and we don't have 'MIGHT GET SEIZURE AT ANY MOMENT' stamped on our foreheads. Thank God.

YAY

We look fine most of the time, even if – shh! – we don't actually feel it. And surely this is to our advantage? It means that people don't stare at us on the street, and that it's completely our choice whether or not to tell. We can practice strategic self-disclosure, picking the right moments to reveal the disability and deciding when instead to 'pass' and appear to society as a stout, able-bodied individual.

Because while we may not be particularly embarrassed about the condition, society still is. A disability can make a person seem inferior in some way, and consequently there is a stigma attached to it. Lots of people with epilepsy don't feel comfortable discussing it at work or with friends, and many dislike using the label 'disability' at all, because it is a word that comes with discrimination.

Therefore we need to be realistic, and relish the fact that staying quiet is an option. We are under no legal obligation to mention epilepsy in a job interview. Time and again you hear stories of how someone was rejected for a post because of their epilepsy, and Ashling certainly knew that it was wise to keep her mouth shut: "The fact that I can hide it to an extent is a blessing," she says. "Your health is inextricably linked with your ability to perform in the workplace and I know that I would never have got past the interview board had they felt that I would need sick leave." In a national survey conducted by Amárach Research in December 2015, a whopping 70% of people said they wouldn't feel comfortable telling their employer that they had a hidden disability. It's just not worth the risk.

NAY

This is a good moment to suggest that such apologetic behaviour might actually be what's causing the stigma in the first place. Allowing epilepsy to stay hidden, like it's something to be ashamed of, only encourages the taboos and the lack of knowledge. If we're too shy to volunteer information, and people are afraid to ask us questions in case they insult us, then the general consensus is always going to be that every seizure is a tonic clonic one triggered by flashing lights. Until everyone is more informed about the condition we are in danger of choking on a spoon.

It's not just the general public who can find epilepsy challenging. The fact that it is hidden makes it more difficult for health professionals to recognise, and it's common for a person to have the odd partial seizure for months or even years before he/she is diagnosed. For Orla it took three years, because her tests were coming back clear and doctors refused to believe her claims. Having a disability is bad enough; we don't want to deal with negative judgements too. "They kept telling me it was all in my head and that the seizures weren't happening," Orla remembers. "I was having two or three a week but the epilepsy specialist nurse didn't believe me or my family... why would I lie about it, and more importantly why would I put myself through all those injuries? It was the worst feeling ever to be told by people who are meant to make you better that it's not really happening."

Eventually she had a seizure in A&E and woke up to nurses and doctors saying how sorry they were and that they should have believed her from the very start.

I was shocked when I first heard that nearly one in 100 people has epilepsy. That many?! There's power in numbers, and it would be very reassuring if we could look around a stadium and see that the hundreds of others who are suffering from it too are getting on with their lives. On days when he is upset, nine-year-old Matthew laments that he's the only one in the world who has epilepsy, who has to go to appointments, and who has to take tablets. The truth is his best friend has it too, but because his friend's parents want to keep it hidden from the world, Matthew has no idea of this comforting fact. "I really wish I could tell him," his mother says. "But it's not my place to do so."

For people who have seizures often, who can be hit anytime and anywhere, epilepsy is far from secret. For all of us, in fact, it's only hidden until the moment we have a seizure. So why try and deny that it's part of us, and part of our identity, when there's a chance that it's going to be discovered anyway? Confidently explaining it to friends and colleagues will suffice... no need to put a stamp on your forehead.



EPILEPSY RESEARCH EXPLAINED ON #EPILEPSYDAY

To mark International Epilepsy Day and highlight new research and developments in the field of epilepsy, Epilepsy Ireland and the RCSI joined forces on February 8th to organise the 2nd Epilepsy Research Explained public seminar at RCSI in Dublin.

A full house attended and heard keynote speaker Dr Tracy Dixon-Salazar from the CURE organisation in the US discuss her own inspirational personal story and explain how genetic testing and personalised medicine may well hold the key to finding epilepsy cures in the future.

Richard Corbridge, HSE's Chief Information Officer discussed recent and upcoming e-health developments in Ireland including the HSE's Epilepsy Lighthouse project (below).

Other speakers included cANP Yvonne Owen from Beaumont Hospital, Dr Veronica Lambert from DCU and Trinity College researchers Prof Agnes Higgins and Dr Naomi Elliott.

Videos of all the talks are now on our YouTube channel.



Dr Dixon-Salazar: youtu.be/y63gsDFnR1A
Richard Corbridge: youtu.be/BDLlhaZish8
Yvonne Owen: youtu.be/3MT941VBX3s
Dr Veronica Lambert: youtu.be/4xOw82hiWsU
Prof Agnes Higgins: youtu.be/eSl6jHGx6cs
Dr Naomi Elliott: youtu.be/xmHy1qpk4NU



Dr Tracy Dixon Salazar gave an emotional and inspiring presentation



Prof Norman Delanty with HSE's Richard Corbridge



A full house at RCSI



Dr Naomi Elliott, Trinity College who spoke about the How2Tell study

LIGHTHOUSE PROJECT TO PROVIDE INVESTMENT IN EPILEPSY E-HEALTH



Minister for Health Leo Varadkar attends a briefing on the Lighthouse Projects

Speaking at the Epilepsy Research Explained event (above) on #epilepsyday, the HSE's Chief Information Officer, Richard Corbridge announced details of the HSE's new Epilepsy Lighthouse Project.

The Epilepsy Lighthouse Project is one of three such e-health projects that has been launched in 2016 in order to better describe the benefits that technology and electronic health records can offer to patients.

Through the Epilepsy Electronic Patient Record (see page 7), epilepsy already

has a technology programme underway that when complete will offer all patients with epilepsy and the clinicians who treat them a more efficient and truly personalised treatment pathway for managing their condition using technology-based solutions.

Through investment in 2016, a number of new elements will be introduced:

- **Genomic sequencing** of an individual patient - this would allow scientists to read genetic codes so they can make comparisons between normal versions of a gene and disease-causing versions of a gene thereby assisting in developing a treatment and care pathway. Initially, 50 children with epilepsy and 50 adults with a diagnosis of both Intellectual Disability and epilepsy, will have their genome sequenced, with the emphasis on measuring the impact that genetic testing has on the patient's care and treatment. It is hoped that the pilot project will lead to a new model of treatment and care that would include extensive genetic testing in future.

- The introduction of **Patient Reported Outcomes** whereby people with epilepsy can report to their treating clinician, via a mobile portal, specific and personalised information on their seizures, quality of life, and medicine compliance. This effectively allows the patient to interact directly online with their own electronic health record.

- **Improved clinical analysis** where clinicians can use aggregate data to analyse and gather insights for the wider patient community to inform future care and population health.

The RCSI will deliver this Lighthouse project as a collaborative research project with the HSE and eHealth Ireland. Other partners including Epilepsy Ireland will continue to be involved in the delivery of the project.

The Lighthouse Projects were also the focus for discussion at the recent meeting of the eHealth Ireland Ecosystem in Dublin and we want to thank all the Epilepsy Ireland volunteers who attended and contributed to the discussion.



www.ehealthireland.ie

THE NATIONAL EPILEPSY ELECTRONIC PATIENT RECORD

AN UPDATE

By Mary Fitzsimons, Programme Manager, National Epilepsy EPR



Timely sharing and exchange of standardised patient information between clinicians is important for achieving effective continuity of care for people with long term conditions like epilepsy. For example, doctors, nurses and other clinicians who are based at different geographical locations often need to share information about an individual patient in order to provide the best care plan for that person. However, such information sharing is seldom straightforward as medical records are still frequently paper-based and different healthcare organisations keep their own exclusive unshareable record. Availability of patient information to clinicians when and where needed can be made possible with the use of an electronic patient record (EPR).

The National Epilepsy EPR

The HSE National Clinical Care Programme for Epilepsy is one of a small number of clinical disciplines in Ireland that uses an EPR to facilitate better integration of care for people with epilepsy across the country. This EPR is a secure web-based system that can be accessed by authorised clinicians who are involved in the delivery of epilepsy services. The system currently holds the medical records for more than 6,000 individuals with epilepsy. Unlike paper-based health records, multiple users at any location can have simultaneous access via the internet to this centrally stored electronic system. This is improving availability of important clinical information at the point of patient care.

The Unifying Force of the Epilepsy EPR

Advanced nurse practitioners (ANPs), consultant epileptologists, non-consultant hospital doctors (NCHDs) and clinic secretaries across Ireland are all using the epilepsy EPR in the course of their work. These people refer to it as a “unifying force” for delivering integrated epilepsy care and services. The following briefly outlines some of the experiences from those using the system.

Telephone Advice Line

When a person with epilepsy or their carer calls one of the telephone advice lines, the ANP taking the call can immediately access the patient’s electronic record from their desktop computer. This means that the nurse can promptly address the caller’s query, as they will have ready access to important information such as details about the patient’s anti-epilepsy medication treatment, the nature of their epilepsy and seizure control, and so forth. In a paper-based system, there would be inevitable delays (sometimes days) while the nurse waits to for

the patient’s paper chart to be retrieved from the filing area. Such timely electronic access to important clinical information promotes safe patient care.

Epilepsy Surgery and Shared Care

If a person with epilepsy undergoes surgery to help control or eliminate their seizures, this will be carried out at Beaumont Hospital in Dublin. However, their epilepsy care before and after surgery will happen at a centre closer to home. For example, if the patient is resident in Cork, they will likely receive before and after epilepsy care at Cork University Hospital. Now with the epilepsy EPR, clinicians at Beaumont and at Cork can share a single version of the patient’s medical record. This helps improve continuity of care as the patient moves between centres and interacts with different clinicians.

Epilepsy Outreach

The epilepsy EPR allows improved access to specialist epilepsy services delivered in a way that more appropriately meets the needs of people with epilepsy who also have an intellectual disability (ID). Without the need to transport paper-based medical records (which has data protection implications) specialists in epilepsy care who are usually based in a hospital setting regularly go to intellectual disability residential centres to provide outreach services. This means that the person with epilepsy can receive specialist care in a setting that is familiar to them and with those who know them best available to provide relevant information to the visiting clinicians. The patient’s health record is accessible for review and update via a secure internet connection at the outreach site. The EPR allows the service to be brought to the patient, rather than the patient be brought into an environment that may feel intimidating.

Sites Using the National Epilepsy EPR

The national epilepsy EPR was originally designed, developed and first used by the epilepsy team at Beaumont Hospital in Dublin. When the National Clinical Care Programme for Epilepsy was initiated in 2010, the EPR was implemented over time in a number of centres across Ireland. As well as Beaumont Hospital, the EPR is now in use at Galway University, Limerick University and Cork University Hospitals, Sligo Regional Hospital, St James’s, Tallaght and Mater Hospitals, Connolly and Cavan/Monaghan Hospitals Group, and in the intellectual disability sector at Daughters of Charity Clonsilla, St Mary’s Drumcar, and Cheeverstown House in Dublin.

Further Information

E-health Ireland Case Study: [GO bit.ly/234LSWF](https://www.go.gov.ie/bit.ly/234LSWF)

Recent video about the EPR: [GO youtu.be/glcVYDcmMZk](https://www.youtube.com/watch?v=glcVYDcmMZk)

Email us: eprsupport@beaumont.ie

See also the feature on the Epilepsy Lighthouse Project in this issue, an initiative which will further enhance the value of the EPR.

EPiC

Epilepsy Partnership in Care

The HSE National Epilepsy Care Programme, in conjunction with Maynooth University and RCSI, has recently received funding to conduct research that aims to understand how epilepsy care services in Ireland can become more patient-centred.

What is Patient-Centred care?

The Institute of Medicine in the US defines patient-centred care (PCC) as “health care that establishes a partnership among practitioners, patients, and their families (when appropriate) to ensure that decisions respect patients’ wants, needs, and preferences and that patients have the education and support they need to make decisions and participate in their own care”. PCC is believed to improve quality and safety, and lead to better health outcomes for people with conditions like epilepsy, as well as result in more cost-effective service delivery.

Epilepsy Partnership in Care (EPiC)

PCC is all about creating a balanced partnership between people who use healthcare services and those who provide the services. For example, people with epilepsy, their family and/ or informal care-giver, together with doctors, nurses, and other healthcare workers can form such a partnership. In epilepsy, this partnership will ensure that the right healthcare decisions are made for each individual. It can also help to make sure that the correct support is in place to help people with epilepsy manage their day-to-day life and healthcare needs.

Traditional healthcare often focuses on a person’s illness rather than on the quality of all aspects of their life. Similarly, the traditional approach usually sees the patient as someone who receives treatment rather than someone who makes decisions in partnership with the clinician about the treatment plan that will best suit their particular needs.

The title “Epilepsy Partnership in Care”, or EPiC for short, has been adopted for this research project as the research team hope to create the conditions that will allow people with epilepsy to work together with health service personnel to design care processes that suit patient needs and respect their individual preferences.

The Research Project

A scheme called the Research Collaborative in Quality and Patient Safety (RCQPS) is funding this project. The RCQPS is made up of the Health Research Board (HRB), the Health Services Executive (HSE) and Royal College of Physicians in Ireland (RCPI).

This research project will examine the degree to which epilepsy services in Ireland are patient-centred. The viewpoint of patients, their families/ friends and healthcare workers will be considered. The project will also identify ways in which epilepsy services might be made more understanding of the needs and preferences of people with epilepsy. The project will also put in place the means to continuously improve patient-centred care for people with epilepsy across Ireland.

Picker Institute Dimensions of PCC



The project is being carried out in a number of sites and epilepsy centres across the country. Postdoctoral researchers will manage the day-to-day running of the project and will invite people with epilepsy, some family members and /or informal caregivers, and health service providers to take part in the research project.

There are different elements to the project. People who wish to take part can decide which part(s) below they would like to engage with:

Part A

Researchers will attend epilepsy clinics and observe how people with epilepsy and their family members interact with the health service providers including doctors, nurses, clinic secretary and others. This observation is called ethnography.

Part B

Researchers will meet one-to-one with research participants, to talk about their experience of health services. These interviews will aim to capture the perspective of people with epilepsy as well as those delivering healthcare services to hear about what works well and what does not. This is called interview.

Part C

Researchers will meet with participants in groups of 8-10 to have a group discussion about experience of patient-centredness in health services. This is called a focus-group.

Part D

A group of healthcare providers (for example, doctors, nurses, secretary) together with patients and/or family members will form a team. There will be approximately 12 people in this team who will work together to design improvements in epilepsy services. This type of activity is called participatory action research (PAR).

Benefits of the EPiC Project

For people with chronic/long-term conditions like epilepsy, PCC is central to maximising health, well-being and quality of life. PCC changes the role of the healthcare professional from “experts that care for patients, to enablers that support patients to make decisions.” (Marshall M, Bibby J. Supporting patients to make the best decisions. BMJ 2011).

Getting involved

To learn more about this project or if you are interested in taking part, please contact the research team on 01 4022763 or at epic@rcsi.ie



My name is Yvonne Cahalane and I'm a proud mama of two wonderful boys, Oscar & Tristan. Tristan is a two-year-old little boy filled with curiosity, resilience & laughter. We call him Mr.T!

When Mr.T was five months old we were awoken one night to his coughing. We took him out of bed and he began to get sick. Straight after that he went into the first of many Status Epilepticus seizures that he was to have in his young life. As we rushed to bring down his temperature and waited for medical assistance, the seizure seemed endless. After 20 minutes, the seizure stopped for two and then began again for another 30 minutes.

He was floppy, drained and needed to be transported to hospital straight away. All I could think was "Is he going to die?". Once Tristan was stable we were able to go home after a few days. Unfortunately his seizures continued and the slightest cold or temperature increase would set off an inevitable chain of events. Mr. T became well accustomed to A&E, the hospital and the paramedics.

After another hospital stay and a lumbar puncture test, we received a diagnosis of Dravet Syndrome. We were told to prepare ourselves for what we were about to find out.

Dravet Syndrome is often called "a catastrophic form of epilepsy". It is characterised by multiple seizure types and is very difficult to treat. We as a family have not received a full genetic diagnosis but I have and also carry the gene and I am no stranger to epilepsy myself.

We were in shock with the diagnosis and in coming to terms with it, we needed to know more. Through our quest to find out more about Dravet's and what to expect, we began to realise that there may be something out there to help Tristan have 'A Future'. Unexpectedly this was medical cannabis.

We did a lot of digging. We read studies from America to Israel; spoke to researchers, doctors and other parents. And so began our goal for Tristan to receive this medicine.

We decided we needed to get this done before Tristan's then 20+ seizures a day escalated into 200+ a day.

If the mountain won't come to Muhammad, then Muhammad must go to the mountain. In our case Colorado in the US where medical use of cannabis has been permitted for some years.

Cannabis and epilepsy have something in common – stigma. We were nervous to tell our world we were looking for cannabis for Tristan. We didn't know if everyone would understand.

We needn't have been worried - we received global support and our gratitude we couldn't express enough. From everybody donating to Tristan's GoFundMe page and holding fundraising events, Tristan's target of €35,000 was exceeded. We put in place our doctors, all the logistics and plans to care for Oscar, my handsome little 3-year old we would have to leave behind. On December 13th last we departed for Colorado.

We visited our doctors and soon were ready to begin Mr.Ts medical cannabis programme using whole-plant cannabis oil. Dosing is low & slow. Tristan was tired after his first few doses but otherwise very well.

As we increased the dose, he changed right in front of our eyes. Such little changes that make such a difference! Within the first week we noticed improved eye contact, more awareness, babbling, new words, imitating, responding to things I would say to him. Within the second week, his stability improved. He wasn't falling after a few steps like he used to. He was turning, trying to run, bending his knees to pick up toys, crawling and kicking a ball.

We spoke with the doctor who agreed how fast results were happening for Tristan, but doctors still don't understand why it works for one child and not work for another. Tristan has had two days of a snotty nose and a high temperature that previously would have put him in hospital and led to seizures, but not now. We're finally beginning to see his character - a bright smiling happy playful little boy full of devilment.

Once the THC (tetrahydrocannabinol) part of the plant was introduced, Tristan's daily but shorter absence and myoclonic seizures stopped. We were able to wean two drugs for the first time without having seizures. For any seizure activity that presented while weaning we gave literally a drop of THC like a rescue and it never escalated into a full seizure.

Tristan has not had a seizure since December when we arrived. He can tell me he's hungry, that he's tired, if he wants me to read to him, wants a bath, play or potty. And recently that he loves me. We have come from videoing him at night, listening out for silent seizures, wiping his bloody noses, packing bags for the hospital whenever he gets a cold and seeing his brother getting an ice pack from the freezer to treat his bruises. After two months of seizure freedom, we are looking forward to weaning Tristan off more medications and updating all who have supported us in giving Tristan 'A Future'. This treatment has changed our family's lives and forever more we will be grateful for all the support we have received.

Find out more on the Tristan's Team Facebook page: [on.fb.me/1UEXAnq](https://www.facebook.com/1UEXAnq)

Note from ed: Yvonne and Tristan's experience has been hugely positive, perhaps even life-changing. They are one of a growing number of families in the US for whom cannabis treatment has had success and the cases so far point to cannabis as a potential new avenue of treatment for some forms of epilepsy. However, to date there is no robust evidence from high quality scientific studies that supports the use of cannabis in epilepsy. Clinical trials are currently ongoing and interim results have been positive. We hope to have final results from the trials later in 2016.

SADDLE UP FOR EPILEPSY 2016 A GREAT SUCCESS

After the inaugural Saddle Up for Epilepsy cycle in 2015, we promised that the 2016 cycle would be bigger and better and it certainly was!

The 2nd Saddle Up For Epilepsy took place on a glorious but cold morning on Saturday 27th February in Co Mayo. It was a fantastic success with over 400 cyclists young and old, and from all parts of the country taking to the roads to support Epilepsy Ireland's services in the West and to raise awareness of epilepsy.

Words can't thank Brenda Quigg and her brilliant team of organisers - Jimmy Durkan, Simon Walsh, Darragh Staunton, Mick Kilcourse and Brendan Quigley - for all the time, effort and dedication that went into organising the event, not to mention the dozens of volunteers – marshals, drivers, support crew, food stop volunteers and many more that got stuck in on the day.

Thank you also to our generous sponsors who were only too eager to support the cause; to legendary cyclist Sean Kelly who helped launch the event in January of course to the 400+ cyclists who made it all happen on the day.

We're delighted to announce that as a result of Saddle up for Epilepsy, we will be expanding the service that we provide in Mayo & the West region with immediate effect. The goal is, as always, to be able to support people and provide people with the tools they need to live life to fullest and manage their epilepsy. The funding will enable Epilepsy Ireland to expand our presence in the local community and deliver additional services such as the Living Well With Epilepsy programme and the STEPS self-management programme.

Saddle Up 2017 is already in the planning – we hope to see you next year!

GO Great video shot on the day: youtu.be/8jJtZ9Ufmq4

GO More stunning pics: on.fb.me/1TdYCr8

All photos courtesy of Robert Justynski: www.robertjustynski.com



Thank you to all our sponsors & partners

Baxter
Beaumont Ambulance
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Lionbridge
Monaghan & Sons
Sean Kelly Cycling

EXERCISE & EPILEPSY: ACHIEVING WELLBEING



Noel was unhappy with the weight gain that followed his epilepsy diagnosis

For people with epilepsy, maintaining good health can play an important part in achieving seizure control. Participating in sports and physical activities is a relatively easy way to improve general health.

Last year, an Epilepsy Ireland survey found that three-quarters of people with epilepsy surveyed undertook regular physical activity (including activities such as walking, jogging, running, cycling, visiting the gym, doing weights etc.) but also found that many people were less likely to participate whether due to advice, exclusion or fear of having seizures.

Noel Gavin, 24, is a Westpark Fitness instructor from Tallaght, Dublin. Seven years ago he was diagnosed with epilepsy. He says,

"Following a blow to the head at the age of seventeen, I unfortunately began to have a number of seizures. It was not long until I was diagnosed with epilepsy. After being diagnosed I began gaining weight. I was advised that the weight gain was a side effect of my medication, Epilim and for a long period of time I was classed as obese".

Like many other people, the diagnosis of epilepsy for Noel was a life changing experience affecting general self-esteem and confidence.

"I was so disheartened after being diagnosed that I stopped exercising completely and I gained weight pretty fast. During Christmas 2013 I got weighed and measured and was disgusted to find out that I was 94kg at 40% body fat. Hearing my weight and body fat statistics proved a real shock to the system, not least because I was still going to the gym,



Noel is now an active participant in runs and challenges

but not really doing anything productive".

Making a New Year resolution shortly afterwards was to be a major step for Noel.

"I decided to set myself some goals, concentrating on reducing my weight and after 4 months, I had completed my first indoor triathlon at Westpark Fitness. I managed a 10k run not long after".

There are many people like Noel who will set goals to make a positive change in their life only to find themselves falling at the first hurdle. Not Noel...

"I'm not sure that it ever got easier the more I did it, but after never seeing myself as a sporty person, it was an amazing feeling to complete those events. In December 2014, I decided to give up alcohol completely and that's when I noticed a massive change. I was training harder because I wasn't waking up hung over on weekends. I went down to 12 and a half stone and my body fat was 12%. I even managed to set up a running club, and I plan to set myself some more goals for next year, like 'Hell & Back'".

Noel's story may inspire many to take the first step to changing their life but the best piece of advice is still to come.

"It's important to remember that things won't change overnight, and it's all about consistency. I show people my 'before' and 'after' pictures and they can barely believe it. I looked like I could have won a pie-eating contest before. But having that experience is great for my new job as a trainer, because I can tell them my story. Training six days a week at 6.00am just comes really naturally by now, I have since qualified as a gym instructor and

now work in Westpark Fitness as a part of the membership team. I now stay around 12% body-fat all year round".

Remember that the first step to positive change is just that - a step, not a marathon - so if you feel inspired by Noel's story, consider the following when making your plan for the new you.

The Four Types of Fitness:

1. Flexibility – meaning you can move more comfortably. Limited flexibility can cause pain, lead to injury and make muscles work harder. Inactivity leads to inflexibility.
2. Strength - Muscles need to be exercised to maintain strength. Inactivity can cause muscles to weaken and shrink.
3. Endurance - Feeling energetic depends on the fitness of the heart, lungs and muscles. The heart and lungs must work efficiently to carry the oxygen-rich blood to the muscles.
4. Balance - Good balance can prevent falls. Strong and coordinated muscles in the trunk and legs are an important part of good balance

A Healthy Exercise Plan should aim to address all four types of fitness.

Walking

Aim to achieve 30 minute brisk walk every day (3 x 10 minutes or 1 x 30 minutes)

Isometrics

For strength a gentle isometric routine could be included on a daily basis.

Yoga

Repetition of a routine of simple and gentle stretching exercises can help realign bodily posture, release muscle tension and Improve balance & breath control.

Check out your local gym for advice on starting your personal fitness plan.

 Exercise, Sport & Epilepsy leaflet: bit.ly/1Y9IGFA

REGIONAL EVENTS

EAST

(Co's Dublin, Kildare, Wicklow)

Contact: Ina Murphy, Community Resource Officer, Epilepsy Ireland, 249 Crumlin Road, Dublin 12. Tel: 01 4557500. Email: imurphy@epilepsy.ie. Office Hours: Mon, Tue & Wed, 10am - 6pm; Thur 1.30pm - 6pm

Upcoming Events

Dublin: Diagnosis Toolkit Group Session For Adults with epilepsy

Carmelite Community Centre, Dublin
Tuesday March 22nd
6.00pm - 9.00pm

Dublin: STEPS Self-Management Programme for adults with epilepsy

Carmelite Community Centre, Dublin 2
18th April (Mondays)
6.00pm - 9.00pm

Dublin: Puppet workshops for Children 4-11 years

Teachers Club, Parnell Square, Dublin 2
Saturday April 23rd
11.00am - 1.15pm - Age 4 - 7 years
1.30pm - 4.00pm - Age 8 - 11 years

Dublin: Diagnosis Toolkit Group Session For Parents (of children with epilepsy)

Carmelite Community Centre, Dublin
Wednesday May 11th
6.00pm - 9.00pm

SOUTH EAST

(Co's Kilkenny, Carlow, Waterford, Wexford and South Tipperary)

Contact: Joan Ryan, Community Resource Officer, Epilepsy Ireland, c/o HSE, St. Joseph's, Waterford Rd, Kilkenny. Tel: 0567789904. Email: jryan@epilepsy.ie. Office Hours: Mon, Tue, Wed 10am - 5.30pm; Thur 10am - 2pm

Upcoming Events

Cashel: STEPS Self-Management Programme for adults with epilepsy

Spafield Family Resource Centre, Cashel, Co. Tipperary,
9th April (Saturdays)
10.30am - 1.00pm

CORK

Address: Epilepsy Ireland, 35 Washington Street, Cork. Tel: 021 4274774

South Lee & West Cork: Niamh Jones, Community Resource Officer. Email: njones@epilepsy.ie. Office Hours: Mon & Tue 8am- 4.30pm; Wed & Thur 8am - 1pm

North Lee & North Cork: Mary Lawlor, Community Resource Officer. Email: mlawlor@epilepsy.ie. Office Hours: Tue, Wed, Fri 9.30am - 5.30pm; Thur 1.30pm - 5.30pm.

Upcoming Events

Cork: Support Group for Parents of Children with Epilepsy

Bishopstown GAA Club
Wednesday April 6th & May 25th
7.30pm

Cork: Puppet workshops for Children 4-11 years

Venue: Contact Cork Office
Saturday May 7th
11.00am - 1.15pm - Age 4 - 7 years
1.30pm - 4.00pm - Age 8 - 11 years

Cork: Epilepsy Information Evening

Vienna Woods Hotel,
Monday May 9th
7.00pm - 9.30pm

MIDLANDS

(Co's Offaly, Laois, Westmeath & Longford)

Contact: Margaret Bassett, Community Resource Officer, Epilepsy Ireland, c/o Carers Association, Market Square, Tullamore, Co. Offaly. Tel: 057 9346790. Email: mbassett@epilepsy.ie. Office Hours: Mon, Tue, Wed & Fri 10am - 2.30pm; Thur 9am - 5pm.

Upcoming Events

Tullamore: Information Seminar for Teachers/SNA's

OCIL, Clonminch Road, Tullamore
Tuesday April 19th
7.00pm - 9.00pm

KERRY

Contact: Kathryn Foley, Community Resource Officer, Epilepsy Ireland, Glenwood, Park Road, Killarney, Co. Kerry. Tel: 064 6630301. Email: kfoley@epilepsy.ie. Office Hours: Mon- Fri 9am - 2.30pm.

Upcoming Events

Tralee: Yoga session for people with Epilepsy

Travel Inn, Fossa
Monday March 21st
11.00am - 1.00pm
Michael Fahy of Kerry yoga will facilitate along with Kathryn from Epilepsy Ireland.

Tralee: Playdium Tralee Family Meet up

Tuesday March 22nd
9.30am - 12.30pm

Killarney: Support meeting for people with Epilepsy

Epilepsy Ireland Killarney Office
Wednesday March 23rd
10.30am

Killarney: STEPS for parents - a programme for parents of Children with Epilepsy

Dromhall Hotel, Killarney
6th April Wednesdays
10.30 - 1.00pm

Killarney: Support meetings for people with epilepsy

Epilepsy Ireland Killarney Office
Tuesday April 19th & Wednesday
May 18th
10.30am - 1.00pm

Killarney Support meeting for parents of children with epilepsy

Epilepsy Ireland Killarney Office
Wednesday May 11th
10.30am.

NORTH WEST

(Co's Donegal, Sligo & Leitrim)

Contact: Agnes Mooney, Community Resource Officer, Epilepsy Ireland, Grand Central Complex, Floor 2B, Canal Road, Letterkenny, Co Donegal. Tel: 074 9168725. Sligo Office: Epilepsy Ireland, 2C Castle House, Castle Street, Sligo. Tel: 071 9141858. Email: amoonney@epilepsy.ie. Office Hours: Mon, Tue, Wed 9am - 5pm; Thur 9am - 1pm.

Upcoming Events

Donegal: Epilepsy Clinics Dr. Kevin Murphy.

Out Patients Clinic
May 4th

Sligo: Outreach Service Epilepsy Ireland Office,

Castle House, Castle Street, Sligo
Tuesday April 12th
2.00pm to 4.00pm by appointment only

WEST

(Co's Galway, Mayo, Roscommon)

Contact: Edel Killarney, Epilepsy Ireland, Westside Resource Centre, Seamus Quirke Rd, Westside, Galway,
Tel: 091-587640. Email: ekillarney@epilepsy.ie.
Office Hours: Mon-Fri
8.30am - 4.00 pm

Upcoming Events

Galway: STEPS for parents - a programme for parents of

Children with Epilepsy

Maldron Hotel, Oranmore, Galway
ONE DAY WORKSHOP
Friday April 15th
10.00am - 3.00pm

Salthill: Puppet workshops for Children 4-11 years

Leisureland, Salthill, Galway
Saturday March 19th
11am - 1.15pm - Age 4 - 7 years
1.30pm - 4.00pm - Age 8 - 11 years

MID-WEST

(Co's Limerick, Clare & North Tipperary)

Contact: Anna Kelly, Community Resource Officer, Epilepsy Ireland, Social Service Centre. Henry St. Limerick. Tel: 061 - 313773. Email: akelly@epilepsy.ie.

Office Hours: Mon 9.30am - 5pm; Wed 9.30am - 5.30pm; Thur 12.30pm - 5pm; Fri 11.30am - 4pm.

Upcoming Events

Limerick: Group Toolkit Meetings

Limerick Education Centre
Wednesday Monday April 18th
To reserve a place contact Anna Kelly

NORTH EAST

(Co's Louth, Meath, Cavan, Monaghan)

Contact: Noreen O'Donnell, Community Resource Officer, Epilepsy Ireland, Unit 1a Partnership Court, Park Street, Dundalk, Co Louth. Tel: 042 - 9337585. Email: nodonnell@epilepsy.ie. Office Hours: Mon, Tue & Wed 9am - 6pm.



March

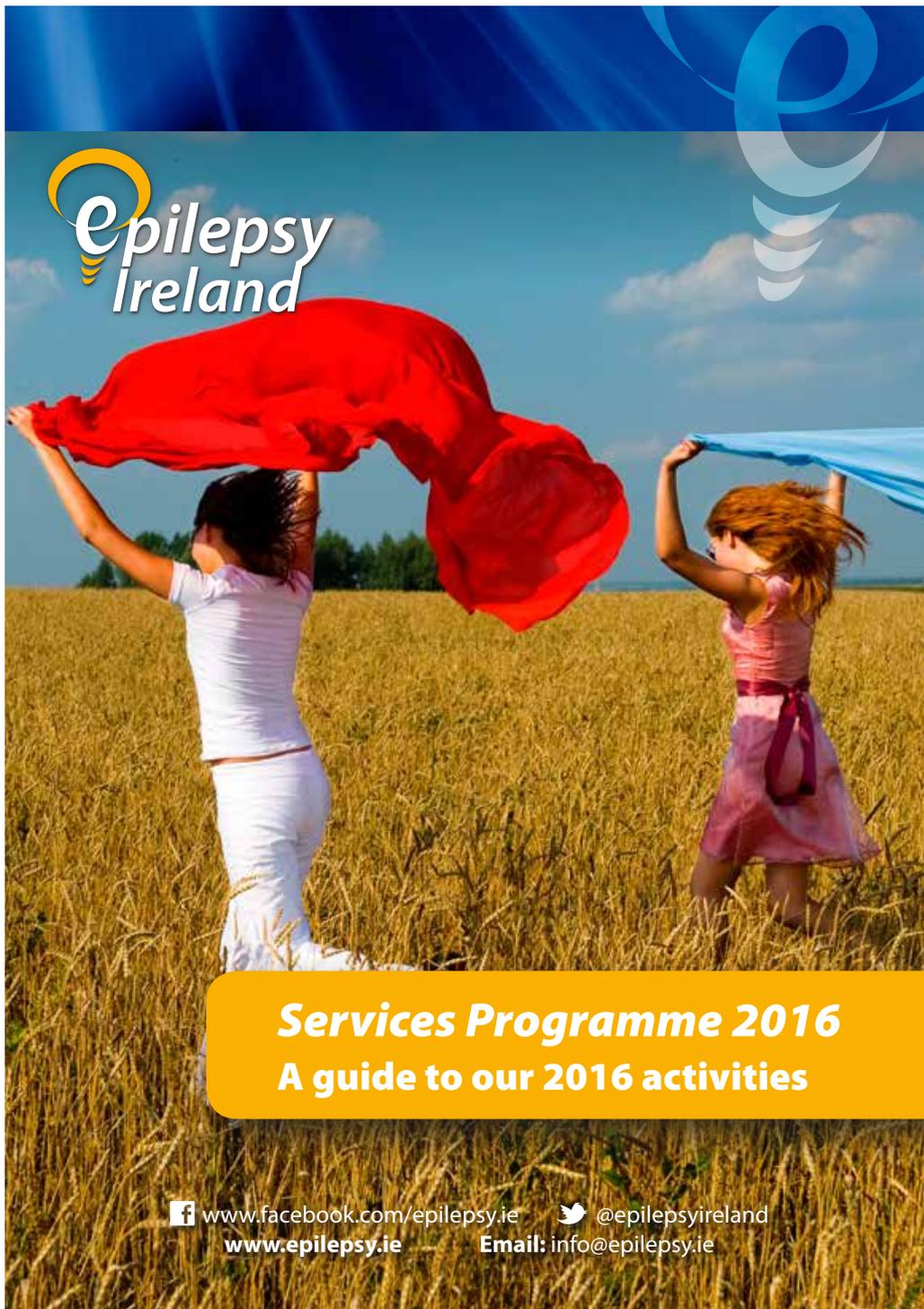
24th, 11am, General Support Group
29th, 7pm, Parents Support Group

April

5th, 7pm, General Support Group
12th, 7pm, General Support Group
20th, 11am, Parents Support Group
26th, 7pm, General Support Group

May

3rd, 7pm, General Support Group
10th, 7pm, Parents Support Group
18th, 11am, General Support Group
24th, 7pm, General Support Group
31st, 7pm, Parents Support Group



**Epilepsy
Ireland**

Services Programme 2016 **A guide to our 2016 activities**

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

Epilepsy Ireland's new 2016 service programme brochure details ongoing services – details also available on www.epilepsy.ie including:

Living Well with Epilepsy – New diagnosis Toolkits

If you or your family member has been recently diagnosed with epilepsy, we offer you a complete 'Toolkit' with all you need to know about the

condition and how to manage it. You can meet us in a one-to-one environment at any of our regional locations, or you can attend a group training session specifically designed for adults with epilepsy or for parents whose children have epilepsy. At our group sessions, you will be introduced to the toolkit, have an opportunity to ask questions about the condition, and meet others in a similar situation.

STEPS self-Management Training programme for adults with Epilepsy.

Our STEPS (Support & Training in Epilepsy Self-Management) are run over six sessions of three hours each in various locations across the country during the year. By doing this course, you will learn how to self-manage your condition and become your own

'epilepsy expert'. You will meet others with epilepsy and learn about many aspects of the condition.

STEPS for parents – a programme for parents of Children with Epilepsy

Our four session programmes for parents are run nationally in various locations, offering a full education programme for parents whose children have epilepsy. This is an opportunity to gain information, to meet other parents, and to learn how to best manage your child's condition. The programme was developed in conjunction with many of the country's leading professionals working in neurological and psychological roles.

Supporting schools and Children with Epilepsy

We are very active in supporting schools across the country by providing the Teachers Pack – a resource for teachers, and other resources to support parents and children, including booklets 'Epilepsy and School' and 'Talking about Epilepsy'. We provide Epilepsy Awareness Talks for schools and organisations by request where possible, in all regions across Ireland. Please contact your local office to discuss further.

In addition, we run Teachers Seminars to support teachers/SNA's in understanding epilepsy and how to respond to children with epilepsy in a school environment. Teachers are welcome to attend these seminars.

 bit.ly/1R45h0C

Epilepsy Ireland is a membership based organisation, run by its members for the benefit of people with epilepsy and their families.

Technological advances in recent years have made it easier for us all to communicate, share experiences and form virtual communities but it is still important that Epilepsy Ireland retains a strong, vibrant membership base in order to best support and represent the epilepsy community.

The membership fee of €12.70 has remained static for over a decade and contributes only in part to the cost of printing/posting this magazine and other membership costs. When you receive your renewal notice during 2016, we hope that you will consider it good value for money and a worthwhile investment in the future of epilepsy services.

Benefits of Membership

- Epilepsy News sent to your home each quarter
- Free epi-alert identity bracelet, Tap2Tag Wristband or safety pillow for new members who join for 2 years
- Reduced rates at events that we must charge for such as the National Conference (most epilepsy Ireland events are free)
- A vote at the Annual general Meeting and a say in setting the organisation's goals and strategy
- Each member makes our voice stronger when representing the needs of people with epilepsy on issues such as the epilepsy Monitoring units or generic substitution.
- Access to all information, support and advocacy services. (Our services are available to anyone affected by epilepsy regardless of membership status).

MEMBERSHIP FORM



Address: 249 Crumlin Road, Dublin 12.
Tel: 01-4557500 Email: info@epilepsy.ie Web: www.epilepsy.ie
Facebook: www.facebook.com/epilepsy.ie Twitter: @epilepsyireland

Please complete and return this form to us at the address above. Note: If you are renewing your membership and you have a change of address since your last renewal, please tell us your old address so that we can amend our records

Membership Type

Renewal New

Membership Category

1 Year Renewal membership subscription €12.70
1 Year New membership subscription €12.70
2 Year New membership subscription €20.00

Epilepsy Ireland requires this information to process your application, post membership-related material to you, and to keep you informed of events, issues, and opportunities relating to epilepsy or to the aims of the Association. If you do not wish to receive such communication, please tick here

Free bracelet, Tap2Tag wristband or safety pillow for new members who join for 2 years. Please select one of:

Safety Pillow Epi-Alert bracelet (we will send you an application form)
 Tap2tag wristband: Wristband size: XS S M L XL XXL
Colour: Blue Red White Pink Purple Black

Voluntary Donation

I would like to help continue the work of Epilepsy Ireland by making a voluntary donation to the Association

€7.30 €20 €30 €50 €100

own amount € _____ **Total Enclosed** € _____

Payment Method

Credit/ Debit Card (see below)
 Standing Order (see below)
 Cheque/ Postal order/ Bank Draft (payable to Epilepsy Ireland)

Name of Person with Epilepsy Please use block capitals

Title _____ Name _____

Address _____

Tel No (Day) : _____ Tel No (Eve): _____ Mobile _____

E-mail _____ Date of Birth _____

I am a person with epilepsy I am the parent/ guardian of a child with epilepsy * Other

* Parents/ Guardians – Please enter your name here if you wish us to send all correspondence to you instead of child
Name of Parent/ Guardian for correspondence: _____

Tick here if you would like to receive our regular e-mail newsletter. Clearly write your e-mail address in the space above.

Tick here if you would like to find out more about volunteering & fundraising for Epilepsy Ireland

Card Payments

I wish to pay by: Visa Mastercard Laser

and I authorise you to debit my account with the sum of € _____

Name on Card _____

Card Number _____ Expiry Date (mm/yy) _____ CWV No _____

Signature _____ Date _____

Standing Order Please return this part of the form to us. Do not detach

Bank _____ Branch _____

Account No _____ Sort Code _____

Please pay the sum of € _____ to the Account of Epilepsy Ireland at Bank Of Ireland, Walkinstown, Dublin 12, Account Number 88644504, Sort Code 90-02-87 on this date and on the corresponding date each succeeding year until further notice.

Signed _____ Date _____



EPILEPSY IRELAND
IN PARTNERSHIP WITH HELIUM ARTS PRESENT:

PUPPET WORKSHOPS FOR CHILDREN



- Saturday workshops with lunch included
- Fun and creativity for children aged 4 - 11
- A chance to meet and talk to other children with epilepsy
 - Social meet up for children and parents
- Time for puppet making and a performance for parents

GALWAY

Saturday 19th March 2016

4 - 7yrs 11am – 1.15pm

8 - 11yrs 1.30pm – 4pm

DUBLIN

Saturday 23rd April 2016

4 - 7 yrs 11am – 1.15pm

8 - 11yrs 1.30pm – 4pm

CORK

Saturday 7th May 2016

4 - 7yrs 11am – 1.15pm

8 - 11 yrs 1.30pm – 4pm

Must be accompanied by an adult. This event is for children with epilepsy and children whose parents have epilepsy. For bookings please contact our Head Office or Regional Offices.

 www.facebook.com/epilepsy.ie

 @epilepsyireland

Email: info@epilepsy.ie

www.epilepsy.ie

Head Office: (01) 4557500

CHY number: 6170

LOCAL CONTACT DETAILS

Blank area for local contact details.

USE YOUR FEET TO SHOW YOU CARE AT THE VHI WOMEN'S MINI MARATHON



Bank Holiday Monday,
6th June 2016, 2pm



Enter online at vhiwomensminimarathon.ie
or pick up your entry forms in the Herald on Wednesdays & Saturdays from February 17th, 2016

Ladies, please step forward and join **Team Epilepsy Ireland!**

3 easy steps to support Epilepsy Ireland

1. Register for the Mini Marathon using the link above
2. Get your Epilepsy Ireland sponsorship pack at www.epilepsy.ie/go/sponsorpack or contact Ashley at abutler@epilepsy.ie or 01 4557500
3. Get training and fundraising!



The closing date to register is **April 29th** (or earlier if places fill up) so don't delay, register today!