



Epilepsy News

Shining a light on epilepsy

Epilepsy Ireland Issue 78 Autumn 2017



2017 National Hidden Disability Awards

IN THIS ISSUE:

- Maria Keegan: back to school advice
- Kate Maher's final personal story
- Epilepsy Ireland's film camp
- New epilepsy employment booklet

CONTENTS

3. News Update
4. Hidden Disability Awards 2017
5. Lights, Camera, Action
6. Back to School: Frequently Asked Questions
8. The Surgery Route
9. Epilepsy - Life goes on
10. Out and About
11. Fundraising
12. New Epilepsy Employment Booklet
13. New Board Members
13. AGM and Proposed New Constitution
14. Epilepsy Ireland - New Policies
15. Regional News

NOTE FROM THE EDITOR

Conor Culkin



Welcome to the autumn issue of Epilepsy News for 2017. For the second issue in a row we feature an influential Kiwi from the world of Irish rugby. Last

time was Joe Schmidt and now it's the turn of much respected rugby pundit Brent Pope. He's featured on the front cover with myself and Rachel Ashe from Hays plc who won the inaugural Hidden Disability Award which took place in the Conrad Hotel. The New Zealander was the MC for the event and spoke candidly about his battle with mental illness. The ceremony is featured on page 4. Participants from our film camp for teenagers had a couple of days they are unlikely to forget which is included on page 5. It's that time of the year when children return to the classroom after the summer break and Maria Keegan has some helpful back to school epilepsy advice for parents on pages 6 and 7. The following

pages include honest accounts of two people's challenges with epilepsy. Sinead Matson is an academic who refused to be covered by the condition and also has fulsome praise for the vital work of epilepsy specialist nurses. Kate Maher's final article of her series focuses on her brain surgery and the difficult recovery that followed. Everyone at Epilepsy Ireland would like to thank Kate for sharing her story over the last five issues – her openness has helped many readers with their own condition.

Our new 'Out and About' section gives an opportunity to showcase some of the events from across the country on page 10. EI will be releasing a new employment booklet for the workplace (p12) and there is also news about our new policies, constitution and board members.

Finally, I'd like to thank all our supporters and volunteers for their support and I hope you enjoy this autumn issue of Epilepsy News.

TFS CORNER

Epilepsy Ireland's award-winning Training for Success course at IT Sligo is going into its 20th year. In each issue we will feature images from the programme's academic year.



Michael Scanlon after his recent graduation



Course Facilitator Maire Tansey and TFS Ambassador Michaela Murphy at a course night out



249 Crumlin Road,
Dublin 12.

Tel: 01 4557500

Fax: 01 4557013

Email: info@epilepsy.ie

Web: www.epilepsy.ie

Registered Charity Number:
20010553

CHY Number: 6170



Design and layout by
PlipSpace.com

Printed by Doggett Print & Design



Sodium valproate public hearing to take place

A public hearing is to be held in London on September 26th to listen to the experiences of women in the EU who have been prescribed valproate-containing medicines for epilepsy, bipolar disorders and migraine.

This will be the first time the European Medicine Agency's safety committee - the Pharmacovigilance Risk Assessment Committee (PRAC) - has held a public hearing to review safety of a medicine.

The public hearing will focus on three questions: What is your view of the risks of taking valproate during pregnancy, including its potential effect on the child? What are your views on the measures currently in place to reduce the risks of using valproate during pregnancy? What other measures should be taken to reduce the risks of using valproate during pregnancy?

The meeting will take place in EMA's London offices in Canary Wharf on September 26th and representatives from Epilepsy Ireland and the FACS Forum will be attending.

[GO goo.gl/2Do69S](https://goo.gl/2Do69S)

Epilepsy Ireland welcomes new world class research centre

An Taoiseach, Leo Varadkar, TD recently announced four new world-class Science Foundation Ireland Research Centres, including the RCSI-led FutureNeuro centre, which is supported by Epilepsy Ireland.

The new SFI Research Centres represent an investment of €74 million from the Government over the next six years, with a further investment of €40m from industry. The investment will support cutting-edge basic and applied research with strong industry engagement, driving economic benefits and positive societal impact.

FutureNeuro is focused on addressing the socio-economic burden caused by chronic

and rare neurological diseases, in particular epilepsy and motor neuron disease. In an internationally unique manner, FutureNeuro links innovative neurotherapeutics development with genomic and biomarker-based patient stratification, a national eHealth infrastructure and a nationwide clinical network. Building initially on world-leading pre-clinical and clinical research, the FutureNeuro Centre is a scalable platform that will expand quickly to focus on other chronic and rare neurological diseases.

Epilepsy Ireland considers the proposal to be patient-centric, offering strong potential for positive short and long term impacts for people living with epilepsy. In addition, the potential of the Centre to bring together the wider epilepsy community in Ireland is something the charity are excited about, as it can only be positive for the people we represent.

[GO goo.gl/UuyGK6](https://goo.gl/UuyGK6)

Selfie-epilepsy described in medical journal

According to a case report published in the medical journal *Seizure* recently, doctors may have found a new trigger for photosensitive epilepsy in some people. A teenager was admitted to hospital in Canada where she underwent routine EEG assessment.

The results of her EEG were normal except for two random bursts of activity on the areas of the brain associated with epileptic seizures. When doctors looked at the video, it showed that each time she would take a selfie, these random bursts would occur. Doctors are calling this phenomenon selfie-epilepsy. There is a setting on some phones with a specific flash that reduces the red eye effect in photos, which is suggested to be the cause of the bursts based on the slight light rhythm but other factors like the phones flash that could also possibly cause seizures. This case suggests that taking selfies may represent a new area of caution for some people with photosensitive epilepsy.

[GO goo.gl/7sNLLd](https://goo.gl/7sNLLd)

Fit Bit for the Brain that Tracks Seizures

St. Vincent's Hospital, Melbourne and the Graeme Clark Institute created a new device that has the potential to predict and prevent epileptic seizures. The device is called The Minder and is fitted on the scalp under the skin and records brainwaves.

The data retrieved from Minder is recorded and stored on an app. The app will be used to alert people with epilepsy when a seizure is likely to come. The data that will come up on the app will be in the form of a weather forecast, "in the next few hours they may be a 60% chance of seizures" for example. The device also has the potential to notify a carer if someone has had a seizure.

Neurologist and lead researcher Professor Mark Cook, believes the data has also aided in diagnosing and adjusting medication for people with epilepsy. This could be a game changer for doctors and people with epilepsy because it is almost impossible to analyze every seizure a person has which makes it even harder to find the best treatment for the individual.

[GO goo.gl/wupa79](https://goo.gl/wupa79)

Epilepsy Ireland supports new study on whether dogs can predict seizures



Epilepsy Ireland is delighted to be supporting research being undertaken at Queens University Belfast which will examine whether untrained dogs have the ability to predict epileptic seizures and if so how they might do this. The study is part of a PhD study being undertaken by Neil Powell, PhD student, and supervised by Professor Peter Hepper of the Queens University School of Psychology.

The research project is designed to increase our understanding of how a dog may alert to the onset of a seizure in its owner and use this to provide the individual with epilepsy with a means to take appropriate action to control the situation. Elucidation of the cues used by dogs to the onset of a seizure, will lead to a greater understanding of canine alerting behaviour and so enable individuals to shape the behaviour of their dogs in a cost effective manner to reliably alert to seizure onset.

[GO goo.gl/yqjMSs](https://goo.gl/yqjMSs)

HIDDEN DISABILITY AWARDS 2017



Rachel Ashe, Philip Bourke and Arlene Sheridan of Hays plc pictured at the awards ceremony

Epilepsy Ireland and Headway have honoured six top companies based in Ireland for their excellence in supporting people with hidden disabilities in the workplace, through the 'I See Beyond' campaign. It has attracted a huge amount of support online for people living with a hidden disability, using social media to spread the message 'iseebeyond'.

Hays won the overall award for their outstanding efforts in providing reasonable accommodations for their employees and for their active work in learning about and creating awareness of hidden disabilities such as epilepsy among their staff.

Representatives from Fáilte Ireland, Hays plc, iSupply Printing, Travelport Digital, Údarás na Gaeltachta and Virgin Media gathered at the Conrad hotel Dublin to accept an award presented by sports broadcaster and former rugby player, Brent Pope, who has also suffered with a hidden disability.

Brent Pope, sports presenter said: "Personally, I have struggled with mental health issues, and can understand how hard it can be to deal with something that people around you can't see. The organisations being honoured today are doing a tremendous job of seeing beyond hidden disabilities in the workplace. I am very pleased to have been invited to present the 'National Hidden Disability Awards' and to help shine a light where it's needed".

A national survey conducted by Amárach Research showed the positive impact of the I See Beyond campaign:

- 78% of people surveyed would hire someone with a hidden disability if they were an employer
- Since 2016 an increase of 36% of people feel comfortable telling their employer they have a hidden disability

The survey was conducted on the 15th May 2017 by Amárach Research and is based on 1,000 respondents across Ireland.

CEO of Headway, Kieran Loughran, commented: "As we know, a hidden disability can be easily overlooked. These companies are a fantastic example of good HR practice and have gone above and beyond for employees living with a hidden disability. It just shows with the correct support network anything is possible. I would like to congratulate each company for achieving this prestigious



Brent Pope addresses the room

award and wish them all the best for the future. While the year on year survey results show positive trends amongst employers regarding hidden disabilities, there is still a long way to go to ensure acceptance and transparency from companies for those with hidden disabilities".

CEO of Epilepsy Ireland, Peter Murphy, said: "Our vision at Epilepsy Ireland is to achieve a society where no person's life is limited by their condition. We are delighted to recognise six brilliant companies that share the same vision as us, and that have faith in their employees. We are very proud to be part of this campaign and delighted to see these companies receiving the recognition that they deserve. I'm encouraged that we have increased awareness of hidden disabilities like epilepsy since the campaign began two years ago. I hope that employers everywhere will be inspired by the culture and practices of these companies and follow their lead in supporting people with hidden disabilities in their own workplaces"

For more information check out: iseebeyond.ie.



The event took place in the Conrad Hotel



Shooting at IMMA with filmmaker Roisin Loughrey

This year Epilepsy Ireland's film making project came to fruition as a group of young people with epilepsy attended our 5-day film-making summer camp at the Irish Museum of Modern Art. We partnered with Helium Arts to complete the film making project, which included workshops around the country followed by the summer camp. Participants addressed their experiences of epilepsy through the creation of a short fictional film with a view to engaging other young people with epilepsy about how to cope with the condition as a teenager. The film will be screened at the Irish Film Institute, Dublin in October and participants as well as their parents will be attending.

The regional one day film making workshops were run in Galway (Huston School of Film and Digital Media NUIG), Dublin (RHA Gallery), Sligo (Training for Success students, Sligo IT), and Cork (Nano Nagle Place). The workshops were a practical hands-on introduction to filmmaking and plot generating, offering a taster of what was to come during the film camp. Helium Arts provided the young people with opportunities to learn and try out film making.



Filming "The Historic Exorcism" – a silent film within the film

Making a film, making friends

The first three days of the summer camp, the young people generated ideas and everyone got a chance to experiment with acting and film making. By Wednesday the three stories were interwoven by Helium to form a storyline for a film, although there continued to be a lot of brainstorming and improvisation until Thursday afternoon.

The art of filmmaking

Participants recount what they did and what they learned:

'I learned how film scripts work and how people throw out ideas'

'writing dialogue'

'setting up and conducting scenes'

'I took part in front and behind the camera'

'I learned about sets and costumes and all of the different ways they can be made'

About our film

The lives of three young people with epilepsy intersect when they find themselves visiting the same exhibition at the Irish Museum of Medieval Archaeology. A silent film exhibit on "The Historic Exorcism" brings home to the young people how little epilepsy was previously understood and how being open about the condition can help with peer relationships and altering people's perceptions.

Our team

The team of Epilepsy Ireland's Community Resource Officers and Helium Arts led the group through the five days – from the development and filming of the script, running the drama and acting workshops, supporting the writing the storyline, supporting participants throughout the process with all aspects of the project. Special thanks to our Epilepsy Ireland participant leaders – Maria, Fiachra, David and Tomas – who brought their own experience of epilepsy to the project and acted as a sounding board for participants.

The film project was created and led by Wendy Crampton, Deputy CEO, Epilepsy Ireland and was project managed by Emma Eager in Helium Arts and Carina Fitzgerald in Epilepsy Ireland.



On set with cinematographer Colm Mullen

Funding Acknowledgements

A great big thanks to John Finnerty for his support in getting our principal funding, to our Principal funder QUALCOMM and to our additional funders - the Arts Council, the Hospital Saturday Fund and the Cork Foundation. Also thanks to the following sponsors: Royal Hibernian Academy (RHA), the Huston School of Film and Digital Media NUIG, Flying Tiger Copenhagen, An Tobar Nua, Renzo Café, Coppa Café, Café Fleur, Dukes Coffee Company.



By Maria Keegan, Paediatric Neurology Clinical Nurse Specialist, Our Lady's Children's Hospital.

Yes, it's that time of the year again; the summer holidays have drawn to a close and families are focussed on getting their children settled into school. You've done the trekking around book shops with lists; traipsed in and out of shoe shops in search of the perfect hard-wearing school shoes; tried on oversized uniforms and reassured your child "you'll grow into it".

Preparing for school affects all parents, whether your child has returned to the same school; started 'big school' or ventured into second level. It's always a stressful time. And for those parents who have a child with epilepsy, there are many other things to consider as the school re-opens.

This article hopefully will help to address some of those concerns and point you in the right direction, now that the new school term has started.

Does the school need to be told my child has epilepsy?

Yes, the school must be told if any child attending has an ongoing condition. The school staff is acting 'in locus parentis'. In other words, they are your eyes and ears whilst your child is in their care, be it in the classroom, the playground or out on school trips. Explain your child's seizures to them, in your own words, so they know what to look out for. Remember, there are more than 40 different types of seizures, so school staff must know what is specific to your child.

Talk to them about:

- what the seizure looks like; how it starts; what alerts you to it; parts of body involved etc
- whether or not your child gets an 'aura' or warning
- how you normally manage the seizure

- how long the event may be likely to last
- how and when to administer first aid
- rescue medication if it's given (see below)
- how your child is likely to behave after the seizure
- how long your child needs to rest after the event
- how frequent seizures are, and if there's a pattern to them
- possible trigger factors such as: flashing lights (only if your child has been diagnosed with photosensitive epilepsy); certain computer games; stress; excitement; tiredness; broken night's sleep, etc.

Computer monitors are unlikely to trigger seizures, although the images on them may if they are flashing at the rate known to trigger seizures. The same applies to interactive whiteboards used in schools.

Check with your neurology team about photosensitivity if you're unsure.

A resource pack called '**Managing Chronic Health Conditions at School**' was developed some years ago by a group of support organisations, namely Epilepsy Ireland, Asthma Society of Ireland, Diabetes Federation of Ireland and Anaphylaxis Ireland in response to regular requests from parents and teachers seeking assistance on managing children with chronic health conditions in the school setting. This is a hugely valuable toolkit overall. The section on Epilepsy covers everything you as a parent would want your child's school to know, including a sample emergency plan; seizure first aid; responsibilities of the Board of Management, the teachers and your responsibilities as the parent and much more.

TIP: It's very helpful to show a video of the seizure to anyone who is responsible for your child in your absence, especially school staff.



What to do?

Review the Emergency Plan with the teacher and draw up an agreed step by step guide on how to manage your child's seizure in school. This must include the information outlined above, as well as:

- location of emergency/rescue medication
- details of rescue medication; name, dose and route by which it is given
- copy of rescue medication prescription
- any special considerations to be aware of who should be informed and how to contact them
- when to call an ambulance

IMPORTANT:

Emergency medication needs to be with the child at all times. So when going on off-site visits, medication must be taken in a sealed bag with the emergency plan protocol.

It should be kept safe by a responsible adult.

Make sure all school staff has attended an education session on epilepsy, either one run by Epilepsy Ireland or by the Neurology/Epilepsy Nurse Specialists in the children's hospitals. Check that all staff received training in the administration of buccal midazolam including a demonstration on how it's given.

If your child is starting school for the first time or switching to a new school,

be sure to give the school details to your neurology team. They will pass this information onto the secretary responsible for organising the 'Epilepsy Awareness Sessions for Schools' run by the children's hospitals.

TIP: I recommend every parent download and keep a copy of *Managing Chronic Health Conditions at School for your own reference. Also, make sure your child's teacher/s has a copy.*

You will find it on www.into.ie and www.epilepsy.ie

Is there anything else I need to keep in mind with regard to school?

Starting back in school, switching schools or taking that first step into "big school" is a time of stress for the family as a whole as has been said. We all feel both the 'good' stress, (the excitement) and the 'not-so-good' stress (the worry/anxiety)!

In a previous article published here in Epilepsy News I wrote in some detail about how stress can affect a child with epilepsy. Particularly, how seizure control might be knocked off kilter. (Epilepsy News Summer 2016)

Here's a brief reminder:

SOME COMMON SIGNS OF STRESS IN A CHILD:

- **Tummy ache**
- **Headache**
- **Diarrhoea (not related to a tummy bug)**
- **Constipation**
- **Withdrawing from friends or usual activities**
- **School grades slipping**
- **Difficulty concentrating**
- **Frequent angry outbursts**
- **Anxious**
- **Unusually quiet**
- **Not eating or overeating**
- **May sleep more or have difficulty sleeping**

Those are some of the more frequent signs that can be triggered off by any upset and can be seen in any child. Do



keep in mind that the fear of having a seizure in the classroom/playground, or front of school friends, is quite a stressor for boys and girls with epilepsy.

Having an open and honest discussion with your son or daughter about their seizures may ease this stress for them. Gently encourage them to disclose their diagnosis to a close friend or two in whom they trust. It's always good to have a pal who'll 'watch their back'.

Be mindful and aware that bullying is something to watch out for. It's one of the most stressful things any child can go through and something every parent hopes their child never experiences.

Alarmingly, a survey here in Ireland has shown that up to 31% of primary and 16% of secondary school students have experienced bullying. Also, one in five children has been bullied online. Thankfully, schools take incidents of bullying very seriously and students are far more alert to bullying behaviour.

Primary and Secondary schools now have very clear policies and protocols in place to manage this serious issue. It's worth familiarising yourself with this document; www.education.ie/en/Publications/Policy-Reports/Anti-Bullying-Procedures-for-Primary-and-Post-Primary-Schools.pdf and make yourself aware of your child's school anti-bullying policy.

As always, if at all concerned about your child's mental health, have a chat with your family doctor, paediatrician or a member of your child's neurology team.

Remember, looking after children with epilepsy is not just about managing seizures and monitoring medications. We take the holistic approach to caring for your child; this means we see your child as a whole person. We, like you, want to see your child healthy and happy and reaching their potential.

If ever there are issues of concern with regard to your child's emotional wellbeing or coping ability, we may suggest seeking the support of a psychologist. If the concern relates to struggling with school work etc., it may be necessary to refer for an Educational Psychology Assessment. This request comes through the school Principal once you the parent have given permission. When this assessment has been completed, the school will be given clear recommendations to put in place to best assist your child.

The first couple of months settling back into the school routine can be more than a bit challenging. Make allowances for your child being more tired than usual. Remember, their brain was on summer holidays too! And now it's being pushed to work harder by having to concentrate and focus in class, and take in lots of new information. On top of that, getting back into the normal school bed-time routine takes a bit of getting used to again.

Then before you know it they're on their Hallowe'en mid-term break!

If you would like to read more information on your child's epilepsy please log onto www.epilepsy.ie and click on our dedicated section.



Kate pictured after her surgery

In the final part of her series of articles charting her personal journey with epilepsy, Kate Maher speaks about her life changing surgery.

During the summer of 2015 along with daily partial seizures I had two tonic-clonic seizures, the second one that September. As a result I was sent to Beaumont to undergo WADA tests. Initially when I'd heard about WADA tests, one year earlier, the prospect of them terrified me. However, I felt things needed to advance now. Essentially, I needed to know if surgery could be an option. The tests showed that the majority of my memory and language skills resided in my right sided hippocampus. My left sided hippocampus held very little of my memory. My consultant and neuro-surgeon decided, based on the various tests I'd undergone, that I would be a suitable candidate for a temporal lobectomy.

So, on November 2nd 2015 in the theatre corridors of Beaumont hospital I said goodbye to my husband Joe. I was put under general anaesthetic and that afternoon, under the watchful eye of

the neuro-surgical team, a Left Anterior Temporal Lobectomy was carried out. After I woke up, I felt as sick as a dog and in some amount of pain, however I was so relieved to be awake and have the surgery behind me. The operation itself lasted just over four hours. The surgeon visited me the following day to tell me the surgery had been a success and that the scarred area of my brain had been removed. I was so incredibly joyful, tears of happiness streamed down my face.

The Recovery

Throughout 2016 I recovered at home whilst relishing in the wonder of seizure freedom. I was graced with seven months of it. Occasionally I'd wonder, "Might this be the end? Could epilepsy finally be behind me?" Slowly I was being weaned off one of my three anticonvulsant medications. It seemed to me everything was working out. I couldn't have asked for more. In June, just before I returned to work we went to see a show in the Cork Opera House. During the show, out of nowhere, I was abruptly hit with a strong sense of déjà vu. Next thing I knew, I was lying on a cold floor, completely powerless, unable to communicate, heavy breathing, and drooling as my husband and an ambulance crew tended to me.



Kate's seizures returned while attending a show at Cork Opera House

I was dealing with the shocking realisation that it was back. I'd had another two tonic clonic seizures. The audience got more than they bargained for that night, that's for sure! So after a brief vacation, my epilepsy was back with a vengeance. I was discharged home the following day and recommenced on the AED I had just finished.

Acceptance

Since then I have had four more tonic clonic seizures. For the first time in my life, I am beginning to wholeheartedly accept my epilepsy. I now realise I never fully accepted it, that I had been constantly fighting against it. Believing it was almost not "part" of me and that the surgeons had simply "disposed of it". Living with an occasional tonic clonic seizure however, feels much easier than the daily struggle I had had with complex partial seizures.

"I wanted to share my story because I feel epilepsy is nothing to be ashamed of"

In February 2016 I was diagnosed with osteoporosis after a bone density scan was carried out. This was due in part to long term use (28 years) of Anti Epileptic Drugs. I am glad I have been diagnosed however, as it means I am more aware of my need to gain adequate calcium intake along with calcium supplements and regular exercise.

I want to thank my husband Joe who throughout these turbulent few years has been my rock of solid support. To my parents who have always been there to support me. To wider family and friends thank you for all your kind words and support. To my Neurology Consultant, Neuro-Surgeon, my GP, and the caring, kind and thoughtful Epilepsy Nurse Specialists I have met along the way, to you all I owe my sincerest gratitude.

My life has changed irreversibly, epilepsy has changed me in more ways than I could have ever imagined. I am no longer ashamed. I wanted to share my story because I feel epilepsy is nothing to be ashamed of - coping and living with this condition on a daily basis is at times an enormous challenge but also an enormous achievement and something we should all be massively proud of. Physically, mentally, and psychologically my life has been altered forever but I wouldn't change a second of it. It has made me who I am.

Epilepsy News would like to thank Kate for sharing her story and wishes her the best of luck for the future.



Researcher and PHD candidate Sinead Matson talks about overcoming fear and anxiety after her epilepsy diagnosis.

Epilepsy: it doesn't even look like a word, just a jumble of letters and yet when I heard it as a diagnosis for the first time I rejected it. I do not have epilepsy. It was (is) a scary word. It is a loaded word. It means my life has changed. They were wrong. They had the wrong patient. I had just survived a craniotomy (eight weeks after the birth of my second child) for the successful removal of a benign brain tumour; which - by the way - was only discovered four days before the operation when I had four successive clonic-tonic seizures out of nowhere. I had re-learned to walk, use the right-hand side of my body, talk in more than nouns and verbs, think and process thoughts properly again. I could wiggle my toes on my right foot for God's sake! I had survived and they had the wrong patient. Except, of course, that they were right and didn't have the wrong patient. I do have epilepsy.

Accepting my epilepsy

Now you may not appreciate how hard that sentence is to say, or maybe you do. For me those words, that bombshell, had come out of nowhere and I did not know what to do with it. The epilepsy specialist nurses were a godsend. They sat me down answered all my stupid, inane questions. They gave me information booklets (well knock me sideways if having a period isn't bad enough but now it can effect my epilepsy too!), they came to visit me at home and most importantly they gave me the number for the epilepsy nurses helpline in Beaumont Hospital. This phone number, those seven little digits, in the early days gave me something to hold onto. I will always be thankful for the way I wasn't made to feel like a bother when I rang with things

which I thought were major crises but understand now they were just run of the mill incidents. Having someone who knew was empowering. I wish I had more people who knew – that I could talk to, in those early days. I would argue that it needs to be made explicit at first diagnosis and the first follow up appointment that there are online forums (such as the Epilepsy Ireland online support group) where you do not have to drive or travel but can reach out, without fear and share your feelings, frustrations, and successes. A place where you can say that sentence: "I have epilepsy" and get a response from people who know, who really know. The more I said that sentence and embraced epilepsy as part of my identity the more empowered I became.

Overcoming the fear

I will forever remember breaking down in a neurologist's office and crying uncontrollably because I thought my life was over. I am a researcher. I am an educator. I have plans. I want to travel. I want more kids! I was supposed to do a PhD. My identity was wrapped up in all of that and now this word 'epilepsy' was threatening all of that. It was attacking my being. It was stripping me of my identity. I remember my neurologist, looking at me slightly bemused and saying "and what is stopping you, Sinead? A lot of people before you have completed PhD's and travelled and worked with epilepsy and a lot of people will do so after you. So, why can't you? You just have to manage it, but it can be done." I immediately stopped crying and, well, did it!

I am in the middle of completing my PhD. I travel to India to research. I travel abroad with my family for holidays. I work, I study, I teach and still go to concerts. I play with my children and can have more children – if I want to. I'm not back driving yet but that's more to do with complications from my surgery and you know what? The bus is fine; the train is better! It's an inconvenience but it's a workable inconvenience.

"I will forever remember breaking down in a neurologist's office and crying uncontrollably because I thought my life was over."

Life goes on. It just goes on with epilepsy. I'm not saying it's easy, but it's not always hard. I've had those scary moments where I worry if I'm going to have a seizure when alone researching on the other side of the world. I've lost friends who don't understand that I need sleep and have to miss events or meet ups because I need to rest – that I have to control my epilepsy by listening to my body in the moment which can cause me to cancel at last minute and understand that it's frustrating for others but I can assure you it's more frustrating (and a little lonely) for me. But (and it's a big but) life does go on and it can be amazing. I'm not saying it's perfect but it can be amazing in the ordinary day to day life. If it wasn't for ongoing research, medication, surgeons, doctors, and nurses - life could be so much more difficult; and for all of that, I am grateful.

OUT AND ABOUT

Epilepsy Ireland is proud to represent the 40,00 people with the condition across the country as well as their careers. In a new Epilepsy News slot we will feature some of the events across the country and further afield.



A recent STEPS group in Tullamore with Community Resource Officer Cliona Molloy



Fundraising Officer Judith Kelleher pictured with a colourful group of ladies at the Cobh ball run



Participants who raised money for Epilepsy Ireland running the Cork Marathon



Jason McGlynn reached Everest base camp and was representing Epilepsy Ireland



Sinead and Conor Townsend raised money with a waxing and shaving fundraiser in Longford



Gonzaga Transition Year students cycling to raise money at their Sports Day



A group of Intrepid explorers taking part in the Peaks Challenge



Rick O'Shea, Kathryn Thomas and Joe Schmidt at a recent charity lunch fundraiser at Fire Restaurant, Dublin



Young participants in the Puppet Workshop at the Mayo Education Centre



Lil Histon with her daughters at the Cobh Ball which was created by her late husband Paddy

Rick O'Shea shows his support



El Patron Rick O'Shea pictured at a recent fundraising event that took place in memory of Liane Deasy who passed away in April. Liane's Husband Mark, family and friends and Gonzaga College have raised nearly €16,500 so far with more funds still coming in. Also a massive thanks to Miriam Donohue who organised a night of music and comedy in McGrattans, Dublin and raised €1700. Additional thanks must go to Emma Somers who was involved in the night of music and comedy raising €975.53 in memory of Liane and Joanne Costello.

Alan Gallagher memorial cycle - Tour de Gaggs



A heartfelt thanks to the Tour de Gaggs team who organised their annual 300k cycle from Cork to Roscommon in memory of their family member and friend Alan Gallagher who passed away in 2009. The team have raised over €55,000 since the cycle began in 2010. Well done to all the team including Brian Gallagher, Olive Heffron and Kevin Gallagher (pictured below and above).



Dublin Chamber Cycle



Dublin Chamber cycled across Spain to raise money for Epilepsy Ireland and Dublin Simon. To date over €10,000 has been raised.

Mini Marathon



Gina Condron and friends who raised €247 with donations from Belgium and Australia.

Thank you

Connie and Ciara Doyle who raised €546 from taking part in the four peaks and a sponsored silence.

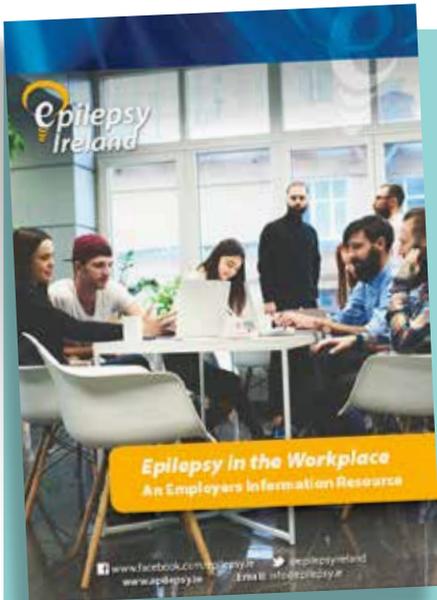
Ciaran Forde who took part in the Wicklow 200 cycle recently and raised €354.48.

Ann Walsh, who organised an Afternoon tea event in aid of Epilepsy Ireland and raised €414.

Thank you to all who supported our All-Cash Mega Raffle last year, over €22,000 was raised for our vital work. We are asking you asking you to once again support the cause this year by selling the tickets enclosed with this issue.

Epilepsy Ireland needs you!

We're looking for volunteers for Cork Rose Week from October 19th -21st. Please contact Judith to get involved on 021 - 4274774.



Epilepsy Ireland will launch our new 'Epilepsy in the Workplace - An Employers Information Resource' booklet this October. This booklet endeavours to provide the information needed for both employers and employees to feel confident addressing the condition.

Below is an excerpt featuring questions employers frequently ask about epilepsy and employment.

What do I do if I find out that a person I have recently hired has epilepsy?

Use the opportunity to inform yourself about epilepsy. You'll be amazed at how little it interferes with day-to-day living. Bear in mind that you or anyone of your employees could become disabled in the future due to accident or illness.

Are persons with epilepsy obliged to disclose their condition to employers?

They are only obliged to disclose their condition if they are specifically asked. They can only be asked as part of a medical examination.

Is it true that people with epilepsy have more absenteeism?

No. Evidence would suggest that, on average, people with epilepsy have fewer accidents at work than other employees, take less time off work and have good job loyalty records. It is important to note that people with epilepsy who are stable on medication may have very few or no seizures.

Can people with epilepsy work with machinery?

Yes. Epilepsy does not restrict a person from operating guarded machinery. If changes need to be made, there are grants available for adapting workplace equipment.

Do people with epilepsy have more accidents?

No. There is evidence to suggest they have fewer accidents, because they are more aware of potential hazards. Epilepsy does not usually force the employer to take extra safety precautions in the work place. People with epilepsy are generally very careful about their own well-being and are no more prone to accidents than anyone else.

Are people with epilepsy less productive?

No. People with epilepsy, being aware of employers' concerns over productivity, are often keen to prove that they are productive, reliable and valuable employees. The difficulty for them is securing the job in the first place. If an employee has a seizure at work, they usually only need a short rest, after which they can resume work as normal.

Are there higher work cover premiums for people with epilepsy?

No. It is often assumed that employing someone with epilepsy is ultimately going to result in an increased premium. This is not the case. No special insurance is required for a worker with epilepsy. At a basic level, employers should ensure that they are covered by Public Liability Insurance and Employers' Liability. Premiums are only affected by claims, and there is no evidence to suggest claims increase by employing someone with epilepsy.

Is job accommodation for people with epilepsy expensive?

No. Most often, employers do not need to make any adjustments, and if changes need to be made, financial support is available.

Are people with epilepsy allowed to drive?

Yes, if seizure free for one year a person would be legally entitled to drive a car.

How do I reassure my customers if an employee has a seizure at work?

Although observing a seizure can be disconcerting, the customer is likely to appreciate an employer who reacts with understanding and fairness towards an employee with epilepsy. Indeed, providing staff with first aid information could be advantageous in the event of a customer having a seizure.

Are people with epilepsy able to handle management positions?

Yes, if they have the job qualifications and skills for doing so.

What do I tell co-workers if I employ a person with epilepsy?

Anything to be said should be done in the presence of the employee with epilepsy. It might be a good time to have an open discussion about epilepsy and other disabilities in general. First Aid measures should also be dealt with. Epilepsy Awareness Training is available from Epilepsy Ireland.

Is stress in the work place a particular risk for people with epilepsy?

Stress is a very individual factor for anyone, regardless of whether they have epilepsy or not. For some people with epilepsy it can be a factor. Everyone is affected by stress to some degree, and everyone has to learn how to cope with it in his or her working life. As with all employees a supportive working environment benefits everyone with their stress levels.

Are there any guidelines or principles for employing people with epilepsy?

Yes, but they have more to do with good practice rather than employing someone with epilepsy per se. The Employment Commission of the International Bureau for Epilepsy (IBE) have produced a document entitled Principles for Good Practice in the Employment of People with Epilepsy. www.ibe-epilepsy.org/employing-people-with-epilepsy-principles-for-good-practice/

If you would like to receive the new booklet please email info@epilepsy.ie.

EPILEPSY IRELAND WELCOMES NEW BOARD MEMBERS



Clare O'Dea

Clare O'Dea joined the board of directors of Epilepsy Ireland in 2017. Clare's interest in the work of Epilepsy Ireland emerged when her son was diagnosed with a rare form of epilepsy. She brings a wealth of experience gained in corporate strategy, finance, investments, marketing and fundraising.

Clare is a director of Select Strategies, a management consultancy, which helps Irish companies grow. Her earlier career included investment management with Ulster Bank and KPMG. She is currently on the board of Orbis Ireland, a non-profit organisation that transforms lives through providing access to quality eye health in developing countries. She has a BA (Science) from Trinity College Dublin and an MBA UCD Michael Smurfit Graduate Business School. She is currently studying for a Higher Diploma in Psychology at UCD.



Tony Caravousanos

Tony Caravousanos joined the board of directors of Epilepsy Ireland in 2017. Tony has volunteered with Epilepsy Ireland for many years previously, as a key member of our Awareness sub-committee which developed awareness campaigns such as the TEAM seizure first aid campaign and

International Epilepsy Day. Tony is an experienced advertising and marketing professional, Client Service Director and Head of Advertising at the creative agency Havas Ireland, where he has worked since 1990. Tony is a Marketing graduate in Retail Business Studies from D.I.T Dublin, a former IAPI board member and well known in Ireland's adland network. Like many of our board members, Tony has a personal family interest in epilepsy and the work of Epilepsy Ireland.

EPILEPSY IRELAND AGM AND PROPOSED NEW CONSTITUTION



The Annual General Meeting of Brainwave The Irish Epilepsy Association (trading as Epilepsy Ireland) will take place on October 16th 2017 at Dublin Chamber of Commerce, Clare St, Dublin 2 from 6pm. Official notice is enclosed with this newsletter for all members, as well as a CD containing financial statements and other relevant AGM materials.

Also on the agenda is a special resolution to adopt a new Constitution for the charity. Constitution is the new term for Memorandum and Articles of Association, the documents that define the purpose, objectives and powers of an organisation, as well as the rules and regulations for its administration and governance.

The proposed new Epilepsy Ireland Constitution includes changes mandated by the 2014 Companies Act, as well as new terms laid down by the Charity Regulator and Revenue. In addition, the Epilepsy Ireland board has undertaken a full review of the existing Memorandum and Articles and are recommending a range of new voluntary amendments

designed to strengthen the organisation's governance and administration.

These amendments include:

- Updating the objects (objectives) of Epilepsy Ireland to be more reflective of the services we provide, the wider work that we do and our overall mission
- Updating the legal powers of Epilepsy Ireland to operate more efficiently in an ever more complex external environment
- Updating clauses on the use of income and property in line with the Regulator's model constitution for charities
- The introduction of term limits for board members and officers, striking a balance between an appropriate level of board renewal while maintaining stability and much needed skills
- Changes to board proceedings and composition, for example a minimum percentage of board members must have epilepsy or a direct family link to the condition
- A range of amendments on issues like the giving of notice for General Meetings (email will now be permitted); voting at general meetings; keeping of accounting records and more

A more detailed explanation on the proposed changes is included on your enclosed CD along with the proposed Constitution. At a time of ongoing scrutiny of charity governance and operations, we encourage all members attending the AGM to review the documents and to vote in favour of adopting the new Constitution. If you have any questions on this, please get in touch at info@epilepsy.ie or 01 4557500.

Epilepsy Ireland has recently adopted new policies to ensure the highest level of service. Over the next three issues of Epilepsy News we will highlight key information for our members and service users.

CHILD PROTECTION



PRINCIPLES OF GOOD PRACTICE – INFORMATION FOR PARENTS

- Epilepsy Ireland acknowledge the rights of children to be protected, treated with respect, listened to and have their own views taken into consideration.
- We recognise that the welfare of children must always come first, regardless of all other considerations.
- We operate a child protection policy and where awareness is raised regarding the possibility of child abuse, we will operate procedures which protect the child. The child protection policy is available to parents/guardians by request to any employee of the organisation.
- We are committed to adopting the safest possible practices to minimise the possibility of harm or accidents happening to children and protect workers from the necessity to take risks and leave themselves open to accusations of abuse or neglect.
- We adopt and consistently apply clearly defined methods of recruiting staff and volunteers.
- We respond to and record any accidents and complaints relating to working with children.
- We believe that early intervention with children who are vulnerable or

at risk may prevent serious harm from happening to them at a later stage.

- We are aware that a child's age, gender and background affect the way they experience and understand what is happening to them.
- We provide child protection training for workers.
- We work from a policy of openness with parents which involves consulting them about everything that concerns their children, and encouraging them to get involved with the organisation wherever possible.
- We do not work with children under 18 in unsupervised circumstances, with the exception of the provision of one-to-one support services to 16 and 17 year olds where parents/ guardians have given their consent.
- Parents/Guardians are required to sign consent and responsibility forms when attending Family Fun Days and other activities for children.
- We co-operate with any other child care and protection agencies and professionals by sharing information when necessary and working together towards the best possible outcome for the children concerned.
- We make links with other relevant organisations in order to promote child protection and welfare policies and practices.

ARE YOU HAPPY WITH OUR SERVICE?



Epilepsy Ireland welcomes feedback from service users relating to our service and we are committed to ensuring that any complaints are dealt with in a fair and consistent way.

If you are displeased about the service/ services that we are providing to you, we would like the chance to put things right. If you feel that we have been unwilling to help you or slow in helping you with your query, or in any other way have not provided the best service to you, please let us know so that we can improve our service.

Anonymous complaints cannot be formally investigated but will be noted for the manager's information. We have a full complaints policy which you can ask us for, or you can read from our website at www.epilepsy.ie

Need help making a complaint?

You can ask someone – friend or relative – to help with your complaint.

How do I make a complaint?

Most problems can be sorted out locally, informally and verbally. First, tell us what the problem is and give us a chance to put things right for you.

Making a Formal Complaint

If that does not work, you can make a formal complaint by writing to our complaints officer at Epilepsy Ireland, 249, Crumlin Road, Dublin 12 or by emailing info@epilepsy.ie letting us know that you wish to make a formal complaint and that it has not been resolved yet through talking to our staff.

How long will it take?

We try to resolve all complaints within 30 days but if it is very complicated, we endeavour to conclude all investigations within 6 months of the receipt of the complaint.

What if I am still not happy?

If you are still not happy after your complaint has been formally dealt with by the staff in Epilepsy, you may ask for an investigation by writing to the CEO, Mr. Peter Murphy, who will designate a senior staff member to investigate your complaint further.

If you have any further questions regarding our new policies please email info@epilepsy.ie.

REGIONAL EVENTS

REGIONAL OFFICES

Cork

Tel: 021 - 4274774
Niamh Jones - njones@epilepsy.ie
Loretta Kennedy - lkennedy@epilepsy.ie

East

Tel: 01 - 4557500
Edel Curran - ecurran@epilepsy.ie
Carina Fitzgerald - cftzgerald@epilepsy.ie

North East

Tel: 042 - 9337585
Email: Mary Baker
mbaker@epilepsy.ie

Midlands

Tel 057 9346790
Email Cliona Molloy: cmolloy@epilepsy.ie

South East

Tel: 0567789904
Email: Mirian Gray mgray@epilepsy.ie

Mid-West

Tel: 061 - 313773
Email: Veronica Bon vbbon@epilepsy.ie

Kerry

Tel: 064 6630301
Email: Kathryn Foley kfoley@epilepsy.ie

West

Tel: 091-587640
Email: Edel Killarney ekillarney@epilepsy.ie

North West

Tel: 074 9168725
Email: Agnes Mooney amooney@epilepsy.ie

NORTH EAST

26-09-17 | Ardee: Epilepsy Awareness and School

Information evening for Teachers and SNAs
Venue TBC
Tuesday 26th September
6.00pm - 8.00pm
Registration is free but places must be booked in advance

05-10-17 | Navan: STEPS Self-management programme

Venue TBC
Thursday October 5th for 6 weeks
6.00pm - 9.00pm
For more information or to register please contact Mary

EAST

Dublin: INNERWISE One Day Workshop for Women with Epilepsy

Red Cow Moran Hotel
Date: TBC
9.30am - 4.00pm
For more information or to register please contact Carina or Edel on 01-4557500 or email ecurran@epilepsy.ie or cftzgerald@epilepsy.ie

19-09-2017 | Dublin: STEPS (Support and Training in Epilepsy Self-Management) for People with Epilepsy

Carmelite Community Centre, 56 Aungier Street, Dublin 2
Commencing Tuesday September 19th for 6 Tuesday Evenings
6.00pm - 9.00pm
For more information or to register please contact Carina or Edel on 01-4557500 or email cftzgerald@epilepsy.ie

28-09-2017 | Dublin: Support, Information & Toolkit Group for People with Epilepsy or Parents of Children with Epilepsy

Carmelite Community Centre, 56 Aungier St. Dublin 2
Thursday September 28th
10.00am - 13.00pm
For more information or to register please contact Carina or Edel on 01-4557500 or email cftzgerald@epilepsy.ie

27-11-2017 | Dublin: Support, Information & Toolkit Group for People with Epilepsy or Parents of Children with Epilepsy

Carmelite Community Centre, 56 Aungier St. Dublin 2
Monday November 27th
6.00pm - 9.00pm
For more information or to register please contact Carina or Edel on 01-4557500 or email cftzgerald@epilepsy.ie

MID-WEST

27-09-2017 | Limerick: Epilepsy Awareness & Administration of Buccal Midazolam

For Healthcare Professionals, Teachers & SNAs ONLY
Kilmurry Lodge Hotel, Limerick
Wednesday September 27th
9.00am - 4.30pm

12-10-2017 | Limerick: Toolkit Support Group

Thursday October 12th
10.00am - 12.45pm

16-10-2017 | Limerick: Inner wise Reunion Support Group

Kilmurry Lodge Hotel
Monday October 16th
7.15pm - 8.30pm

NORTH WEST

20-09-2017 | Donegal: Neurology Outpatients Clinic

Out Patients, Scally House, Letterkenny
Date
Wednesday September 20th
Wednesday November 15th
Agnes will be available to meet with you at Dr. Murphy's Clinic. Please call 074 91 68725 to confirm dates.

MIDLANDS

09-10-17 | Tullamore: Epilepsy Awareness & the Administration of Buccal Midazolam

For Healthcare Professionals, Teachers & SNAs ONLY
Charleville Centre, Tullamore
9.30am - 4.30pm
Please contact Cliona on 057 9346790 or cmolloy@epilepsy.ie

24-10-17 | Longford: Outreach Service

Venue TBC
Tuesday October 24th
Please contact Cliona on 057 9346790 or cmolloy@epilepsy.ie to book an appointment

13-12-17 | Tullamore: Christmas Coffee Morning

Charleville Centre Tullamore
Monday December 13th
11.00am
Please contact Cliona on 057 9346790 or cmolloy@epilepsy.ie to book an appointment

KERRY

12-09-2017 | Killarney: Support Meeting for Parents of Children with Epilepsy

Manor West Hotel - Tuesday October 17th
Venue TBC - Tuesday December 5th
10.00am

20-09-2017 | Killarney: Support Group meeting for people with epilepsy

Killarney Office
Wednesday September 20th
Wednesday October 18th
Wednesday November 15th
Wednesday December 13th
10.30am

25-09-2017 | Tralee: Information evening for Teachers and school staff

Education Centre, ITT North campus, Tralee
Monday September 25th
4.30pm - 6.00pm

12-10-2017 | Kerry: STEPS Self-management Programme for people with epilepsy commencing on

Thursday October 12th
For 6 consecutive Thursday mornings from 10.00am - 1.00pm

24-10-2017 | Killarney: Epilepsy Awareness & Administration of Buccal Midazolam

For Healthcare Professionals, Teachers & SNAs ONLY
Brehon Hotel Killarney
Tuesday October 24th
9.00am - 4.40pm

02-11-2017 | Kerry: Family Morning

Venue TBC
Thursday November 2nd
Hospital outreach service available at Kerry University Hospital on the 1st, 2nd and 4th Monday of each Month. Please contact Kathryn at 064-6630301 or kfoley@epilepsy.ie for further information or to book a place at any of the events.

WEST

18-09-2017 | Mayo: Teachers Evening

Mayo Education Centre
Monday, 18th September
6.00pm - 7.30pm

25-09-2017 | Galway: Epilepsy Awareness & Admin of Buccal Midazolam

Training day for Healthcare Professionals; Teachers and SNAs
Maldron Hotel, Oranmore
Monday, 25th September
10.00am - 4.00pm

02-10-2017 | Mayo: Adults STEPS Self-management Programme

Venue TBC
Mondays October 2nd/ 9th & 16th
10.00am - 1.00pm

23-10-2017 | Roscommon: Support Group

Cuan Aire Resource Centre
Monday 23rd October
6.00pm 8.00pm

25-10-2017 | Galway: Support Group

Imperial Hotel, Eyre Square, Galway
Wednesday 25th October
11.00am - 1.00pm
New members welcome. Phone 091 587640 for more information

SOUTH EAST

03-10-2017 | Kilkenny: Teachers and SNA seminar

Kilkenny Education Centre, Callan Rd, Kilkenny
Tuesday October 3rd
6.30pm - 8.00pm

26-10-2017 | Waterford: Epilepsy Awareness & the Administration of Buccal Midazolam

For Healthcare Professionals, Teachers & SNAs ONLY
Dooley's Hotel, The Quay Waterford
Thursday October 26th
9.00am - 4.00pm

CORK

20-09-2017 | Cork: Support Group for Parents of Children with Epilepsy

Bishopstown GAA Club
Wednesday September 20th
Wednesday October 25th
Wednesday November 29th
7.30pm

26-09-2017 | Cork: Information Evening for Teachers and SNA's West Cork

Venue TBC
Tuesday September 26th
6.00pm - 8.00pm

20-10-2017 | Cork: Information Stand Rose Week

Wilton Shopping Centre
Friday October 20th
10.00am - 4.00pm

31-10-2017 STEPS Self-management programme for Adults

Bru Columbanus, Wilton
Commencing Tuesday October 31st for six weeks
7pm-10pm



All-Cash Mega Raffle

2017

1st Prize €2,000

2nd Prize:

€1,000

3rd Prize: €500

Seller's Prize:

€200

Tickets just €3

Please do what you can to help.
Every euro raised helps us continue our
work for and on behalf of people with
epilepsy in Ireland.

Draw: 10th November 2017

(Epilepsy Ireland Head Office,
249 Crumlin Rd, Dublin 12)

Permit issued by Inspector M. Cryan, Dublin
Metropolitan Region to Peter Murphy, C/o Epilepsy
Ireland, July 11th 2017. Winners will be published
on epilepsy.ie and notified week commencing 13th
November 2017.

**Return this slip with your ticket stubs and proceeds in the freepost
envelope provided by: Wednesday 8th November 2017**

Name _____

Address _____

Tel No _____ Email _____

Number of tickets sold _____ Total Enclosed € _____

Please send me _____ extra books of tickets (10 tickets per book)

You can pay by cheque, bank draft, postal order or credit/debit card. Cheques, drafts & postal orders should be made payable to Epilepsy Ireland.

Credit/ Debit Card payments: Visa Credit Visa Debit Mastercard

Card No. _____ Expiry date _____

Cardholder's name _____ Security code _____

In order to benefit fully from the proceeds raised, we do not automatically issue receipts.
If you would like one, please tick here

ORDER MORE TICKETS

- Phone 01 4557500
- Email info@epilepsy.ie
- Return this slip to us in the FREEPOST envelope

Epilepsy Ireland
249 Crumlin Road, Dublin 12

01 4557500

www.epilepsy.ie

Charity number: CHY 6170

Charity Registered No: 20010553

