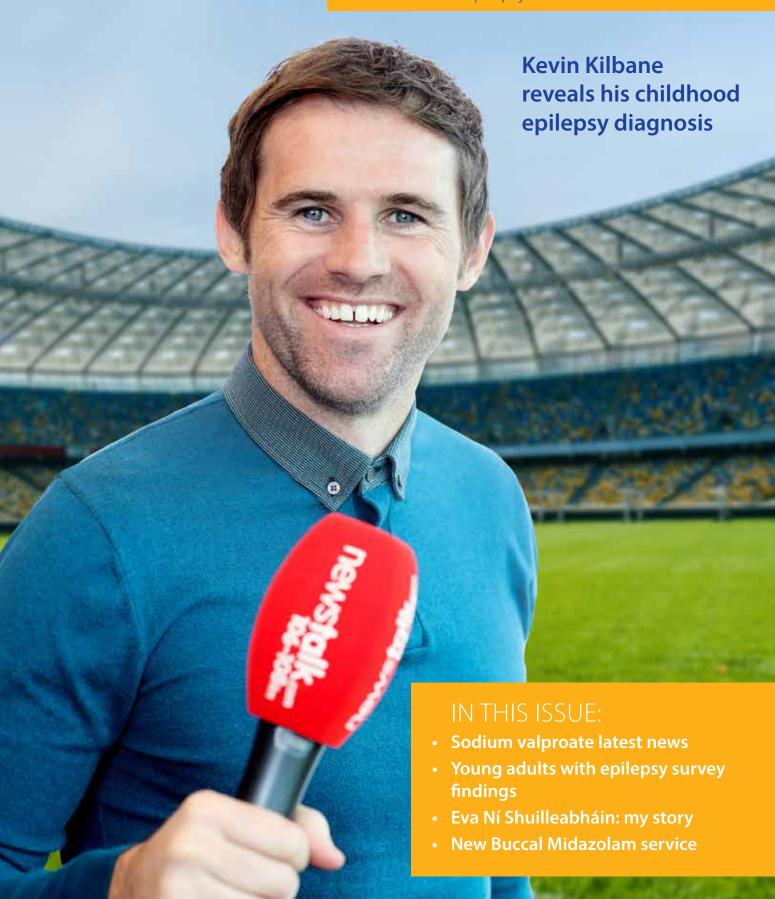


Epilepsy News

Epilepsy Ireland Issue 81 Summer 2018



CONTENTS

- 3. News Update
- 4. Kevin Kilbane Reveals Epilepsy Diagnosis
- 5. Sodium Valproate Latest Developments
- 6. Young People's Concerns about Epilepsy Survey
- 7. Young Adult Resources
- 8. Women with Epilepsy
- 9. My Attitude Towards Epilepsy
- New Treatment Booklet POASSO Award
- Teenagers show Creative Spark
 Buccal Midazolam

Information Sessions

- 12. Fundraising
- 14. Regional Events
- 15. Membership Form

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NOTE FROM THE EDITOR



In recent years, Epilepsy Ireland has been lucky to be associated with many high profile names like Joe Schmidt and Rick O'Shea who have increased awareness

of our work. In this issue, we can include one of the country's leading sports broadcasters and three Irish soccer legends. Huge thanks to Joe Molloy, Damien Duff, Brian Kerr and Kevin Kilbane who volunteered their time not to mention our many supporters who attended the event on the day. During the event, Kevin Kilbane revealed that he had epilepsy in his younger years before growing out of the condition. As someone who works to spread epilepsy awareness, I cannot emphasise how crucial it is to have well known people talk about their condition. You can read more about this great day on page 4.

In the last issue of Epilepsy News, we reported on the latest European Medicines Agency (EMA) recommendations regarding the use and risks of the epilepsy drug sodium valproate (Epilim) in women and girls. On page 5 we cover the significant

progress which included a meeting with the Minister For Health, Simon Harris.

Conor Culkin

This summer edition has a particular focus on women and teens. For National Epilepsy Week (May 14th-20th) we asked teens and young adults what were the main issues that they faced and the results are outlined on page 6. In the last three issues Epilepsy Ireland Transitional Nurse, Yvonne Owen gave advice to teens and she is back with a list of important resources on the following page.

Women with epilepsy face a number of unique challenges with the condition and Candidate Advanced Nurse Practitioner, Sinead Murphy shares her knowledge on page 8. Epilepsy News always searches for personal stories that the reader can identify with and this edition is no different on page 9 as Eva Ní Shuilleabháin reveals how she struggled to accept her epilepsy.

Also in this issue is our new treatment booklet, PQASSO approval and information about new Buccal Midazolam training sessions for parents.

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

NEW WEBSITE FOR EPILEPSY IRELAND

NEARS COMPLETION

Epilepsy Ireland is in the latter stages of updating our website to reflect the importance of modern day communication for the benefit of our service users and the non- epilepsy community. Our new site wishes to inform, support and engage anyone who visits.

We are aiming for simplicity and an interface that is intuitive and easily navigable

for the user. The new website will have an innovative and modern design to accommodate the new features and layout. It will include new sections for women, teenagers and children with epilepsy. We hope to have the new website live in the near future – keep following our current website and social media channels for more updates.



A sneak preview of the new epilepsy.ie site.



RCSI to study genetic targets for childhood epilepsies

Developing new treatments for childhood epilepsies and neuro-developmental diseases is the aim of a new partnership between the FutureNeuro Research Centre at the Royal College of Surgeons in Ireland and F. Hoffmann-La Roche Ltd. The 3-year partnership aims to guide scientists to new gene targets to control some of the devastating childhood epilepsies that do not respond to existing therapies. The research will be conducted from Professor David Henshall's lab in FutureNeuro.

"We are excited by the potential of this collaboration to advance our treatment options for children with currently untreatable epilepsy. The opportunities presented by a better understanding of epilepsy at a genetic and molecular level offer great hope for the future, especially for those with rare and severe forms of treatment resistant epilepsy", said Professor Henshall.

The team will look for unusual gene expression patterns in brain tissue and cell models of childhood epilepsies, focusing on the genome's so-called 'dark matter' stretches of DNA which do not code for proteins but work as molecular switches to activate or inhibit protein production. FutureNeuro have also announced new partnerships with Greenlight and Congenica this year. For more info log onto www. futureneurocentre.ie.



GO https://goo.gl/qDGB2K

Low dosage of CBD may reduce seizures according to new study

Cannabidiol (CBD) was shown in a recent large-scale, randomized, controlled trial to reduce the number of seizures in patients with a severe form of epilepsy called Lennox-Gastaut syndrome. The study was conducted with Epidiolex - a cannabis based drug recently approved by the FDA and awaiting approval in Europe.

Patients taking a 10-milligram (mg) daily dose of Epidiolex experienced nearly as great a reduction in seizures as patients on 20 mg, and with fewer side effects,

according to lead researcher Dr. Orrin Devinsky, Director of NYU Langone's Comprehensive Epilepsy Center in New York

He explains: "This new study adds rigorous evidence of cannabidiol's effectiveness in reducing seizure burden in a severe form of epilepsy and, importantly, is the first study of its kind to offer more information on proper dosing."

The researchers also noted that while Epidiolex was found to be both safe and effective in children with Lennox-Gastaut Syndrome it's not clear yet whether this would translate to more common forms of epilepsy or if non-pharmaceutical grade CBD would have the same effect.



GO https://goo.gl/pnfvxf

Prediction system for seizures developed

Researchers at the University of Sydney are using artificial intelligence to develop a method to predict seizures that will not require surgical intervention.

Dr Omid Kavehei from the Faculty of Engineering and IT and the University of Sydney Nano Institute said: "We are on track to develop an affordable, portable and non-surgical device that will give reliable prediction of seizures for people living with treatment-resistant epilepsy."

In a paper published in Neural Networks, Dr Kavehei and his team have proposed a seizure-prediction method that can alert people with epilepsy within 30 minutes of when a seizure may occur. The device works by "learning" how people's brain patterns change just before a seizure and the next step is to make a 'wearable' prototype to test in humans.



GO https://goo.gl/nAN1WZ

Cognitive-behavioural therapy does not reduce depression in most people with epilepsy

Nearly 70% of people with epilepsy do not experience significant reductions in symptoms of depression following cognitive-behavioral therapy (CBT), according to a systematic review published in the Journal of Neurology, Neurosurgery, and Psychiatry.

The review consisted of 8 clinical trials involving almost 500 patients and found that following CBT, the depressive

symptoms for approximately 30% of people with epilepsy improved which compares to 10% of patients in the control conditions who improved without intervention.

Study Author Adam Noble said: "Trials in the wider mental health literature shows we should be aspiring to get 70-80% of our people experiencing mental health problems improving and, indeed recovering, not just 30%. Whilst we acknowledge better and bigger trials are needed to be 100% confident that CBT is not the right approach, we contend that the priority should be on exploring alternative treatment approaches. Distress is after all a key predictor of quality of life in epilepsy and appears to hold a varied relationship with seizure frequency. More effective treatments might be realised through a better understanding of the psychological mechanisms that contribute to anxiety and depression in people with epilepsy."



GO https://goo.gl/wQ5bnq

Epilepsy Ireland continues support for 'Invest in Neurology' campaign



Epilepsy Ireland were delighted to show our support to the Neurological Alliance of Ireland presentation in Leinster House recently as part of the "Invest in Neurology" campaign.

The "Invest in Neurology" campaign is calling on the government to take immediate action to tackle unacceptable staffing deficits in neurology services across the country as well as longer term investment to develop specialist services for specific neurological conditions.

Over 40 TDs and Senators attended the briefing and the NAI was encouraged with the response.

For more information about the campaign log onto www.nai.ie.



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FORMER SOCCER STAR KEVIN KILBANE REVEALS

CHILDHOOD EPILEPSY



Former Ireland football International Kevin Kilbane has talked about having epilepsy in his childhood years at a recent Epilepsy Ireland fundraising lunch.

Kilbane explained how he had over 20 seizures from the ages of 9 to 12 and continued to take medication in his teenage years, before eventually becoming seizure free.

Speaking to Joe Molloy in the Radison Blu Hotel (Dublin), he said: "I was one of the fortunate ones with my epilepsy with the fact I grew out of it and was able to have a prolonged football career."

Kilbane, who now works as a football pundit for BBC and Newstalk, said he remained "defiant" despite his epilepsy diagnosis. He told the room that his mother used to take him to epilepsy information evenings during his teenage years while he was a player at Preston North End football school of excellence.

"As a teenager, I thought to myself I do not want to be here, this is interfering with my football training. I obviously later realised how important these evenings were." Kilbane never told Preston North End about his epilepsy. "I kept it quiet as there was still a taboo with the condition in the late 80s and I was afraid it would affect my football career", he said.

His seizures stopped in teenage years and Kilbane went on to achieve a top-level football career playing for Premier League clubs such as Everton and Sunderland while also gaining over 110 caps for his country.

He believes having an epilepsy diagnosis should not prevent anyone from pursuing a sporting career. "Today I would say that there is hope for anybody with the condition – you live to tell the tale and fight another day on the back of it", said Kilbane.

The event also included former Irish soccer legends Damien Duff and Brian Kerr who has a family connection with epilepsy. The guests regaled the room with stories from their successful football careers. Epilepsy Ireland would like to thank everyone who supported the lunch fundraiser.



L-R: Epilepsy Ireland CEO, Peter Murphy, Joe Molloy, Brian Kerr, Damien Duff, Epilepsy Ireland Chairman, Mark Dowdall and Kevin Kilbane.



L-R: Joe Molloy, Damien Duff, Kevin Kilbane and Brian Kerr share a light moment.



Gillian and John Halpin supporting the event.



Brendan Hoban and Joan Connolly supporting the Epilepsy Ireland cause.

DEVELOPMENTS ON SODIUM VALPROATE CAMPAIGN



In the last issue of Epilepsy News, we reported on the latest European Medicines Agency (EMA) recommendations regarding the use and risks of the epilepsy drug sodium valproate (Epilim) in women and girls. Since then, there has been much activity for the FACS Forum campaign which focuses on three main demands:

- Supports for those who have been affected by in-utero exposure to valproate in the past
- 2. Services to families affected in the present
- 3. Reduce the risk of children being born with valproate-related disabilities in the future.

FACS Forum Ireland is a group of organisations that have come together to advocate on these issues, including Epilepsy Ireland, OACS Ireland and the Disability Federation Ireland.

Meeting with Minister for Health Simon Harris

In March, the Forum met with Minister Harris (pictured) to discuss the responses now needed on behalf of the government to address the needs of patients on valproate and families who have been affected by foetal anti-convulsant syndrome (FACS). The meeting led to the establishment of a HSE Valproate Response team within the HSE (see below). The Minister also promised to respond to the Forum as soon as possible on how he proposes to address historical issues related to the drug. Speaking in the Dáil, he stated his commitment to resolving the issue and said that families affected by the drug have been 'let down'. At the time of writing, the Minister has not yet responded to the Forum.

Oireachtas Health Committee hearing

In April, the Oireachtas Health Committee held a hearing on the issue, attended by HSE, the Health Products Regulatory Authority (HPRA) and the FACS Forum including Epilepsy Ireland CEO Peter Murphy. A wide range of issues were discussed including full implementation of the new EMA ruling, developing diagnostic pathways for children potentially affected, gathering data on the scale of FACS in Ireland and the need for HSE to engage with families about the supports required.

Oireachtas Committee Report

In June, the Committee published a report from the hearing which makes 12 recommendations to the government. Epilepsy Ireland and the FACS Forum welcome these recommendations, which address our key demands:

- Full and immediate implementation of all of the new EMA risk reduction measures
- Continued close collaboration between the HSE, HRPA and the FACS Forum to achieve implementation.
- All risk reduction measures to be reviewed regularly to ensure they are working
- Establish a HSE/HPRA-funded register to record individuals who were prescribed valproate during pregnancy and all those affected by FACS
- Families affected by FACS to be provided with a central point of reference within HSE
- Children exposed to valproate to be assessed and diagnosed as appropriate
- A full suite of services for those affected to be agreed with families within 8 weeks of the publication of the report.
- HSE to report back to the Committee on progress in establishing support services within 12 weeks
- The establishment of an independent investigation to examine the historical use of valproate in Ireland and into its ongoing effects
- Further consideration and examination to be undertaken with regard to compensating FACS patients

The committee highlighted that some of these concerns require immediate action and "should be considered as a high priority".

HSE Valproate Response Project

The HSE has now established a multidisciplinary working group to ensure safe prescribing, prevent current and future harm and develop diagnostic and care pathways.

Over the next six months, the group will develop work streams in a number

of clinical areas including genetics, epilepsy services, psychiatric services and disability as well as work streams covering communications with patients and professionals. The FACS Forum are represented on the project's steering group and project team.

HSE to write to all women and girls on Valproate

An important development has been the HSE's decision to write directly to over 3,500 female patients currently prescribed Epilim.

Letters will also be sent to each patient's GP encouraging them to organise consultations with patients to explain the risks in person and to make appropriate referrals to a specialist for treatment reviews as now required by the EMA ruling. We believe these steps will help to resolve long-standing issues about awareness and generate better doctor-patient communication.

However, these letters are also likely to cause distress for some people who were not previously aware of the issues and we are encouraged that HSE have agreed to set-up a nurse-led helpline service to respond to queries and manage referrals. Work is currently underway to establish this helpline and other supports required prior to the letters being sent.

As of June 20th, these letters have not yet been sent by HSE. While it is important to ensure that supports are in place to deal with enquiries and new cases, unnecessary delays put women and children at further risk.

New valproate booklets

HPRA have authorised a new valproate patient information booklet which can be downloaded from the link below. A new range of resources have also been distributed for prescribers and pharmacists.

For the latest updates, see www.epilepsy. ie. If you are a woman taking valproate or the parent of a girl on the drug and have any concerns, please contact your healthcare team or your local El office.

Further Information: Oireachtas Committee Video/ Transcript, Oireachtas Committee Report, Epilepsy Ireland Valproate page, HSE Valproate page, HPRA Valproate page, new patient booklet on Valproate and OACS Ireland.

82% OF YOUNG PEOPLE REVEAL CONCERNS ABOUT THEIR EPILEPSY



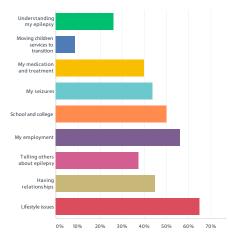
To mark National Epilepsy Week (May 14th – 20th), Epilepsy Ireland announced results of a survey conducted among young people aged 16-21 on their experience of living with the condition.

The results showed 82% said they had concerns of some nature relating to epilepsy. 65% of respondents have concerns about lifestyle issues such as drinking alcohol, socialising, sport and travel. 56% were worried about employment and 64% said they were concerned about anxiety issues. 56% of respondents have confidence and selfesteem worries and 71% felt that they are able to explain their epilepsy to others. When asked what two words best sum up your epilepsy, "angry" and "annoyed" were the most common words.

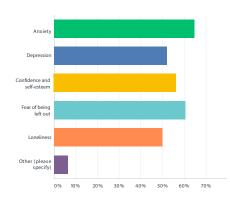
Speaking after the results were published, Peter Murphy, CEO of Epilepsy Ireland believed the survey shed new light on the experiences of the condition among young people. He explained: "The teenage years can be a difficult time with exams, social pressures and transitioning into adulthood. With an epilepsy diagnosis on top of all that, you can feel like you are on an emotional rollercoaster. The survey has shown that young people often feel like the condition is a heavy burden, resulting in feelings of anger and frustration. If anyone is feeling like this, it is important you find someone to talk to, whether it's friends or family or engaging with the services of Epilepsy Ireland or your healthcare team."

Meanwhile, Epilepsy Ireland has also released a new resource entitled—'Moving Forward', a guide for young people with the condition. The guide has information about transition and moving to adult services. It addresses the key challenges for young people with epilepsy identified in the survey as well as for their parents and aims to support teenagers as they

Which of the following aspects of epilepsy are causing you concern?



Which of the following are a concern for you?



make the often difficult move from paediatric to adult care.

Author and Epilepsy Transition
Coordinator with the National Children's
Hospital Group and Epilepsy Ireland,
Yvonne Owen said: "In the development
of this book we have worked with many
young people with epilepsy and their
parents who have provided great insight
about what it's like to live with epilepsy
and the challenges they have to face. They
have helped us to identify what young
people want to know about at this stage
of their lives and with their help we have
developed this new resource."

The resource is spilt into 4 sections:

- Transition and moving to adult services
- Top tips for young people living with epilepsy
- Advice for parents of young people with epilepsy
- Resource section

The guide also contains a section for you to keep record of your own epilepsy information, who cares for you and a

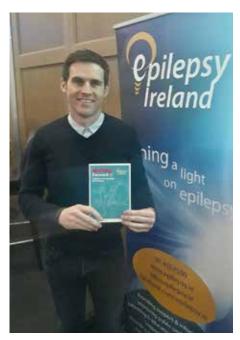
checklist of what things you should know about as you transition into adulthood.

Yvonne Owen adds: "Don't panic though, you are not expected to know everything. If there is something you don't know

about and want to find out more you should ask your doctor, nurse or local Epilepsy Ireland office. Gradually you will start to learn more and in time you will feel more empowered and in control. Additionally, there are lots of links to further resources included so you can find out even more information about the condition."

Epilepsy Ireland also offers a range of services which include one-to-one services, a dedicated helpline for teens and their parents (01 4554133) and our new How2Tell app which addresses the major concern of disclosing epilepsy. We also offer our pre-employment training course Training For Success. Based on campus at the Institute of Technology Sligo, the programme has helped over 250 young people with epilepsy attend since its inception in 1998. Additionally, Epilepsy Ireland also offers support groups or self-management programmes such as the STEPS programme to help teens and young people talk about the difficulties they experience.

To download a copy of 'Moving Forward' visit www.epilepsy.ie.



Former Ireland international Kevin Kilbane with Epilepsy Ireland's new 'Moving Forward' resource.

IMPORTANT RESOURCES FOR YOUNG ADULTS



To mark the launch of the new 'Moving Forward' resource Epilepsy Ireland Transition Nurse Yvonne Owen discusses resources to help young adults manage their epilepsy.

Tools to Help with Transition to Adulthood

Taking more responsibility for yourself and your health is all part of growing up. This can seem a bit daunting at times especially if you don't have the information you need. As part of our series we are going to focus on what tools are out there to help you control your epilepsy and prepare for adulthood.

Get informed

Being informed is the best way to help you manage your epilepsy. Last month we launched the "Moving Forward" booklet (see page 6) which is specifically for young people with epilepsy.

Keep a Seizure Diary



It's a good idea is to keep a seizure diary so you can keep track of when you've had a seizure, any changes to your medications, any side effects of your medications and anything else you think might be important. This information is really useful when you go to a clinic to meet your doctor or nurse and can help them make better informed decisions about your care.

You can get an actual diary to write in or download an app on your phone, whatever you prefer. Bring your diary with you to your appointments so your doctor or nurse specialist can see how things are going for you. More information about The **Epilepsy Ireland App** is available in the booklet or on our website - epilepsy. ie.

Services available to you

Epilepsy Ireland has lots of information that can help you learn more about epilepsy as well as provide support for you and your family. You can check out www.epilepsy.ie or get in touch with Dublin headquarters or at regional offices in Cork, Dundalk, Galway, Kerry, Kilkenny, Letterkenny, Limerick, Sligo and Tullamore.

Transition Nurse Advice line – you can speak directly with a specialist nurse if you have any queries about epilepsy, adolescence or transition to adult services. The advice line is open on Mondays 2-5pm on 01 4554133.

Other useful online resources

Stepping Up (www.steppingup.ie) is an Irish website dedicated to supporting transition. It has lots of useful information and videos about transition and details of some of the adult epilepsy clinics in Ireland.



Young Epilepsy (www.youngepilepsy. org.uk) is a UK-based charity that supports children and young people under 25 with epilepsy in the UK. They provide information and support for young people with epilepsy, parents and

professionals. Some of this information may be useful but note it is for UK services.

The TEA Room (www.thetea-room.com) in an online, worldwide forum available to young people with epilepsy between the ages 13 and 19. TEA stands for 'Teenage Epilepsy Agenda'. Young Irish people are welcome to join in the conversation with a worldwide community about the challenges that young people with epilepsy face. The website is managed by the Scottish Epilepsy Initiative, a registered charity based in Scotland. For more information visit their website or like their Facebook page www.facebook.com/thetearoomchat.



Girls with Nerve (www.girlswithnerve. com) is a US website where teens with epilepsy can find information about sexual health, stories from other teens with epilepsy, suggestions for talking with doctors about the tough stuff, and more.

Talk About It (www.talkaboutit.org) is a US website where TV and movie stars share information about epilepsy and encourage kids to talk about living with epilepsy.

Youth Health Talk (www.youthhealthtalk. org) provides real, reliable health information by young people sharing their experiences in a specific section for people with epilepsy.

There are more useful websites and resources available in the resource section of the "Moving Forward" booklet so go check it out on www.epilepsy.ie.



To mark the launch of the new 'Women With Epilepsy' resource (see page 9) Candidate Advanced Nurse Practitioner at Beamount Hospital, Sinead Murphy gives her advice to women with epilepsy.

The latest models of care recognise that women with epilepsy (WWE), especially those of childbearing age, require greater access to specialist care. I currently work as the first appointed Candidate Advanced Nurse Practitioner (cANP) for women with epilepsy. As a qualified nurse and midwife I have taken a special interest in caring for women with epilepsy prior to, during and post pregnancy. Women need to be given accurate, up to date and individualised information regarding treatments available for epilepsy; in particular for those planning a pregnancy.

Many of the women I meet want clear, consistent information delivered in a timely manner. They require the various health professionals involved in their care to communicate effectively with each other.

Collaboration

I would advise that all women do as much as they can to educate themselves about their own condition. In today's health service managing epilepsy is a collaborative approach, by that I mean we all work together to achieve a common goal; no seizures, no side effects and minimum amounts of medication.

Very often the women I see have not been seen by a specialist in some time - they often tend to trivialise their epilepsy and do not recognise some of the symptoms as seizures. In my opinion, that underreporting of seizures is significant in this population. A typical example of this is a woman attending her GP with vague symptoms of anxiety and fear often associated with a "butterfly" sensation in her tummy that comes out of nowhere. I have been told "this is just me", or "no anxiety medication has worked for me". These women are not aware that what they are experiencing are possible seizures. Education on these matters is crucial.

Epilepsy Specialist Nurse

Women with epilepsy who are currently cared for in public specialist services now have access to epilepsy nurse specialists and I would advise all women to contact your local nurse at your local hospital if you have any queries or concerns in-between their appointment times.

If you are a woman with epilepsy and have not been seen in some time by a specialist service and have ongoing issues I would suggest you talk to your GP about a specialist review. I would also advise that you check with your pharmacist in relation to the possible side effects of your medication - for example some of the older epilepsy medications can cause bone loss and this can lead to bone health problems later on in life.

Pregnancy

All women with epilepsy should be treated in an individual manner but for those considering a pregnancy I would say preconceptual counselling is the most important thing that needs to be considered. If you plan the pregnancy together then you are prepared for all eventualities. The management of epilepsy in pregnancy is particularly tricky because the doctor must take into account the needs not only of the woman but also the potential adverse effects on the unborn child.

Over time we have questioned the effects of medication during pregnancy and with the establishment of epilepsy and pregnancy registers around the world, including the UK and Irish Pregnancy Register (www.epilepsypregnancyregister. ie), we have learned about the difficulties associated with seizure medication.

Women with epilepsy have additional issues and complexities and should be empowered to make informed decisions concerning their epilepsy and medication. They should be warned about the dangers of abruptly stopping or reducing their medication unless under medical supervision. It is my opinion that women should be continually educated about risks of medication as known and offered ongoing preconceptual counselling where appropriate.

Key Points

- Women with epilepsy (WWE) should be prescribed Folic Acid 5mg once an anti-seizure medication is commenced and should be continued until at 3 months into the pregnancy
- WWE should be counselled on adequate methods of contraception as well as planning a pregnancy
- WWE should attend for preconceptual counselling and educate themselves about the most up to date information when planning a pregnancy
- WWE planning a pregnancy should attend an epilepsy specialist for a review prior to planning a pregnancy and anti-seizure medication drug levels measured if necessary
- WWE should never stop taking their anti-seizure medication without discussing it with their doctor/nurse first
- WWE should be encouraged to register their pregnancy with the Epilepsy and Pregnancy register (1800 320 820)
- WWE with ongoing issues or concerns should first report these to their GP and a specialist review considered.

Contact our Nurse Helpline every Monday from 9.30am -1pm on 01 4554133.

EVA NÍ SHUILLEABHÁIN - MY ATTITUDE TOWARDS EPILEPSY



Eva Ní Shuilleabháin's epilepsy story highlights her struggle to initially accept her condition.

I looked at epilepsy as having a disability, something to be ashamed of and I would lose everyone in my life if they knew I had it. The problem wasn't with everyone else, it was with me. I started out with epilepsy which was very controllable to one that took control.

My first seizure was when I was in college sitting in a lecture and I collapsed. When I came home to Kerry, my family saw these seizures where I would just sit and stare lasting about a minute.

My MRI and EEG came back normal but I was diagnosed as having 'Petit Mal' epilepsy. Years later and that is still a bit strange to say.

I was prescribed with daily medication, encouraged to have a regular sleep routine, good diet, no alcohol and epilepsy would have minimal control on my life. I didn't really think I had the condition and thought it would go away.

The move to Dublin

I moved to Dublin to begin my career. I began socialise, late nights, sleep late, drink alcohol and didn't really think about my epilepsy as I wasn't having seizures.

I felt more comfortable having a drink than telling people I didn't because of my epilepsy as I thought they wouldn't feel comfortable in my company, worrying that I could have a seizure. However, epilepsy is not something that can be ignored. After nights out I started having auras, in a state of confusion but I didn't think that anyone was noticing this. This even became so normal for me I started not take any notice of it.

However, everyone was noticing that something was wrong. After a night out there were days in work where I sat holding on to my desk, having auras and not telling anyone as I thought they would think less of me. They would ask if there was something wrong and I would tell them I was fine, maybe a bit tired but that was it. They were also my friends and having good friendships in work is important.

Most days I would come in as normal, very friendly and go for lunch with them. There were also days I would ignore everyone, having lunch on my own and really it was strange for them to understand.

Impact on career

It did impact my career. I started to lose confidence in myself and had very little self-esteem. I didn't apply for promotions as I thought there was no point; if they found out I had epilepsy, I wouldn't be given the job or would even lose my current job. As well as that, I had terrible mood swings because of what was going on and it was my family who bore the brunt of this.

Epilepsy took control over my life when I started to have tonic-clonic seizures which I'd experience over the course of a few days. My neurologist made it clear if I didn't start to take it seriously, the impact could be long-term.

I took time off work as I knew things had to change to be able to live a normal life with epilepsy. I am not sure why I initially adopted the attitude that I shouldn't tell people that it was a disability, maybe I thought I would be judged.

It isn't easy having to look back and say, how different things would be for me if I had accepted it, how much more I would have achieved in my life, advanced in my career if I just told people but I didn't and I can't change that.

Acceptance

The best thing that has happened to me is learning to live a real life with epilepsy, changing my attitude and it is not something to be ashamed of; even writing this helps me a lot.

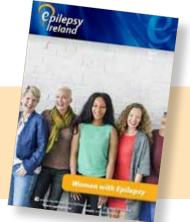
I started to tell people I have epilepsy and it didn't have any impact on how they felt about me one bit.

When I did tell colleagues I couldn't get over the fact that they were very happy to hear as they had noticed something was wrong and were relieved that there was an explanation.

I have a better relationship with my family now that I have learned how to live with epilepsy. I used to find the constant questions annoying - was I looking after myself, alcohol, taking medication. I would come home, saying all was well, wishing they would just forget about my epilepsy as I am trying but they could see things were not good and it would then result in arguments .

Having a different attitude towards epilepsy makes such a difference. I am much more relaxed in every aspect of my life. I appreciate the support of my family both in Kerry and in Dublin. I sometimes don't know how they put up with so much from me.

I think now I am very glad to share my story about my epilepsy. It's incredible the impact adopting the wrong attitude towards it can have personally and professionally and I hope it helps anyone who feels the same way as I did.



Epilepsy Ireland's new booklet for women

Our new booklet has been written for women with epilepsy, to help navigate the many concerns and challenges women face in managing their health and well-being. Download from www.epilepsy.ie.

NEW GUIDE TO EPILEPSY TREATMENTS



Epilepsy Ireland has published a new booklet called 'Epilepsy Treatment' which aims to bring together in one publication all aspects of epilepsy treatment. The booklet covers all the currently available medications as well as non-drug options. Additionally, it describes existing and new services and future directions in treatment.

Epilepsy services are described in terms of the Referral Pathway from GPs to A&E and on to specialist services. The roles of those professionals who might be involved in epilepsy care such as neurologists, epileptologists and specialist nurses are all outlined. This section also briefly explains the role of specialist services such as neurosurgery, neuropsychology, psychiatry and the involvement of other hospital doctors, paediatricians, pharmacists and dietitians.

The section on medication discusses why it is prescribed, when it is prescribed and the process of starting treatment. It covers all 30 currently available antiepileptic drugs. The free medication scheme is explained as are the issues

around generic medicines. Forms of medication are described including emergency medication. The risks of not taking medication are discussed. Many questions people with epilepsy might ask are covered, such as how drugs work and how long they take to work, questions about changing medications under supervision, preventing missed doses and taking medication during illness. The importance of consulting with the doctor or pharmacist is emphasised.

Side effects are a common concern and source of many queries. These may be common or rare, short or long-term, mild or serious. The section on side effects covers reporting suspected side effects, interactions with prescribed drugs, interactions with over the counter medicines and interactions with food and drink.

The booklet discusses complementary therapies and approaches to help with stress reduction. It explains which aromatherapy oils aren't recommended and why caution is advised with certain herbal remedies and supplements. It recommends always checking with a doctor or pharmacist before choosing to use alternative therapies.

The section for women discusses epilepsy medication and pregnancy, pre-conception advice, the importance of antenatal care, the need for the folic acid higher dose to be prescribed, Foetal Anti-Convulsant Syndrome (FACS) and the importance of avoiding valproate in women and girls of childbearing age

unless no other AED works.

Caring for and taking medication safely is important to everyone and this section covers keeping medications safely, using pill dispensers and blister packs, phone apps to track meds and reminders, travelling with medication, prescriptions within the EU, the European Health Insurance Card and travel insurance

Epilepsy treatment isn't only about medication and so the non-drug options to treatment are covered also. These included epilepsy surgery, vagus nerve stimulation and the ketogenic diet which is now used both for children and adults.

Self-management is an important aspect of managing seizures too in terms of avoiding or reducing lifestyle triggers and improving well-being. Self-management programmes can help support people with epilepsy to take control back over their condition. Epilepsy Ireland runs STEPS self-management programmes as well as meditation programmes to help manage stress.

The booklet concludes on a hopeful note of future developments and gives a brief overview of the main ones including medical cannabis, more advanced therapeutic devices such as neurostimulators, laser thermal ablation techniques for surgery, new medications in development and genetic approaches.

Copies of the booklet are available to download at www.epilepsy.ie or from your local Epilepsy Ireland office.

EPILEPSY IRELAND AWARDED PQASSO APPROVAL



We are happy to announce that following an intensive assessment process Epilepsy Ireland has again been

awarded Certification at Level 1.

Practical Quality Assurance System for Small Organisations is a quality assurance system that offers a straightforward, user-friendly approach to strengthen all areas of an organisation; used systematically, it can help an organisation run more effectively and efficiently.

The quality system comprises 12 specific standards and almost 100 individual indicators which show precisely how the standard can and should be met. Failure to fully meet these indicators results in failure to receive certification.

Epilepsy Ireland first adopted the PQASSO process as a means of measuring our performance in 2012, receiving certification in January 2015. Following its commitment to continuous improvement Epilepsy Ireland began to review the entire PQASSO system in preparation for its application for recertification.

PQASSO is an evidence-based system so the independent assessor spent 3 days on site examining documented evidence of Epilepsy Ireland's achievement of the 12 standards and conducted personal interviews with a wide range of staff and board members.

Having completed his assessment the recommendation to certify is presented to National Council for Voluntary Organisations (NVCO) in London, the independent body who processes the PQASSO system. They issued confirmation of Epilepsy Ireland's re-certification on May 25th. The current certificate will be valid for a further 3 years at which point Epilepsy Ireland's goal will be to apply for certification at PQASSO Level 2.

TEENAGERS SHOW THEIR CREATIVE SPARK WITH ELECTRIC FEATHERS



Epilepsy Ireland in conjunction with Helium Arts have been working together to provide a new art programme for young people with epilepsy between the ages of 12 and 16 years of age. The artist working with us is Rachel Tynan and she has an extensive amount of experience of working with this age group through her work with Helium Arts and Temple Street Children's Hospital. Three workshops took place last spring and 16 young people have taken part in the programme to date.

The young people have worked with various different art forms through the workshops, such as animation, plaster paris, clay, fabric and painting of all types. They developed and created their own avatars / superheroes and through this process they got to discuss elements of themselves and similarities between them and their avatar! There was also opportunities to discuss their own epilepsy while they were working on their art while learning more about their condition and to meet other young people with similar experiences to them.

During the third workshop, the group were assigned the task of coming up with a name for their group and designing a logo (pictured) that would be unique to them for all activities moving forward. There were many great ideas to name the group and in the end they voted for 'Electric Feathers'. Each member of the group then designed a logo to symbolise this and the group had the opportunity to choose the logo that best represented them as a whole.

This July there are a further three days scheduled for the Electric Feathers group in The IMMA, Kilmainham. The young people will get to work on a larger piece of art during this time and will also have their own personalised t-shirts and/or hoodies with the group logo printed onto them for these days. The group have given a list of suggestions of what they would like to complete during the next sessions and it promises to be an interesting and exciting three days of learning, fun and relationship building.



Nicole O'Donovan shows artist Rachel Tynan her work.

PARENTS BUCCAL MIDAZOLAM INFORMATION SESSIONS



Epilepsy Ireland are pleased to announce that our community resource officers are now delivering Buccal Midazolam (BM) Rescue Medication Information Sessions for parents and carers in all regions of the country outside Dublin. This exciting development commenced in early 2018 with our full community resource officer team being trained up to deliver this programme. The programme was designed and developed in conjunction with Quarriers UK and Our Lady's Childrens' Hospital Crumlin.

This new service meets a very important need for parents and carers of children with epilepsy. Epilepsy Ireland already offers a very busy and highly sought after training programme for healthcare professionals and teachers on the administration of BM which is certified by Quarriers UK, but did not have an information service available for parents or carers. This was because no information resource had been developed specifically for this group, and Epilepsy Ireland staff were not trained to provide such support. Pharmacists and GPs often fulfilled this role.

The ability to administer rescue medication to a child who is having a tonic-clonic seizure in order to stop the seizure in a very critical component in keeping a child safe, by reducing the incidence of Status Epilepticus, a state of prolonged seizure. Emergency

medications are also an important tool to ensure that the child lives as normal a life as possible.

Without this support, parents and carers have been relying on either a pharmacist or GP explanation, or have to travel to Dublin to attend a session for parents in one of the paediatric hospitals. Parents themselves often reported having experienced quick explanations by their medical practitioner/pharmacist regarding delivery of BM which left them feeling unsure of the process.

We invite parents and carers to attend our information sessions in regional locations. Please note that we are not currently providing the service in Dublin as it is already provided by the paediatric hospitals.

For more information visit www.epilepsy.ie.

Dublin Mini Marathon

A huge thank you to everyone who ran the Dublin Mini-Marathon when at the time of print over €10,000 was raised. Don't forget to return your sponsorship cards to Epilepsy Ireland.



Maria Ward-Brennan and her friend Courtney who went that extra mile for Epilepsy Ireland.



Deirdre Brophy who raised in excess of €1,500 for Epilepsy Ireland.

Cork Marathon



Judith Kelleher from our Cork Office putting her best foot forward with her friends and family and Pat Buckley, Chairman of Cork County Board of Athletics.

Permanent TSB



The 'Milan Shah' Staff Charities Cup Match, which pitted Permanent TSB against AlB, raised money for selected charities who include Epilepsy Ireland.



Over 100 Permanent TSB staff completed the Hell and Back Run raising funds for Staff Charities Fund who include Epilepsy Ireland.

Blarney Golf Resort



Thank you to Blarney Golf Resort Captain Alan Kelly for presenting Judith Kelleher from Epilepsy Ireland with a cheque for €1,600.

Coast to Coast Run



We wish all the best to Derek Mackessy who is undertaking a mammoth 620k Coast to Coast Run for Epilepsy Ireland and to help raise SUDEP Awareness.

Cake and Bake sale



Thank you to Elizabeth Brindley and Emma Casey (RCSI & Future Neuro) who organised a cake and bake sale and raised a fantastic €410.

In memory

You may have read in earlier editions of the newsletter about Liane Deasy who passed away in April 2017 from SUDEP. Since Liane's passing her husband Mark Earley has set up a fundraising page and at the time of print the amount stands at €53, 707.80. A heartfelt thanks to everyone who has raised funds and organised events, especially Mark Earley.



25th - 26th AUGUST 2018

Featured Mountains:

Lugalla 595m, Lugnaquilla 925m, Blackstairs 732m and Ridge of Capard 509m.

Followed by a medieval banquet, storytelling and much more.



To receive an information pack, please contact our fundraising team on 01 4557500 or email mcarty@epilepsy.ie

To register, please go to www.epilepsy.ie

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

MIDLANDS

Tullamore: Adults with Epilepsy STEPS PROGRAMME

Charleville Centre, Church Avenue, Tullamore Wednesday July 18th 10.30am – 1.30pm for 6 Wednesdays To book a place contact Cliona - 057 9346790 - 085 8766585 - cmolloy@ epilepsy.ie

Portlaoise: Outreach Service

Venue: Citizens Information Office, Portlaoise Monday July 23rd 10am – 4pm To book a place contact Cliona - 057 9346790 - 085 8766585 - cmolloy@ epilepsv.ie

Tullamore: Women's Seminar

Charleville Centre, Church Avenue, Tullamore Wednesday September 12th 7.00pm – 9.00pm To book a place contact Cliona - 057 9346790 - 085 8766585 - cmolloy@ epilepsy.ie

CORK

North Cork Cork: Parents Steps Programme

Vienna Woods Hotel, Cork Tues September 4th, 11th, 18th & 25th Contact: Loretta on 021 4274774 Ikennedy@epilepsy.ie

Innerwise Day for Adults

Venue TBC Saturday Sept 15th Contact: Loretta on 021 4274774 lkennedy@epilepsy.ie

South Cork

Autumn dates for Adult and Parent Support Groups TBC

Contact: Niamh on 021 4274774 lkennedy@epilepsy.ie

Cobh Ball Run

August 6th

Epilepsy Ireland Ball

Fota Island Resort September 22nd Contact Judith in Cork Office for tickets 021 4271447/ 0858037275

Cork Mini Marathon

September 23rd

Cork Rose Week

October 18th, 19th and 20th

The Cork Summer Church Gate

Collection – Volunteers Needed.
Ballincollig - 11th/12th August
Crosshaven/ Macroom/ Caum 18th/19th August
Clonakilty/ Carrigaline/Glouthaune/
Little Island – 25th/26th August
Fermoy – 15th / 16th September
Mayfield – 22nd /23rd September

EAST

Arklow: Outreach ServiceArklow Health Centre, Castle PARK,

Arklow, Co. Wicklow Tuesday 10th July 11am – 4pm By appointment only - please contact Carina on 01-4557500 or email

Wicklow: Family Fun Day

cfitzgerald@epilepsy.ie

Clara Lara Fun Park, Vale of Clara, Knockrath, Rathdrum, Co. Wicklow Saturday 14th July

11.00am – 4.00pm (families are welcome to stay until the park closes at 6pm)

For more information or to register please contact Carina or Edel on 01-4557500 or email cfitzgerald@ epilepsy.ie

Bray: Outreach Service

Bray Health Centre, Block B, the Civic Centre, Main St, Bray, Co. Wicklow, Wednesday 18th July 10.00am – 4.00pm By appointment only - please contact Carina on 01-4557500 or email cfitzgerald@epilepsy.ie

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. Dublin 2 Monday August 20th

6.00pm – 9.00pm
For more information or to register

please contact Carina or Edel on 01-4557500 or email cfitzgerald@ epilepsy.ie

Swords: North Dublin Support, Information & Toolkit Group

For people recently diagnosed with epilepsy or parents of children recently diagnosed with Epilepsy
Carnegie Court Hotel, Swords, Co.
Dublin

Monday September 4th 6.00pm – 9.00pm

For more information or to register please contact Mary Baker on 042-9337585 or mbaker@epilepsy.ie

Swords: STEPS (Support and Training in Epilepsy Self-Management)

For people with Epilepsy. Carnegie Court Hotel, Swords, Co. Dublin

Tuesday September 18th for 6 Tuesday Evenings

6.00pm – 9.00pm

For more information or to register please contact Mary Baker on 042-9337585 or mbaker@epilepsy.ie

SOUTH-EAST

Kilkenny: Epilepsy Awareness & the Administration of Buccal Midazolam,

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

WEST

Galway: Teenagers Morning

Planet Centre, Headford Road Shopping Centre, Galway Tuesday August 14th 11.00am – 1.00pm

NORTH-WEST

Sligo: Outreach Service Sligo Office

Tuesday 24th July - 10.30am to 12.30pm

Tuesday 14th August - 10.30am - 12.30pm and 2.00pm to 4.00pm Please call to make an appointment and to confirm your attendance: 071 91 41858 or text 0858689433, email: amooney@epilepsy.ie

Donegal: Neurology Out patients Clinic

Venue: Out Patients, Scally House, Letterkenny Wednesday 22nd August Agnes will be available to meet with you at The Neurology Clinic

Letterkenny: STEPS Programme for

Adults with Epilepsy

Starting Monday 3rd September for 6 weeks

6.00pm to 9.00pm.

To Book your place please call Agnes 0858689433, 0749168725 or email: amooney@epilepsy.ie

Letterkenny: Teachers & SNAs Seminar

Station House Hotel, Letterkenny Tuesday 18th September 7.00pm – 9.00pm To book your place please call Agnes 0858689433 or 0749168725 or email:

KERRY

amooney@epilepsy.ie

Killarney: Support Group for People with Epilepsy

Epilepsy Ireland office, Killarney Wednesday 29th August Wednesday 19th September 10.30am

Tralee: Support Meeting for Parents of Children with Epilepsy

Manor West Hotel Tralee Tuesday 11th September 10.30am

Tralee: Teachers information evening

Education Centre, IT North campus, Tralee Monday 24th September 4.30-6.30pm

NORTH-EAST

INNERWISE Oone Day Workshop

Kilmore Hotel, Cavan July 17th

Group TOOLKIT Meeting

Swords, Co. Dublin Information meeting for people with epilepsy or Parents of children with epilepsy September 4th 6.00 – 9.00pm

Open BM Training (Epilepsy Awareness and the Administration of Buccal Midazolam) for staff

working with people with epilepsy. Certified Training to take place in the Kilmore Hotel, Cavan September 6th 9.30am – 4.00pm

Start of the STEPS selfmanagement programme for people with epilepsy

6 week self-management and support programme for people with epilepsy. September 18th 6.00 – 9.00pm

MID-WEST

Teacher/Information Evening

Limerick Education Centre, Marshal House, Dooradoyle Road, Limerick September 3rd 7pm

Teacher/Information Evening

Clare Education Centre, Ennis September 10th pm Epilepsy Ireland is a membership based organisation, run by its members for the benefit of people with epilepsy and their families.

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

The membership fee of €12.70 has remained static for over a decade and contributes only in part to the cost of printing/ posting this magazine and other membership costs. When you receive your renewal notice during 2018, we hope that you will consider it good value for money and a worthwhile investment in the future of epilepsy services.

Benefits of Membership

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

EPILEPSY IRELAND MEMBERSHIP FORM

To renew your membership Epilepsy Ireland, simply complete this form and return it to us with your cheque/postal order, or visit our website at www.epilepsy.ie where you can join and pay online by Visa/MasterCard. Alternatively, call us 01 4557500 and we can set up your payment with the Splink payment method. Thank you.

Membership Type: New ☐ Renewal ☐			
1 Year membership subscription ☐ €12	70		
2 Year membership subscription ☐ €20	.00 Renewal Membership		
Epilepsy Ireland requires your personal details to process your membership application. We may also use them to keep you informed of our services and events and to send you the Epilepsy News newsletter. Please tick here to confirm you wish to receive such communication.			
		I would like to add a voluntary donation	to Epilepsy Ireland of
		 €7.30	
Name of Person with Epilepsy (please use block capitals)			
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Email:	Date of Birth:		
☐ I am a person with epilepsy ☐ I am th	ne parent/guardian of a child with epilepsy * 🔲		
Other:			
*Parents/guardians - please enter your name here if you wish us to send correspondence to you rather than to your child:			
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Please pay the sum of € to the Account of Epilepsy Ireland at Bank Of Ireland, Walkinstown, Dublin 12. Account Number: 88644504, Sort Code: 90-02-87 IBAN: IE63BOFI90028788644504 BIC: BOFIIE2D on this date and on the corresponding date each succeeding year until further notice.			
Signed:	Date:		





Epilepsy Ireland National Conference 2018

Saturday 29th September 9.30am - 4pm Radisson Blu Royal Hotel, Golden Lane, Dublin 8

Conference programme includes:

'Life Beyond Epilepsy'

Donna Kennedy, Author, Psychologist and Life Coach

Cannabis and Epilepsy - Current Developments

Dr. Peter Widdes Walsh, Consultant Neurologist, Beaumont Hospital

Epilepsy and Scientific Research - Current Developments

Dr Colin Doherty, Consultant Neurologist, St James's Hospital, Dublin

News updates

Young People Epilepsy - Emma Eager, Helium Arts Epic Project - Jarlath Varley, RCSI and Beaumont Hospital EPR and the Lighthouse Project - Mary Fitzsimons, Beaumont Hospital Sodium Valproate - Peter Murphy, CEO, Epilepsy Ireland

Epilepsy Surgery

Patricia Ennis, CNS Epilepsy Surgery, Beaumont Hospital Breege Staunton, CNS Epilepsy Surgery, Beaumont Hospital

Diet and Nutrition with Epilepsy

Laura Healy, Dietician, St. James's Hospital, Dublin Emma Williams, MBE CEO/Founder, Matthews Friends

Epilepsy and ID

Dr. Liz O'Mahony, Paediatric Neurologist, University Hospital Limerick Maire White, Clinical Nurse Specialist in Epilepsy, Beaumont Hospital

Mindfulness and Wellbeing for Adults with Epilepsy

Dr. Sarah Clarke, Senior Clinical Neuropsychologist, Beaumont Hospital

Adults with Epilepsy - Nurse Q & A Session

Sinead Murphy, Clinical Nurse Specialist, Epilepsy Ireland & Beaumont Hospital

Maire White, Clinical Nurse Specialist Epilepsy, Beaumont Hospital

Children with Epilepsy - Nurse Q & A Session

Dr. Liz O'Mahony, Paediatric Neurologist, University Hospital Limerick Yvonne Owen, Epilepsy Transition Co-ordinator, Epilepsy Ireland and Children's Hospital Group

BOOKINGS

epilepsyconference 2018.eventbrite.ie or email/phone to reserve and pay for your place: info@epilepsy.ie

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