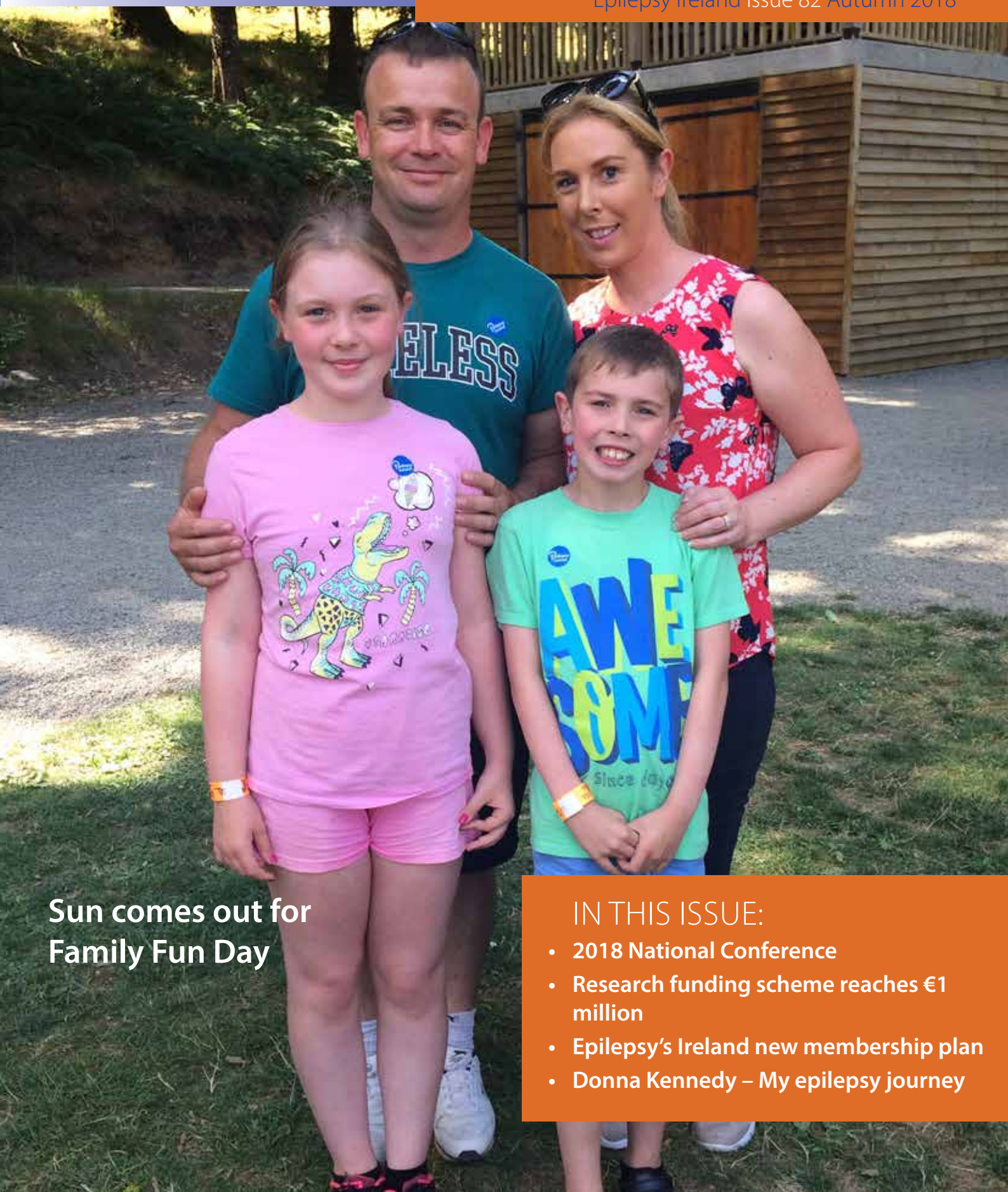




Epilepsy News

Epilepsy Ireland Issue 82 Autumn 2018



**Sun comes out for
Family Fun Day**

IN THIS ISSUE:

- 2018 National Conference
- Research funding scheme reaches €1 million
- Epilepsy's Ireland new membership plan
- Donna Kennedy – My epilepsy journey

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Front cover image:

The O'Neill family from Co. Laois enjoying the Family Fun Day.



249 Crumlin Road,
Dublin 12.

Tel: 01 4557500

Fax: 01 4557013

Email: info@epilepsy.ie

Web: www.epilepsy.ie

Registered Charity Number:
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NOTE FROM THE EDITOR

Conor Culkin



As the hottest summer for 40 years comes to an end, we now look forward to autumn as children go back to school and we make our plans for the rest of the year. Indeed

children play an important part in this issue as Epilepsy Ireland were delighted to hold our annual 'Family Fun Day' in Clara Lara Fun Park. Thankfully, the sun was shining and some nice images can be found on page 8 as well as on the front cover. As a charity, we are always proud to team up with other like minded organisations and in July there was another wonderful collaboration with Helium Arts which can be read on the following page.

The National Conference continues to be Epilepsy Ireland's most important annual event and brings people together from all over the country to share experiences about the condition. This year the event comes back to Dublin and we have a host of top quality speakers which are detailed on page 4. One of the speakers, Donna Kennedy, outlines her incredible story on the next page which has led her to become an

expert in areas such as improving people's lives and business development. We have another personal story on page 7 with Síle Ní Dhubhghaill who discusses overcoming her fear of seizures.

On page 5 we outline a significant achievement as Epilepsy Ireland has now committed over €1million in funds to Irish epilepsy research! Gianpiero Cavalleri and Naomi Elliot, who received funding, discuss why research is so important.

Since the foundation of Epilepsy Ireland in 1966, we have always been a membership-based organisation. As part of our current Strategic Plan, Epilepsy Ireland have recently completed a full review of our membership offering, aimed at both growing and improving the benefits of membership. The main details of the new plan can be read on page 10.

Also in this issue the our new Teachers Pack, Epilepsy Ireland's Triple Lock approval and the regular fundraising page.

Finally, I'd like wish our readers a great autumn and I hope you enjoy this issue of Epilepsy News.

TFS ENROLING STUDENTS FOR

2018/19 YEAR



Students from the Training For Success class of 2018. The pre-employment training course is still looking to fill its final few places for the 2018/19 year. For more information log onto www.epilepsy.ie.



Sodium valproate latest news

In the last issue of Epilepsy News, we reported that the HSE, through their recently established Valproate Response project team, were to write to all female patients currently taking valproate (Epilim) outlining the risks of the drug in pregnancy and the need to discuss treatment with their medical team.

These letters are scheduled to be sent in late August to 3,500 patients. All women prescribed under the GMS will be written to, as well as parents of girls aged 8 and upwards. The letters will contain a copy of the new Patient Information Leaflet on Epilim as well as contact details for the HSE's new nurse-led Valproate Patient Support Team. Similar letters will be sent to GPs, naming specific patients on valproate and encouraging them to arrange appointments with patients as soon as possible. If you have received this letter and wish to discuss any of the issues included, please contact the HSE support team at 1800 810077 (Monday - Friday 10am -4pm) or www.hse.ie/epilim.

Meanwhile, Minister Simon Harris has written to the FACS Forum to indicate that he does not believe that an investigation into the historical use of valproate in Ireland is currently warranted. The Forum has been campaigning for an inquiry and in June, received the support of the Oireachtas Health Committee which recommended the establishment of an independent investigation to examine the historical use of valproate in Ireland and into its ongoing effects.

[GO https://goo.gl/UwUc71](https://goo.gl/UwUc71)

Huge reaction to RTE documentary featuring epilepsy

An RTE documentary ('My Broken Brain') which focused on a number of neurological conditions, including epilepsy, received a huge reaction when it aired in July.. The programme was the most talked about topic on Twitter in Ireland the night of the broadcast and is being credited with opening the eyes of Irish public to the realities of living with neurological conditions.

This programme featured 40 year old Brian Byrne from Swords who has severe intractable epilepsy which has affected him since his was an infant. The documentary followed Brian as he attended Beaumont Hospital, under neurosurgeon Mr Donncha O'Brien, as he underwent surgery to remove the seizure-causing tissue from deep within his brain.

The programme also stressed that 700,000 people in Ireland suffer from some form of neurological condition. As this number is set to increase as the population ages, the importance of brain research and improving public understanding cannot be underestimated.

[GO https://goo.gl/8MVCkz](https://goo.gl/8MVCkz)

Parents of children with epilepsy wanted for UCC study on how children adjust to having epilepsy

Researchers at University College Cork are inviting parents of children and adolescents with epilepsy to participate in family-focused research aimed at improving adjustment for your child.

The study will look at outcomes (medical, behavioural, school) in children who have epilepsy and at what medical, personal and family factors help or hinder the child in adjusting well to epilepsy.

The study is being carried out by UCC in collaboration with the Department of Paediatric Neurology at Cork University Hospital and Epilepsy Ireland. By enrolling in the study, there is an opportunity for some parents to take part in a one-day parent workshop, which has shown promise in research with other populations of children with chronic illness and disability.

Parents of school children aged between 6 and 16 years can take part, with a diagnosis of epilepsy and a seizure frequency of at least 1 per 12 months. For more information please contact Emma Hennessy (emma.hennessy@hse.ie).

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

Spider venom may help treat Dravet Syndrome

A new study carried out in University of Queensland (Australia), has discovered that a protein found in spider venom called Hm1a could potentially help to create an effective medication for Dravet syndrome. Prof. Glenn King, an author of the study published in the journal Proceedings of the National Academy of Sciences, explains:

"About 80 percent of Dravet syndrome cases are caused by a mutation in a gene called SCN1A. When this gene doesn't work as it should, sodium channels in the brain, which regulate brain activity, do not function correctly... In our studies, the peptide from spider venom was able to target the specific channels affected by Dravet, restoring the function of the brain neurons and eliminating seizures".

Although the findings are based on early-stage animal models, the team is hoping that in the future, Hm1a can be developed into a precision medicine for treating Dravet.

[GO https://goo.gl/D57Z2i](https://goo.gl/D57Z2i)

Dublin Students take Gold at Global Innovation and Enterprise World Cup



Three teenagers from St Joseph's College, Lucan, Co. Dublin have won Gold at the SAGE World Cup 2018 taking place in Durban, South Africa. The Global contest recognises Teen Entrepreneurship and Business Literacy. The students were announced last Monday evening as world champions of the Socially Responsible Business category for writing and publishing children's books that feature a hero/heroine with a disability which included epilepsy. Aoife Dardis, Katie Grogan and Caoimhe Currie travelled to South Africa to compete in the prestigious competition. The girls have already produced three original illustrated story books which promote their important message of inclusion. One of the books 'Anna's Amazing Aura' tells the story of a mermaid with epilepsy who uses her knowledge of the condition to rescue a Dolphin.

Aoife Dardis said: "We are so proud to represent Ireland at the SAGE World Cup and are delighted to be bringing home the Gold Award. We believe we are making a real difference and are looking forward to developing our project throughout Ireland and beyond."

[GO https://goo.gl/8wD6GY](https://goo.gl/8wD6GY)

The 2018 National Epilepsy Conference will be held on September 29th (9.30am-4pm) in the Radisson Blu Royal Hotel in Golden Lane, Dublin 8. Here we outline some of the contributors who will speak on the day.

Dr. Colin Doherty



Dr. Colin Doherty is a consultant neurologist and Honorary Senior lecturer in neurology at St James's Hospital in Dublin. He was trained in the Partners neurology residency programme at Harvard Medical School, Boston and subsequently completed Fellowships in Epilepsy and Cognition. He has published widely in the areas of brain imaging in epilepsy, the genetics of epilepsy,

functional imaging of language and clinical epileptology and neurology.

Dr Doherty will be discussing the current developments in epilepsy and scientific research. He will be paying special attention to the latest findings in brain imaging, genetics and epigenetics of epilepsy. Dr Doherty will also discuss information technology and how the latest gadgets and devices can help patients monitor their epilepsy.

Donna Kennedy



Donna Kennedy is a three time best-selling author, psychologist, business and life coach and a highly sought after professional speaker. She regularly

features in national and international media as an expert in the areas of personal and business development and she has given seminars to thousands of people and companies worldwide. Her work has also been recognised and cited in international journals by leading organisations and faculties.

Donna experienced several challenges including an epilepsy diagnosis in her early years but overcame those challenges against all odds (see page 5). Donna's passion is to teach others to reach their potential.

Donna's presentation will focus on 'The Confidence to Succeed', showing that no matter what the circumstance, there is a way to achieve your goals with confidence and dignity. Donna says: "Epilepsy is still a bit of a taboo in that it can frighten people and is sometimes seen as something to be hidden. It shouldn't be. I would like people to understand that they are not their epilepsy. They are a person who happens to have seizures. With the right attitude, anything is possible."

Emma Eager, Helium Arts – Young People with Epilepsy



Helium Arts is the national children's arts and health organisation. The organisation brings art, creativity and play to children and teenagers in hospitals and healthcare settings across Ireland. Emma will be discussing Helium and Epilepsy Ireland joint projects which have helped young people with the condition through creativity.

Mary Fitzsimons Beaumont Hospital - EPR and Lighthouse Project



Mary will discuss the Epilepsy Lighthouse project, which was built upon the success of the Epilepsy Patient Record in Beaumont Hospital. The Project is currently working with 50 children and 50 adults with Intellectual Disabilities who also have epilepsy to develop a new paradigm of healthcare delivery for Ireland.

Jarlath Varley, RCSI and Beaumont Hospital – EPiC Project



Jarlath will be discussing "Epilepsy Partnership in Care" or EPiC. The project allows people with epilepsy to work together with health service personnel to design care processes that suit patient needs and respect their individual preferences.

The EPiC project is a collaboration between the Health Research Board (HRB), the Health Services Executive and The RCSI.

Peter Murphy, Epilepsy Ireland CEO – Sodium Valproate

Peter Murphy will discuss recent developments concerning the use of sodium valproate (Epilim). An epilepsy drug which has led to serious birth defects and developmental disorders.

For more information and to book your place at the National Conference please see the leaflet enclosed with this issue. You can also call 01 455 7500, email info@epilepsy.ie or book online at www.epilepsy.ie.

Epilepsy Ireland would like to thank UCB, GSK, Nutricia and LivaNova for their support of our conference through educational grants.

DONNA KENNEDY – MY EPILEPSY JOURNEY



After a misdiagnosis, Donna Kennedy's life faced a crisis but she overcame her challenges to have a flourishing career.

I was top of my class at university, I was modelling, I had good friends and a lovely family - my life was made. On March 18th 1998 everything changed.

"Once you're in here, you'll always be back. This place has a revolving door". A woman in a dirty green cardigan towered over me as I sat in the waiting room of a psychiatric unit. She reeked of cigarettes, her skin was pale and her eyes were lifeless. The certainty in her voice terrified me.

"Donna, it's your turn to see the doctor now" - my mother and father beckoned me into a psychiatrist's office.

I sat down and the psychiatrist asked me to explain what had been going on for the last couple of weeks. I explained that I had been in a car accident and hit my head and that I began to hear mumbles in my head, my head hurt and I felt "dreamy". It was the only way I could describe it. I had gone to my GP to investigate what was going on and, due to the emotional difficulties I had as a child, I was prescribed anti-depressants, even though I insisted I wasn't depressed. I took them anyway as I was told they'd make me "feel better". They didn't. I was still getting symptoms. After a series of questions, the psychiatrist told me to wait outside. She called my parents back in and within five minutes they returned to me, my mother crying, and my Dad devastated. My heart sank. Had I cancer? Was I going to die?

Shock

"Donna the doctor said you are a danger to yourself and you have to stay here. She said you have schizophrenia." I sat frozen in shock. I didn't have schizophrenia! What was she talking about? My mother and father knew I didn't either, but they were bound and I had to stay.

I spent three months in that hospital. The day I was admitted I was given an anti-anxiety pill to "take the edge off" and a sleeping tablet to "help me get through the night". When I woke up upset (understandably) I was given a pill "to help me feel more comfortable" and then another to "get me through the day", before being sent later for a CAT scan. Looking back now, I was treated like a human guinea pig. I was prescribed 14 medications during that time. I came into the hospital a normal girl with symptoms that needed to be investigated but within three months of degradation and pills I had turned into a zombie-like robot. My initial symptoms were still there.

The second opinion

Eventually I was taken out of the hospital and brought to a private hospital for a second opinion. The next doctor requested my file, asked me and my family questions to get an overall picture of my situation, and monitored me for a few days. My Dad was frustrated and confronted the doctor. "Can you tell me why Donna was perfectly fine before the accident and now she's like this? Surely the bang on the head had something to do with it?" The doctor was horrified. There was no mention of the accident or the brain scan, which showed a haematoma on my left temporal lobe, in my file. There was no account of seizures my parents had reported either.

With further investigation, the doctor suspected temporal lobe epilepsy. He was correct. I have lived with epilepsy now for twenty years.

Admittedly I felt a part of my life had been taken away from me needlessly, but I knew I only had two ways to go, to give up or build up and I have chosen the latter. Despite everything I have become successful.

Not giving in

I have come to realise that having a condition like epilepsy does not mean you have to stop living. It's easy for a condition or situation to seem bigger than you but I am living proof that if you approach a messy situation with a positive attitude then it doesn't have to take up so much of you. It's important to take your power back so you don't stay down when you fall down. Circumstance should never define you or your identity.

“It's easy for a condition or situation to seem bigger than you but I am living proof that if you approach a messy situation with a positive attitude then it doesn't have to take up so much of you.”

I still zone out sometimes, I look weird sometimes, my head hurts, and I feel vulnerable and stupid, but the reality is every person on the planet is equally vulnerable in some way at some time. I guess having epilepsy is just a more visible form of vulnerability. It's not something to be ashamed of or to be limited by. Once you learn to manage those symptoms with the right approach life is pretty good!

Donna Kennedy will be talking about how she overcame her epilepsy and giving motivational advice at Epilepsy Ireland's National Conference in The Radisson Blue Hotel, Golden Lane, Dublin on September 29th. Book your place at The 2018 National Conference by logging onto www.epilepsy.ie or calling 01 455 7500 and also email info@epilepsy.ie.



Donna frequently features in national and international media as an expert in the areas such as improving your life and business development.

EPILEPSY IRELAND REACHES €1 MILLION MILESTONE

FOR RESEARCH FUNDING

A new research grant awarded under the 2017/2018 round of the Epilepsy Ireland Research Funding Scheme has resulted in a significant milestone – since the establishment of the Scheme in 2009, we have now committed over €1 million in funds to Irish epilepsy research! We will have more information on the latest project to receive funding in the next issue of Epilepsy News.

In total, we have funded 11 Irish based projects since 2009 at RCSI, Trinity College, University College Dublin and other research institutions. Many of these projects have been co-funded by the Health Research Board under the Medical Research Charities Group Joint Funding Scheme. Projects have investigated a wide range of issues including epilepsy genetics, molecular mechanisms, health services, psychosocial issues and SUDEP.

Dr Gianpiero Cavalleri, Royal College of Surgeons in Ireland



Project: A pharmacogenomic study of chronic refractory epilepsy (funded 2009)

What did your research project achieve?

Our project explored the contribution of genetic factors to treatment-resistant epilepsy. The work supported the generation of dense genetic signatures for treatment resistant epilepsy. These datasets were further analysed to identify new risk genes for epilepsy, and to identify genetic predictors for severe skin reactions relating to the use of Tegretol.

Why is epilepsy research important?

In order to create more effective treatments for epilepsy, we need to improve our understanding of the brain generally, and how epilepsy develops specifically. This is what research is about – improving our understanding of complex systems and situations, in a manner that leads to better treatment and care, and ultimately, a cure for epilepsy. Research can span from how healthcare is delivered at a population level, right down to how our cells behave at a microscopic level.

Why is it important for Epilepsy Ireland to continue to fund research?

Research is essential if we wish to see an improvement in the lives of people with epilepsy. However, traditionally, epilepsy is very underfunded compared to other neurological conditions. This not only slows progress but also limits our ability to get the best researchers working to solve epilepsy. Ireland is becoming globally recognised for epilepsy research, and a significant part of that success is due to support from Epilepsy Ireland. That research success allows Irish researchers to compete for, and attract more money to research from overseas – e.g. from the European Union, from international epilepsy charities and national funders such as the Health Research Board. This is illustrated through the establishment by Science Foundation Ireland of the FutureNeuro Centre of Excellence, which is studying epilepsy as a key condition of interest.

Dr Naomi Elliott, Trinity College Dublin



Project: How2Tell (funded 2014)

The Scheme was set up to provide epilepsy researchers in Ireland with an avenue to access funding for world-class research and we are proud of the impact that has been made. This would not have been possible without the generosity of hundreds of donors over the past decade who have donated or fundraised for our work. Thank you to everyone who has supported our work and we hope that you can continue to do so.

Since inception, we have focused not only on the scientific quality of proposals received but also on their relevance to people with epilepsy and on their potential to deliver tangible benefits to the lives of people with epilepsy.

In the first of a two-part series, we speak to researchers who have received grants from Epilepsy Ireland to discover more about what was achieved by our investment and why it was important.

What did your research project achieve?

Using the experiences of adults (aged 18+ years) with a range of forms of epilepsy and personal backgrounds, How2tell developed a set of multi-media educational resources on self-disclosure. The resources including the How2tell website, app and booklet, assist people to develop effective strategies, so it is less challenging to tell others that 'I have epilepsy'. How2tell gives practical information in the following areas: how to become comfortable with your epilepsy; decide why, who and when to tell; use different opportunities to tell; tell people depending on who they are and deal with people's reactions.

Why is epilepsy research important?

Epilepsy research is important in understanding how it affects people's lives and to developing resources that will help people with epilepsy manage their condition in everyday life situations. There are many gaps in what we know about epilepsy, so research is important in growing knowledge that is evidence based which is then used to inform educational resources that assist in supporting the day-to-day living of people with epilepsy.

Why is it important for Epilepsy Ireland to continue to fund research?

Epilepsy Ireland has an invaluable role to play in setting the research priorities for people with epilepsy in Ireland. Members of Epilepsy Ireland therefore, can influence the decisions regarding what research is important and can make a difference to managing epilepsy in their everyday lives.

OVERCOMING 'THE FEAR' OF SEIZURES



Music teacher and political activist Sílė Ní Dhubhghaill (35) discusses how she has come to terms with her fear of seizures.

I was diagnosed with epilepsy at the age of 19. To say it was a shock is an understatement. I never had any symptoms or signs. One day, I was in my apartment, minding my own business, and I had a tonic-clonic seizure. My housemate called an ambulance and I spent a few days in hospital. I don't remember any of this – probably due to the fact that I hit my head quite hard on the coffee table as I fell. Apparently, I had many different brain scans. A relative of mine had a brain hemorrhage because of a malformation of the blood vessels in his brain and it can be hereditary, so they did lots of tests to rule that out. No brain hemorrhage thankfully, just a common tonic-clonic seizure with no apparent cause. At the time, they didn't say it was epilepsy. I learned that it is quite common for people to have them once in their lives and never again. It's all a bit of a blur, but I left the hospital that time assuming it was just a weird blip and wouldn't happen again.

It did happen again. Pretty soon in fact. When I had the second seizure, they diagnosed it as epilepsy. I was prescribed medication and went through the awful trial and error of trying to get the dose right. In the beginning, the amount I was on made me feel like a zombie. I couldn't function, couldn't study, couldn't practice properly (I was studying music). Things improved, partly because they lowered the dose, and partly because I got used to it.

Acceptance

I got used to a lot of things: the medication every day, looking after myself a bit better, not being able to drive, trying to get enough sleep, leaving gigs and nightclubs if there were flashing lights. There are two things I found it more difficult to get used to: having seizures and living with the fear of having seizures.

Seizures are horrible. They are hard to explain and they are different for everyone. When I feel one coming I get this huge rush of something that is a mix of euphoria and terror. I want to scream but my jaw locks. I really need to call for help but I can't. Then I black out and when I come around I have no idea what's going on for a while. Apparently, I say some really weird words in that half hour before my brain kicks back in properly. I always ask people to tell me what I said because, to be honest, it's pretty hilarious. That's not the worst of it though. How can I describe the day or two after? Imagine not having been to the gym in ages, and you do a crazy hard workout. After that you decide to get really drunk. You wake up the next day with a pounding hangover, that stiff, sore, day after a mad workout feeling, and you get a blinding migraine to top it all off. That's how I feel for the couple of days after a seizure. It's not pleasant.

Fear of seizures

For me, seizures aren't the worst part of epilepsy. They didn't happen too often and I haven't had one in 6 years. The worst part is living with the fear. At the time of my diagnosis, I was studying music and a big part of that is performing in front of people. Getting up on stage is scary. It's even scarier when you're worried you might have a seizure and wet yourself in front of an audience. You know what else is scary when you are living in fear of having a seizure? Walking around town, being in a busy pub, a shopping centre, crossing a busy road, being on public transport, in the cinema, in a restaurant, anywhere that people can see you. Conversely, it's also really scary being on your own, whether that's out and about, or in your own home. You wonder what would happen if you were alone and you hit your head, or drowned, or started a fire. You start to fear everything you ever thought was normal.

Overcoming the fear

I suffered from anxiety when I was young, which probably didn't help matters much. I went from spending days or weeks hiding out at home, to days or weeks of being reckless. Gradually, I settled down. I accepted my diagnosis, accepted that fear was part of it, and that the fear helped me to be careful and look after myself. I wouldn't say that we are friends, the fear and I, but we have come to an understanding. We have a truce. I'm 35 now and seizure free for 6 years. I have my own business, a music school. I teach and my work is very rewarding. I drive, I socialize, I enjoy my life. I have achieved everything that I would have achieved had I not had epilepsy. Maybe I even achieved more, because I think it gave me a determination to succeed that I didn't have before my diagnosis. I'm still afraid sometimes but I choose to see the fear as a healthy reminder of what I have overcome.

It can be difficult to understand these feelings if you don't have epilepsy, but I imagine those of you who do can relate to some of what I describe here. Remember though, if you are currently experiencing any of this, that things can really change for the better if you face your fears, and ultimately overcome them.

FAMILY FUN DAY AT CLARA LARA FUN PARK

Community Resource Officer, Carina Fitzgerald looks back on another successful family fun day.

On Saturday July 14th we had our annual Family Fun day at Clara Lara Fun Park in Co. Wicklow. Clara Lara comprises of 30 acres of countryside in the Avonmore River valley and is very scenic in a beautiful setting.

There was huge demand for places and we were thrilled that over 120 people attended including almost 70 children. Like last year, we gave everyone an Epilepsy Ireland sticker so families could identify each other, though the children probably lost theirs quickly in one of the many water activities! One parent commented to me that it was a good chance to chat with other families living with epilepsy, it being optional not compulsory!

With the amazing weather in July, it was great to have lunch outside at one of the many picnic tables reserved for our families. A special moment was when we brought out the cake to mark Lorcan Keely's birthday. One family gave me the good news that their son was being weaned off his medication. Mum and Dad were delighted; however, Mum told me her son was upset that he may no longer have epilepsy as he would not be able to come to our Family Fun Day! Active epilepsy or not, our families are always welcome at our events.

The Family Fun day has become one of everyone's favourite events in the calendar, and we are looking forward to next year's event already!



Evie Boylan pictured with Epilepsy Ireland Community Resource Officer, Carina Fitzgerald.



The Spillane family pictured at the Family Fun Day.



Community Resource Officer, Edel Curran pictured with Karen Keely and her sons Lorcan and Harry.



Karen Keely and Evie Boylan.

ELECTRIC FEATHERS SHOW THEIR SPARK

The Electric Feathers teen art group took part in another three day art camp at IMMA last July in partnership with Helium Arts. Epilepsy Ireland were again proud to collaborate in another project which inspired young people with epilepsy. The three days were led by artist Rachel Tynan and these photos capture

the final day which included a mini exhibition for families and guests. Funded by the 'Artist and Youth Work Residency Scheme' which is managed by the National Youth Council of Ireland on behalf of the Arts Council Ireland and the Department of Children and Youth Affairs.

Photos by Thom McDermott.



Electric Feathers t-shirts screen printed by participants.



Gemma, Melissa, Francesca and Nicole putting their best foot forward.



Gemma pictured with her proud dad Geoff Conroy.



Robert creating his sculpture.



Artist Rachel Tynan and Robert work on group artwork.



Gemma getting involved with hand painting.



End of camp exhibition with Sophia and her brother.

EPILEPSY IRELAND'S NEW MEMBERSHIP PLANS



Since the foundation of Epilepsy Ireland in 1966, we have always been a membership-based organisation. This means that we are run by our members in accordance with our constitution for the benefit of people with epilepsy and their families.

While technological advances in recent years have made it easier for us all to communicate and form virtual communities, it remains vitally important that there is a strong, vibrant membership base in order to best support and represent the epilepsy community.

As part of our current Strategic Plan, we have recently completed a full review of our membership offering, aimed at both growing membership and improving the benefits of membership. Other issues that were addressed included the need to present better choice to members

and the membership fees. As part of the review, feedback was invited from current members via an online survey which was completed by over 100 people.

A range of new packages outlined below are being introduced from October 1st 2018. Instead of the old one-year or two-year options, there are now options for one, three and five year memberships. In addition, members can now select whether they wish to receive Epilepsy News by post or by email, meaning that there are now six payment options to choose from to suit your needs.

Under the new structure, all members will receive four issues of Epilepsy News by email each year, have access to all support services, receive a silicone epilepsy wristband, avail of a cost-price safety pillow and can attend/ vote at the AGM and in setting the organisation's strategy.

Members who join for three years will in addition receive our new Membership Card which can be used to obtain discounts with Bus Eireann and Select Hotels (to begin with); our full range of information booklets on a pre-loaded memory stick and discounts on our National Conference (the only EI event for which a fee applies).

The best value can be had by joining for five years. In addition to all of the above, you will receive the new MediMee emergency bracelet (RRP €20) and a free safety pillow (RRP €40).

As has always been the case, each member we have makes our voice stronger when representing the needs of people with epilepsy to the government and health services. Weight in numbers means more can be achieved.

These represent the most significant changes to membership in over 20 years. In that time, membership fees have not been increased (the rate of €12.70 p.a. is a direct conversion of the old £10) while costs have significantly increased, in particular the cost of postage. For that reason, it has become necessary to revise the fees, but we have carefully considered members' feedback in this regard and worked to ensure the best possible value is delivered across all of the options.

We hope that you agree and we look forward to your continued membership. For more information, see www.epilepsy.ie or contact us at info@epilepsy.ie or your local office.

Please see the new membership form on page 15.

	1 year	3 year	5 year
Epilepsy News PDF by email	✓	✓	✓
Support Services	✓	✓	✓
Free Silicone Wristband	✓	✓	✓
AGM Voting Rights	✓	✓	✓
National Conference Discount	×	✓	✓
Pre-loaded Memory Stick Resource Pack	×	✓	✓
Free Membership ID Card Select Hotel and Bus Eireann Discounts	×	✓	✓
Free Medimee Wristband	×	×	✓
Free Safety Pillow	×	×	✓
	Available at cost price (€22)	Available at cost price (€22)	
WITHOUT PRINTED NEWSLETTER	1 year	3 year	5 year
Membership Fee	€15	€40	€65
Epilepsy News by Post	×	×	×
WITH PRINTED NEWSLETTER	1 year	3 year	5 year
Membership Fee	€25	€70	€115
Epilepsy News by Post	✓	✓	✓

EPILEPSY IRELAND IS NOW 'TRIPLE LOCKED'



Best Practice in Transparency and Accountability

Epilepsy Ireland is delighted to announce that we have been awarded 'Triple Lock' status by the Charities Institute Ireland (CII).

Triple Lock status is awarded to charities that uphold the highest standards in transparent reporting, ethical fundraising and strong governance structures. This recognition is the

gold standard for Irish charities to offer assurances to donors, members and the general public and comes just three months after we were awarded the PQASSO Quality Mark for the second time.

To achieve the Triple Lock, we:

- Adopted and maintain compliance with the Guidelines for Charitable Organisations on Fundraising from the Public.
- Prepare our annual financial statements in compliance with the Charity SORP (Statement of Recommended Practice under FRS102) accounting standard.
- Recently completed the implementation of the Governance Code for the Community and Voluntary Sector. The Code comprises a set of recommended practices for the boards of Irish charities and was adopted in full by the Epilepsy Ireland board in July 2018.

We have also committed to keeping our compliance under ongoing review, and we look forward to the publication of a new code of governance by the Charity Regulator later this year.

NEW PACK FOR TEACHING STAFF



Epilepsy Ireland is updating and expanding on our Teachers Pack for the coming Autumn. The existing pack has served the needs of teachers in primary and secondary schools very well since it was first launched and distributed to every teacher in the country.

Since then many changes have taken place in education and there have also been plenty of changes in how epilepsy is managed, treated and even the names of seizures. It is increasingly true to say that for many children education is starting earlier and for many adults it is continuing longer than was the case previously. Initiatives such as the ECCE preschool scheme and the continued growth of the further education sector coupled with higher participation rates in higher education mean that there are many more opportunities for staff across education sectors to come into contact with students with epilepsy. Our updated pack

will reflect the needs of staff in these settings as well as the traditional schools sector.

Since the first pack was developed we have seen expansion of the pre-school sector with further developments of specific supports for children with disabilities accessing preschool. There have been changes too in supports available to school students through the new model of special needs supports which was rolled out last September. This has meant that for the first time children with epilepsy who may struggle in school will be eligible to access supports. For school leavers and those returning to education there are improved options within PLCs and Access courses, and students with disabilities have increased participation through schemes such as DARE for higher education.

The new pack will aim to inform staff across education setting about the particular needs of students with epilepsy of all age ranges. It will cover topics such as what epilepsy is, how it can be managed in education settings, how to support students with epilepsy, roles of education partners, families and students in developing Care Plans and policies, educational impact of epilepsy and supports available to schools and colleges to assist with training staff in epilepsy awareness and use of emergency medication.

We hope this new pack will be as successful in breaking down barriers and informing staff in all education sectors as the original pack has been, while reflecting the changes within preschools, schools and colleges around the country.

If you're a parent or teacher who wishes to receive the new pack please contact your local Epilepsy Ireland office or call 01 455 7500. Thank you also to Bon Secours for sponsoring this resource.

Gerry Tobin – RIP



Epilepsy Ireland were saddened to learn of the death of Gerry Tobin while taking part in the Annual Tour De Gaggs cycle, an annual fundraiser on behalf of Epilepsy Ireland in June.

Gerry was an enthusiastic cyclist who participated in the event for the last 5 years. The cycle was an unmissable weekend in Gerry's calendar and he made many friends in the Gaggs peloton over the years.

Gerry, who was from Clonsilla, Dublin is survived by his wife Mariea, sons Derek and Mark. Mariea and Mark were also taking part in the cycle.

At the time of writing a fundraising page was set up by Gerry's son Mark and raised €3,566.33 on top of the €6,722.53 for the 2018 Tour De Gaggs Cycle. Find out more via the link below.

goo.gl/rfbMYg

Liane Deasy Memorial Swim



The inaugural Liane Deasy memorial swim took place in Killiney in August. 262 swimmers took part and helped raised €2,100 for



Epilepsy Ireland in memory of Liane Deasy who passed way from SUDEP last year. Since her death, Mark Earley (Liane's widower) has raised over €55,000.

Cobh Ball Run



The annual Barrack Hill Ball run in Cobh took place in August. Huge crowds turned out for the annual spectacular to see thousands of



coloured numbered balls bouncing down the steepest hill in Cobh, all in the cause of Epilepsy Ireland and other local charities.

In memory

- We would like to acknowledge donations we received in Memory of John Newcombe RIP, Mayo
- Thank you to Cian Hyland, Google and LinkedIn for further donations in memory of Liane Deasy RIP
- We also received donations in memory of Catherine Kilbride RIP

Thank you

- Well Done to Derek Mackessy whose mammoth coast to coast walk of just under 400 miles to raise funds for Epilepsy and SUDEP Awareness. Derek undertook this walk during the hottest days in 40 years. Derek has raised a brilliant €2,429.89
- Congratulations to Rob Lee from Limerick who took part in the Curraghchase 10k in aid of Epilepsy Ireland
- Well done to Triona O'Neill who took part in a 3km swim in Loch Lomond (Great Scottish Swim) in Scotland in August, and who is soon taking part in the half marathon in London on September 16th
- Thank you to Louise Doyle and staff in the Commission for Regulation Utilities who raised €231 from their fundraising event in support of Epilepsy Ireland
- Thanks to Emma O'Leary, Cork, who raised a brilliant €1040 in the Cork Marathon
- Well done to Dunshaughlin GAA Club who raised €625 for Epilepsy Ireland from their cycle

Black tie

Epilepsy Ireland Ball



**Fota Island
Resort Hotel**

Saturday 22nd September 2018

Music by Love Bugs - Disco till late

Tickets €80

EPILEPSY IRELAND

Unit 1, 83 Beech Road, Muskerry, Estate Ballincollig, Cork.

Tel: 021 4274774 | info@epilepsy.ie | www.epilepsy.ie

CHY 6170: Charity Number: 20010553



REGIONAL EVENTS

REGIONAL OFFICES

Cork

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

East

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

North-East

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

Midlands

Tel 057 9346790
Cliona Molloy
cmolloy@epilepsy.ie

South-East

Tel: 0567789904
Miriam Gray
mgray@epilepsy.ie

Mid-West

Tel: 061 - 313773
Veronica Bon
vbon@epilepsy.ie

Kerry

Tel: 064 6630301
Kathryn Foley
kfoley@epilepsy.ie

West

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

North-West

Tel: 074 9168725
Agnes Mooney
amooney@epilepsy.ie

CORK

Cork: Parents STEPS self-management programme

The Vienna Woods Hotel, Cork
September 11th, 18th and 25th
6.45 pm to 9.15pm

Cork: Support Group for Parents of Children with Epilepsy

Bishopstown GAA Club
17th October and 28th November
7.30pm
Please contact Niamh for further information

Cork: Innerwise Day for Adults with epilepsy

The Rochestown Park Hotel, Cork
Saturday September 15th
10.00am – 4.00pm
A day of mindfulness, meditation and self-development

Cork: Support Group for Adults with Epilepsy

Bru Columbanus, Wilton
Tuesday 2nd October
7.15pm
Please contact Niamh for further information

Clonakilty: Information Morning for PARENTS on Administration of Buccal Midazolam

Quality Hotel, Clonakilty
Tuesday 16th October
10.00am
Also suitable for Grandparents/ Babysitters but NOT for Professionals
There is no charge but places must be booked by contacting Niamh in the Cork Office

Cork: Information Sessions on Epilepsy Awareness for Teachers and SNAs

Tuesday 9th October - Cork Education Support Centre
Tuesday 16th October - West Cork Hotel, Skibereen
4.30pm

Please contact Cork Education Support Centre and West Cork Education Centre for bookings.

KERRY

Support group for people with epilepsy

Killarney office from 10.30am, on the following dates 19th September, 24th October, 21st November and 12th December.

Support meetings for parents of children with epilepsy

Tuesday 11th September and Tuesday 4th December from 10.30am.

Teachers information evening on Epilepsy

Monday 24th September at the Education centre, IT Tralee from 4.30pm -6pm

Family morning at the Playdium, Tralee

Tuesday 30th October from 9.30am.

Outreach appointments available on the 1st 2nd and 4th Monday of each month at University hospital Kerry.

Public BM training day in Killarney on the 8th November.

EAST

Swords: STEPS Self-management programme for People with Epilepsy

Carnegie Court Hotel, Swords
Tuesday September 18th for 6 weeks
6.00pm – 9.00pm

Dublin: STEPS Self-management programme for People with Epilepsy

Carmelite Community Centre, 56 Aungier Street
Monday September 24th for 6 weeks
6.00pm – 9.00pm

Dublin: Parents STEPS Self-management Programme for Parents

Carmelite Community Centre, 56 Aungier Street
Monday October 1st for 4 weeks
6.00pm – 9.00pm

Arklow: Outreach Service

Arklow Health Centre, Castle Park
Wednesday October 10th
10.00am – 4.00pm

Dublin: Support, Information & Toolkit Group for People recently diagnosed with Epilepsy or Parents of Children recently diagnosed with Epilepsy

Carmelite Community Centre, 56 Aungier St
Wednesday October 17th
10.00am – 1.00pm
&
Carmelite Community Centre, 56 Aungier St
Monday November 26th
6.00pm – 9.00pm

MIDLANDS

Tullamore: Women's Seminar Charleville Centre, Tullamore

September 12th
7.00pm – 9.00pm

Laois: Outreach Service

Citizens Information Centre, Portlaoise
September 24th

Tullamore: Innerwise for Adults with Epilepsy

Charleville Centre, Tullamore
October 3rd for 4 Wednesdays
6.30pm to 9pm

Tullamore: Teachers & SNA Seminar Charleville Centre, Tullamore

October 18th
7.00pm to 8.30pm

Tullamore: Christmas Coffee Morning

Charleville Centre, Tullamore
December 5th
11.00am – 1.00pm

SOUTH-EAST

Kilkenny: Epilepsy Awareness & the Administration of Buccal Midazolam,

Springhill Court Hotel Waterford Rd, Kilkenny
Wednesday 19th September
9.00am – 4.00pm

NORTH-WEST

Sligo: Outreach Service

Sligo Office
September 26th 10.00am - 12.00pm
October 23rd 10.30am - 12.30pm
November 14th 10.30am - 12.30pm
December 11th 10.30am - 12.30pm

Donegal: Neurology Out patients Clinic

Out Patients, Scally House, Letterkenny
Wednesday 17th October 2018
Wednesday 12th December 2018

Letterkenny: Parents Support Group

Epilepsy Ireland Office
11th September
7.00pm – 9.00pm

Letterkenny: Administration of Buccal Midazolam - Information Suction for Parents, Families & Carers

Epilepsy Ireland Office
Wednesday 3rd October
7.00pm – 9.00pm.

Letterkenny: STEPS Self-Management Programme for Adults with Epilepsy

Station House Hotel, Letterkenny
from Monday 3rd September for six Mondays
6.00pm – 9.00pm.

Letterkenny: Epilepsy Awareness Teachers & SNAs Seminar

Station House Hotel, Letterkenny, Co. Donegal
Tuesday 18th September
7.00pm – 9.00pm

Leitrim: Epilepsy Awareness Teachers & SNAs Seminar

Education Centre Marymount, Carrick on Shannon, Co. Leitrim
Tuesday 9th October
6.30pm - 8.30pm

NORTH-EAST

INNERWISE One Day Workshop Swords: STEPS Self-Management programme for people with epilepsy

Starting Tuesday September 18th
6 week programme every Tuesday evening in Swords
6.00pm – 9.00pm.

Castleblaney: Nurse led discussion and Q&A for parents of children with epilepsy

Iontas Centre, Castleblaney, Co. Monaghan
Wednesday 21st November
6.00pm

WEST

Mayo: Epilepsy Nurse Talk

Mayo Education Centre
Friday, Nov 2nd
10.00am – 2.00pm

MID-WEST

Limerick: Thursday 20th September, Time: 5.30 - 7.30pm – Venue: Limerick Education Centre, Marshall House, Dooradoyle, Co. Limerick

Tipperary: Thursday 13th September, Time: 19.00-20.30

Venue: Anner Hotel, Thurles, Co. Tipperary (venue TBC)

Buccal Midazolam Demonstration: Clare Education Centre, Kilrush Road, Ennis.

11th October
9.30am-4.00pm.

BM in Limerick education Centre.
17th October
10.00am – 12pm.

MEMBERSHIP FORM

Please tick Membership Category:

Membership Options with Members Newsletter by Email

1 Year: Free Silicone Wristband & Safety Pillow Discount; Epilepsy News PDF by email; AGM Voting Rights

☐ €15.00

3 Year: Free Silicone Wristband; National Conference Discount; Safety Pillow Discount; Discounts on Bus Eireann & Select Hotels (Subject to conditions); Free Epilepsy Resource Pack; Free Membership Card; Epilepsy News PDF by email; AGM Voting Rights

☐ €40.00

5 Year: Full Membership Package; National Conference Discount; Free Safety Pillow; Free Silicone Wristband; Free Medimee Band; Discounts on Bus Eireann & Select Hotels (Subject to conditions); Free Epilepsy Resource Pack; Free Membership Card; Epilepsy News PDF by email; AGM Voting Rights

☐ €65.00

Membership Options with Members Newsletter Posted

1 Year: Free Silicone Wristband & Discount on Safety Pillow; Epilepsy News by Post; AGM Voting Rights

☐ €25.00

3 Year: Free Silicone Wristband; National Conference Discount; Safety Pillow Discount; Discounts on Bus Eireann & Select Hotels (Subject to Conditions); Free Epilepsy Resource Pack; Free Membership Card; Epilepsy News by Post; AGM Voting Rights

☐ €70.00

5 Year: Full Membership package; National Conference Discount; Free Safety Pillow; Free Silicone Wristband; Free Medimee Band; Discounts on Bus Eireann and Select Hotels (Subject to conditions); Free Epilepsy Resource Pack; Free Membership Card; Epilepsy News by Post; AGM Voting Rights

☐ €115.00

For 1 and 3 Year Packages: Safety Pillow, RRP €40.00, special offer €22.

☐ €22.00

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 wish to receive such communication, please tick here ☐

and Methods of Contact - Tick Box

Post ☐ Email ☐ Phone ☐

Sms Text ☐

*Your data will be processed in accordance with our privacy policy, please see www.epilepsy.ie

Payment Method

☐ Credit/ Debit Card (see below)

☐ Cheque/Postal order/Bank Draft (payable to Epilepsy Ireland)

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

☐ €10 ☐ €20 ☐ €30 ☐ €50

☐ €100 ☐ own amount €

Total Enclosed €

All our Epilepsy Support Services are free of charge

Title Name

Address

..... Tel No

Mobile Email 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 EZINE news Bulletin. Clearly write in your e-mail address 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 and I authorise you to debit my account with the sum of €

Name on card Card number

Expiry date (mm/yy)..... CVV number

Signature Date



All-Cash Mega Raffle 2018

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: 16th November 2018

(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, 10th August 2018. Winners will be published
on epilepsy.ie and notified week commencing
November 19th 2018.

**Return this slip with your ticket stubs and proceeds in the freepost
envelope provided by: Wednesday 14th November 2018**

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 ☐

Your data is processed in accordance with our Privacy Policy. Please see www.epilepsy.ie for details.

ORDER MORE TICKETS

- Phone 01 4557500
- Email info@epilepsy.ie
- Return this slip to us in the
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www.epilepsy.ie
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Best Practice in Transparency and Accountability