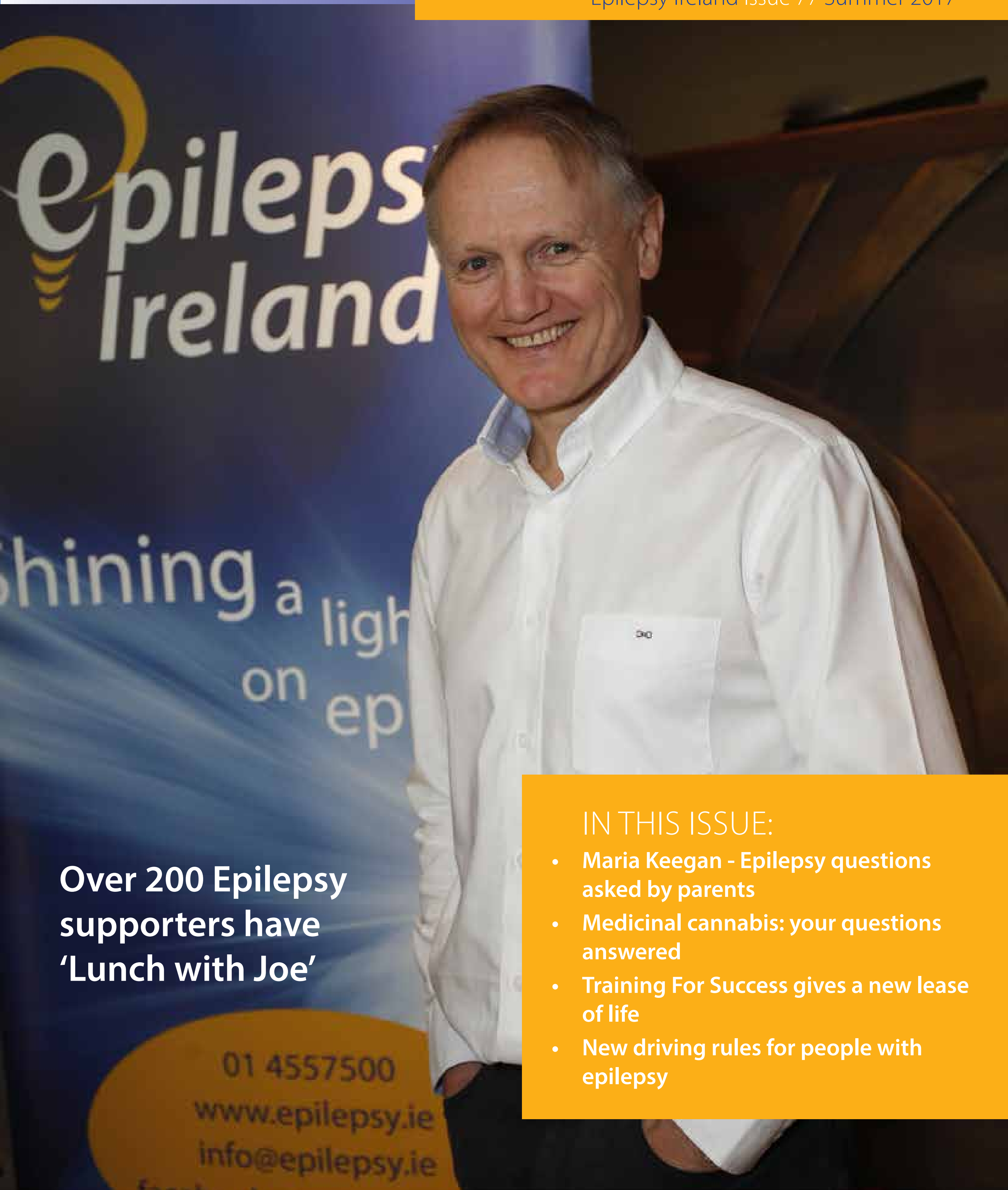
Epilepsy News

Shining a light on epilepsy

Epilepsy Ireland Issue 77 Summer 2017



Over 200 Epilepsy supporters have 'Lunch with Joe'

IN THIS ISSUE:

- Maria Keegan - Epilepsy questions asked by parents
- Medicinal cannabis: your questions answered
- Training For Success gives a new lease of life
- New driving rules for people with epilepsy

CONTENTS

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NOTE FROM THE EDITOR

Conor Culkin

Welcome to this bumper summer edition of Epilepsy News. The front cover features Ireland Rugby Coach Joe Schmidt who continued his support for Epilepsy Ireland by speaking at our recent charity lunch. We would like to thank everyone who supported the event in Fire Restaurant and Lounge, Dublin which included over 200 people from a range of businesses and organisations. Prior to Joe's speech, Nikki Saarsteiner discussed her epilepsy with great candour and humour which informed the diners of her challenges. Praise must also be given to event MC Kathryn Thomas who was a consummate professional on the day.

EI is proud of our Training For Success course based in IT Sligo and Michaela Murphy reveals how the programme gave her a renewed sense of confidence on page 4. Beside this piece we reveal the results from our new workplace survey which shows the stigma associated with epilepsy is reducing. The award winning epilepsy Lighthouse Project will improve the delivery of care and Dr Kevin Power discusses its benefits on page 6. Epilepsy Ireland is delighted to welcome new members of our team on page 7 and we also have a medicinal cannabis double page spread where your questions are answered as well as key insights from Yvonne Cahalane. The following pages feature personal stories from regular contributor Kate Maher and Niamh Hegarty who both talk about their epilepsy.

Both Trinity College Dublin and the Royal College of Surgeons In Ireland have exciting new projects which are featured in this issue. Additionally, Maria Keegan is back with an informative article answering frequently asked questions by parents on pages 14 and 15. The NDLS have introduced new driving guidelines which are included on page 16 and our usual fundraiser page includes those who went above and beyond for Epilepsy Ireland.

Hopefully you'll enjoy this summer edition of Epilepsy News and thank you for your continued support.

Helium Epilepsy Ireland

OUR LIVES WITH EPILEPSY FILM MAKING CAMP

For young people aged 16-21 living with epilepsy

Irish Museum of Modern Art, Royal Hospital, Kilmainham,
Dublin 8 | 3-7 July 2017

To REGISTER contact Carina at Epilepsy Ireland's Dublin Office
Ph: 01 455 7500 Email: cfitzgerald@epilepsy.ie
Places are limited and will be offered on an available place basis.

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www.epilepsy.ie
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Epilepsy Ireland welcomes new warnings on Irish boxes of Sodium Valproate (Epilim)

The drug Sodium Valproate (Epilim), linked to up to 4,000 birth defects in France, according to a recent French government report, will finally have clear risk warnings on the outside of the box in Ireland which is in line with other European countries. The HPRA (Health Products Regulatory Authority) has approved the update and Epilepsy Ireland understands the updated packaging (see image above) will be introduced within the next few months. The campaign group FACS Forum (which Epilepsy Ireland is a member of) has been advocating for clearly visible outer packaging warnings similar to those used in the UK, and the development is welcomed. The FACS Forum estimates that up to 400 children could have been born in Ireland with a range of physical and developmental disabilities following in-utero exposure to valproate over the past four decades. Surveys conducted by Epilepsy Ireland over the past three years have found that while awareness of the risks of valproate is growing, there is still a significant minority of women taking the drug who are not fully aware of the risks.

GO *goo.gl/i1Txj8*

New data on Epidiolex for Dravet syndrome

New research has been published in The New England Journal of Medicine on the efficacy of Epidiolex, a cannabis derivative in treating Dravet Syndrome, a severe form of paediatric epilepsy.

This is the first time that the anticonvulsant properties of cannabidiol (CBD), the non-psychoactive component of cannabis were tested in a large-scale, double-blind, randomized clinical trial.

Researchers led by Prof. Orrin Devinsky from New York University studied Epidiolex, a formulation of purified, plant-derived CBD in 120 children and teenagers with Dravet syndrome. The drug significantly reduced monthly seizure frequency compared to placebo in highly treatment-resistant children when added to existing treatment. Over the 14-week treatment period, patients taking Epidiolex experienced a 39% reduction in seizures compared to 13% taking placebo. Treatment was generally well tolerated, and a New Drug Application for Epidiolex is expected to be made in the US in the coming months.

"Cannabidiol should not be viewed as a panacea for epilepsy, but for patients with especially severe forms who have not responded to numerous medications, these results provide hope that we may soon have another treatment option. We still need more research, but this new trial provides more evidence than we have ever had of cannabidiol's effectiveness as a medication for treatment-resistant epilepsy", said Prof Devinsky.

GO *goo.gl/zgFSNR*

HSE accepts new epilepsy drug Briviact for use in Ireland

The HSE has accepted Briviact (brivaracetam) for use within Ireland as an add-on treatment for partial onset seizures (POS), with or without secondary generalised seizures in adults with epilepsy (aged 16 years and older).

The new medication provides patients with this particular type of epilepsy, an additional opportunity to better manage their seizures. Briviact use is restricted to patients with refractory epilepsy and treatment should be initiated by physicians who have appropriate experience in the treatment of epilepsy.

Briviact was developed by UCB and is already approved for use in several European countries following the European Medicines Agency (EMA) authorisation in January 2016.

GO *goo.gl/iTpKwF*

New SUDEP Practice Guidelines For Clinicians and Health Professionals

New practice guidelines on Sudden death in Epilepsy (SUDEP) were published recently by the American Academy of Neurology and the American Epilepsy Society. The author of the guidelines Dr. Cynthia Harden said it is critical for health professionals to communicate about SUDEP rates and risk factors with people with epilepsy and families and that the guidelines give clarity for the purpose of having these discussions focussing on practical information for reducing risk.

The major risk factor for SUDEP is having tonic-clonic seizures and the SUDEP risk increases as the frequency of seizures increases.

The guidelines advise that clinicians treating children should inform parents and guardians that in one year SUDEP affects 1 in 4,500 children. Clinicians treating adults should inform them that in a year SUDEP affects 1 in 1,000 adults. According to the guidelines, those with more than 3 seizures per year are at most risk but evidence for risk factors, apart from having tonic-clonic seizures, was low.

GO *goo.gl/3h7x0t*

Discontinuation of Trobalt (Retigabine) from June 2017

The anti-epileptic drug Trobalt (Retigabine) is being discontinued from June 2017.

GlaxoSmithKline (GSK), the manufacturers of Trobalt contacted health care professionals in June 2016 to advise that the drug would be permanently unavailable from June 2017.

Trobalt was already subject to restricted use as an add-on therapy for drug resistant partial onset seizures in those 18 and over since 2013. This was due to reported side effects such as changes in pigment colour of the eye found in patients on high doses long term as well as of the skin, lips and nails in some.

The decision to discontinue Trobalt is due to the low numbers currently on this drug and the decline in new patients being started on it, and not due to any further safety concerns.

If you are currently taking Trobalt your doctor should have already discussed taking you off it and changing to another drug. If you have not spoken to your doctor, please contact them as soon as possible or call us at 01 4557500.

GO *goo.gl/Bili9j*

TFS GAVE MICHAELA A NEW LEASE OF LIFE

18 year old Michaela Murphy from Mayo has found a new lease of life thanks to Epilepsy Ireland's Training for Success (TFS) Course.

I have recently completed the Training for Success course in IT Sligo.

In 2013 I had my first seizure and was diagnosed later that year. When I was told that I had epilepsy I didn't know what it was or what happens.

I was just entering my senior cycle of secondary school and I couldn't have asked for more support. From the principal right down to the Special Needs Assistants everyone was very supportive. Each and every one of them went above and beyond to be there for me.

Even though I had great support I lacked a great deal of confidence and a feeling of independence because I was afraid. A past student of Training for Success whom I know recommended the course and I got in touch straight away.

In April 2015 I came for my interview in IT Sligo. I was so nervous but Honor the Course Manager was so warm and welcoming which put me at ease. I was offered and accepted a place on the course.

In August 2015 I started the course. At 17 I was so nervous about moving away from home and everything I knew but especially about meeting new people. Despite my worries, it was great and there was a group of 10, so we all made a close bond with each other and we were like our own little family.

The lecturers within Training for Success were fantastic - they made you feel equal to them and not like a student. This helped me a lot to grow and mature because now I was no longer a student in the back of a classroom just listening. People now wanted to hear what I had to say and the ideas I had.

> *"The lecturers within Training for Success were fantastic - they made you feel equal to them and not like a student."*

When I first started Training for Success I wanted to go on to study Fine Art but through Training for Success I learned that even though I love art I was better off somewhere else where I could do more. So I applied for Social Care.

Training for Success is something I will look back on very fondly and with a lot of warmth and happiness. With the team at Training for Success I never felt alone or that I wasn't being heard because there is always someone there to listen to you.

Honor and Maire are two fantastic women. They taught me so much in my year with them and because of them and the rest of the team I am confident, happy and driven towards my future goals, because they taught me that even though I have epilepsy it doesn't it stop me from doing what I truly want to do. There would never be enough thanks to give them.

I think if you're in two minds about doing the Training for Success course, just do it because believe me, you won't regret it.

There are a limited number of places left for Epilepsy Ireland's award-winning Training for Success course which is currently recruiting for the new programme starting this August.

Gemma Doyle pictured with Michaela at her TFS graduation

TFS is taught at Institute of Technology, Sligo

EPILEPSY BECOMING LESS OF A STIGMA IN THE WORKPLACE

To mark National Epilepsy Week (May 15th - 21st) Epilepsy Ireland announced results of a survey conducted among over 300 people with epilepsy on their experience of the condition within the workplace.

The results showed that:

- **58%** of people with the condition who are in employment now feel comfortable telling their employer and work colleagues that they have epilepsy – an increase of 14% when compared to a 2012 Epilepsy Ireland survey
- Just **33%** of people with epilepsy found that their employers and work colleagues attitudes towards them changed after they told them of their epilepsy, when compared to 50% in 2012
- **56%** said their epilepsy gave them a greater motivation to succeed in their career

However, not all the figures are encouraging:

- **34%** stated their epilepsy has prevented them from fulfilling the responsibilities of their job
- **47%** said their epilepsy prevented them from applying to a new job
- **31%** of those with epilepsy have experienced discrimination in the workplace as a result of their condition
- **50%** don't think there is enough support in place for a person with epilepsy in the workplace
- **54%** of a person with epilepsy's colleagues would know what to do if someone had a seizure in the workplace

Peter Murphy, CEO of Epilepsy Ireland said: "Epilepsy affects over 37,000 people in Ireland and historically there has been a stigma associated with the condition. The results of our national survey are extremely encouraging and indicate that attitudes towards epilepsy are changing and people are more comfortable talking about it with their employer. However stats from our research indicate that negative attitudes towards the condition still exist.

"It is important for employers to remember that most people with epilepsy have been able to stabilise their condition through a medical regime. Furthermore, for the majority of people with epilepsy, the condition is unlikely to impinge on their working lives. Sick leave and accidents at work are no more frequent among people with epilepsy than in other workers. Epilepsy Ireland has anecdotal evidence that shows a common cold or flu is likely to account for more sick leave than any time taken off due to seizures.

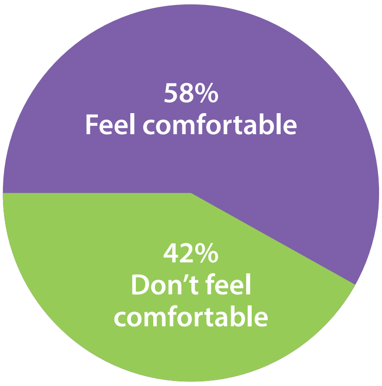
"Contrary to popular belief, people with epilepsy can drive cars and use computer screens. In fact, people with epilepsy can work in the vast majority of jobs. Furthermore, employers rarely, if ever, incur extra costs through employing someone with epilepsy.

"A number of myths have grown up around epilepsy in the workplace, probably dating from times when medical treatment was not as successful in treating the condition and from common historical portrayals of seizures. People with epilepsy make just as good employees. From our experience because they find it difficult to obtain employment, they tend to be more motivated in seeking and retaining jobs."

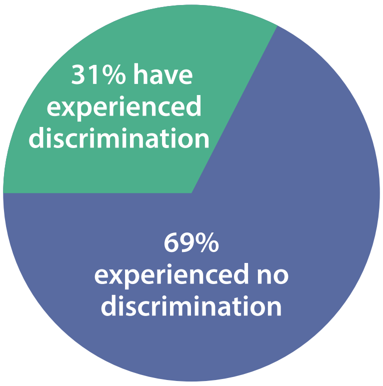
*Epilepsy Ireland surveyed 337 people online who have the condition from April 28th to May 10th 2017.

In addition to this survey Epilepsy Ireland will release a new employment booklet later this year and we're also proud to be part of the I See Beyond hidden disability awareness campaign. For more information log onto www.iseebeyond.ie.

Percentage of people with the condition who are in employment who feel comfortable telling their employer and work colleagues that they have epilepsy

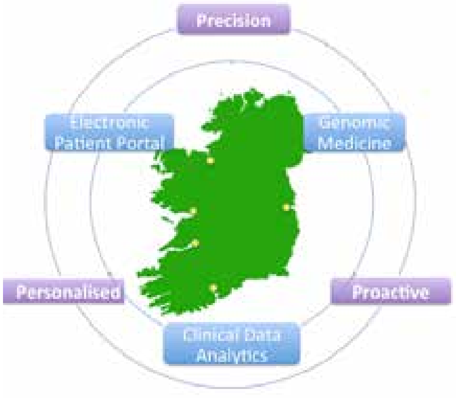


Percentage of people with epilepsy who have experienced discrimination in the workplace as a result of their condition



THE EPILEPSY LIGHTHOUSE PROJECT

PROVIDING INDIVIDUALISED SERVICES AND CARE IN EPILEPSY (PISCES)



By Dr Kevin Power, Research Engineer, Royal College of Surgeons in Ireland

What is the Epilepsy Lighthouse Project?

In 2016, Health Service Executive (HSE) selected the national epilepsy electronic patient record (EPR) as a Lighthouse Project to demonstrate how eHealth technologies can help improve quality and safety in delivery of health care. The lighthouse project is called "Providing Individualised Services and Care in Epilepsy (PISCES)". PISCES is a nationwide project and is using the epilepsy EPR to bring three new developments into clinical care of people with epilepsy. These developments which can improve diagnosis and treatment are:

- Genomic Medicine
- Electronic Patient Portal
- Data Analytics

eHealth and Epilepsy

eHealth is a term used to describe the use of information and communication technology to support the delivery of healthcare and services. Electronic patient records (EPR) are a form of eHealth technology. An EPR is a computer-based medical record where nurses, doctors and other healthcare providers record and store notes about the clinical care of their patients. Epilepsy centres across Ireland are using an EPR to manage services for people with epilepsy. More than 7000 individuals have a record in the national epilepsy EPR. When they attend the epilepsy centre or contact the epilepsy telephone advice line, their EPR record will be reviewed and updated. Compared to a traditional paper-based medical record, the EPR has many patient safety benefits.

For example:

a. Approved epilepsy nurses can quickly access important information about anti-epilepsy medications that the patient is taking and how well these medications are working.

b. Doctors at different locations who are involved in an individual patient's care can look at the same medical record. This helps improve co-ordination of patient care.

Genomic Medicine and Epilepsy EPR

Genomic medicine is sometimes called precision medicine because it uses information about an individual's genes to tailor their medical care. Everyone's body is made up of lots of tiny cells that contain thousands of genes. Genes are the parts of our body that control things like eye colour, whether an individual has straight or curly hair or if they are likely to develop a disease. Sometimes a gene can cause a person to have epilepsy. In PISCES work is being carried out to understand more about how genes influence the development or treatment of epilepsy. PISCES will recruit 100 individuals with epilepsy (50 adults and 50 children) together with their parents to have genetic sequencing. To date 41 patients and their parents have enrolled.

Analysing genetic test information requires input from scientists and neurologists. The epilepsy EPR has been enhanced with new genomic medicine features to support this team-work.

Patient Portal and Epilepsy EPR

Offering individuals with epilepsy access to their EPR via a secure internet connection can help improve their care and health outcomes. For example, it can improve compliance with anti-epilepsy medications and patient's healthcare goal setting. Patients and families who have enrolled in PISCES are working with the project team and software engineers to design, develop and implement a portal to the epilepsy EPR. The epilepsy patient portal can be accessed via a desktop computer, smartphone or tablet and provides authorized and approved users with a view of the patient summary epilepsy record. It also provides tools for patients to report outcomes from their day-to-day life about their seizure severity and quality of life as well as prompts for preparing for clinical appointments with their doctor or nurse. The portal technology meets highest data security standards. Its usefulness is currently being evaluated by participating PISCES families.

Data Analytics and Epilepsy EPR

EPRs allow large sets of patient data to be easily examined to discover patterns and other information about who is at risk of developing a disease, what action can be taken to prevent illness, what is the best medical treatment plan for an individual patient. This is known as 'data analytics'. PISCES is developing data analytics visualisation features to allow for safe interrogation of data contained within the EPR.

Award Winning Project

Pictured receiving the Tech Excellence 2017 Award, members of the PISCES team: Sean O'Donoghue (ERGO), Derek Kehoe (ERGO), Graham Frazer (Citrix), Maire White (RCSI), Gianpiero Cavalleri (RCSI), Brendan Dunleavy (ERGO), Wilton Rodriguez (ERGO), and Gemma Garvan (HSE).

PISCES is a pioneering project that is using the national epilepsy EPR to bring the growing fields of genomic medicine, patient portals and data analytics into the clinical care pathway for people with epilepsy in Ireland. The project recently won the Public Sector IT Project of the Year at the 2017 Tech Excellence Awards.

Acknowledgements

Partners in the PISCES project include: Epilepsy Ireland, eHealth Ireland, HSE National Clinical Care Programme for Epilepsy, RCSI, Beaumont Hospital and Industry partner ERGO.

For further information about PISCES email kevinpower@rcsi.ie or telephone 01 4025019.

STAFF CHANGES AT EPILEPSY IRELAND

Over the past six months Epilepsy Ireland has seen the retirements of four of our Community Resource Officers. After many years of dedicated service, we have recently said fond farewells to Noreen O'Donnell, after 14 years working in the North-East office; Anna Kelly after 18 years working in the Midwest Office; Joan Ryan after 6 years in the South East Office and Mary Lawlor after 16 years in the Cork Office. We deeply appreciate the commitment and service that they put into their work, the passion for and commitment to people with epilepsy and their families and carers. We wish them all the very best of luck in their retirement years.

Wendy Crampton – New Deputy CEO

Wendy has worked in Epilepsy Ireland since January 2013 as Director of Services. She holds a BA Hons (Psychology) Degree from UCD, a PGDiploma in Business Studies from Michael Smurfit School of Business (UCD,) an MA in Development Studies (Kimmage Manor) and a PGDiploma in Psychotherapy from Dublin City University.

Wendy has worked in a number voluntary sector organisations over the past 15 years, including Women's Aid, Pavee Point, Merchants Quay Ireland, DePaul Ireland and Pieta House. She has held a variety of training, research, policy, community development, and senior service and HR management roles.

Wendy has led on service management and development for the past five years including the introduction of the New Diagnosis Toolkit and the STEPS and INNERWISE programmes.

Miriam Gray - South-East Region

Miriam has studied in both Carlow and Cork and attained a B.A. in Social Studies in Social Care, and more recently she also studied advocacy in WIT. Her career started in the Mid-West in residential mainstream and high support services, where she worked as a childcare leader with children and young people at risk.

Throughout her career Miriam has consistently worked towards person centred, empowerment of the individuals she supported as well as developing, delivering best practice models of information, support and training. She is excited by her role with Epilepsy Ireland in the way it promotes the same ethos and values where, regardless of any challenges people with epilepsy can achieve a life they choose.

You can contact Miriam in our Kilkenny office on 0567789904 or email her on mgray@epilepsy.ie.

Veronica Bon - Mid-West Region

Veronica is originally from Limerick but has lived in Clare for many years. She is a graduate of European Studies (Social Research) from the University of Limerick and then went on to complete her Masters in Community Development at NUI Galway. Veronica has worked in a variety of organisations in the community sector for 16 years, primarily in the Mid West Region with Community Development Projects and Family Resource Centres in a policy and support capacity and has also spent time with both Limerick and Clare based Local Development Companies where she gained a broad range of experience.

You can contact Veronica in our Limerick office on 061313773 or email her on vbon@epilepsy.ie.

Edel Curran – East Region

Edel is from Kildare and is a graduate of Applied Social Studies in Social Care (specialising in Disabilities) from Carlow College. Edel has over 13 years experience of working within the community in the voluntary sector. Through this experience she has gained a broad and diverse range of knowledge in many aspect of working within the community and she has a particular interest in advocacy, entitlements, community work, awareness campaigns, funding both at local and national level. Edel is covering North Dublin and Kildare services and will be based in our Dublin Head Office. She is looking forward to helping the already strong Epilepsy Ireland regional team which includes ten offices across the country.

You can contact Edel at our Dublin office on 01 455 7500 or by email on ecurran@epilepsy.ie .

MEDICINAL CANNABIS: YOUR QUESTIONS ANSWERED

Medicinal Cannabis has consistently been featured in the news in recent months with impassioned debates for its use for certain types of epilepsy and other medical conditions.

In this article, we will answer a number of the most frequently asked questions in what has become a complex and evolving issue.

Does medicinal cannabis work?

Anecdotal evidence suggests that treatment with medicinal cannabis may reduce seizures in some individual patients, particularly those with severe forms of paediatric epilepsy. However, as with any potential treatment, anecdotal evidence is not sufficient to establish whether or not a treatment has a proven efficacy and safety that would justify its widespread use.

A report by the Health Protection Regulatory Authority (HPRA) in February found a lack of scientific data to demonstrate the robust effectiveness of medicinal cannabis. It stated that there was *"At best, a moderate benefit for cannabis in a small number of conditions and conflicting evidence, or no evidence at all, in a large number of other medical conditions. The effectiveness and safety of cannabis in large numbers of medical conditions is simply not proven."* In addition, *"The HPRA considers that there is not currently evidence that cannabinoids are an effective treatment in epilepsy".*

In the UK, a recent All Party Parliamentary Group report by Professor Michael Barnes of Newcastle University found that there is a reasonable evidence base for the management of chronic pain, spasticity and nausea/vomiting in the context of chemotherapy. However, his detailed report also concluded that cannabis has limited effectiveness in relation to epilepsy.

"Whilst there is a theoretical basis and animal model studies and early human studies are promising, at the moment robust trials are lacking but further results are awaited. There is only limited evidence at the moment", he said.

Are there side-effects?

All medicines can potentially have side effects and a significant amount of caution is needed regardless of the drug. Medical supervision is also essential.

According to the HPRA report: *"The medical treatment of children and adolescents with cannabis requires careful consideration due to the potential impact on the developing brain. In addition, there is compelling evidence linking cannabis use in adolescence with the development of psychosis in later life."*

Are any cannabis drugs already legal?

If a substance contains THC (the psychoactive element), then it is illegal under the Misuse of Drugs Acts. The exception to this is Sativex, a licenced medication that is used to treat spasticity in MS. A cannabis-based product that does not contain THC is legal in Ireland. Therefore, CBD substances such as Charlotte's Web are available in Ireland, marketed as food supplements. For any of these products, no scientific efficacy or safety data exists, and in many cases, there are significant concerns over the composition and quality control of the products.

What about the Medicinal Cannabis Bill that was discussed in the Dail?

Gino Kenny TD introduced the Medicinal Cannabis Bill to the Dail in 2016 and it passed the 2nd Stage with cross-party support earlier this year. However, most parties acknowledged that significant changes are required and the Bill has since been debated at committee stage where significant opposition was expressed. The future of the Bill is unclear due to numerous concerns including references to recreational use, the proposed role of medical professionals, the setting up of two new 'quangos' and the separation or medicinal cannabis regulation from the regulation of all other medicines.

Can the Minister for Health authorise a cannabis product?

It is currently within the Minister for Health's powers to issue a licence for medicinal cannabis if a formal request is made for a particular patient by a specialist. To date, one such licence has been approved (see page 9). As has been reported in the media, at least one other application was denied because it did not have the support of a specialist. However it remains open for any neurologist to request for their patient a licence for a cannabis-based product that would otherwise be illegal. The Minister does not have any other powers to intervene in the doctor-patient relationship.

Is there going to be some kind of Compassionate Access Programme?

The HPRA report was clear that any decision to permit access to cannabis for medical use would be a societal and policy decision rather than a scientific one. It recommended that if treatment with cannabis is permitted it should be under tight control and in limited circumstances. Three conditions were highlighted including *"Severe, refractory (treatment-resistant) epilepsy that has failed to respond to standard anticonvulsant medications whilst under expert medical supervision".*

Following this, the Minister established an Expert Reference Group to recommend guidelines on how an access programme could be established; in what circumstances medicinal cannabis could be supplied and what form this might take. The group has met three times (at the date of writing) and may complete its work later in the summer. It is likely that legislation would then be needed to give effect to an access programme.

Is there any licenced cannabis-based medication available for epilepsy?

Not at the moment. A British pharmaceutical company, GW Pharmaceuticals has developed a drug called Epidiolex which is currently undergoing clinical trials. Emerging data from the trials has been positive. Last month, data was published which found that Epidiolex reduced the number of seizures by 39% in children with Dravet syndrome over a 14-week period, compared to 13% taking placebo. 43% of patients experienced a 50% or greater reduction in seizures compared to 27% taking placebo. It is hoped that an application will be made to authorities like the US FDA and the European Medicines Agency in the coming months. It is important to note that these findings cannot be applied to other cannabis-containing products.

What is the Medical Professionals position?

The National Epilepsy Clinical Care Programme (NECCP) has issued a statement highlighting the lack of scientific evidence for all cannabis products other than Epidiolex. They state: *"No other cannabis derivatives or products have been adequately studied to a level that they are proven to be effective and safe to use in clinical practice. Specifically, products containing THC remain inadequately tested."*

What is Epilepsy Ireland's stance on medicinal cannabis?

Given the devastating impact of rare epilepsies like Dravet Syndrome and the limited success of existing drugs in treating these conditions, it is understandable that many affected families are reaching out for the potential benefits provided by medical cannabis.

Epilepsy Ireland has long held an evidence-based position on medical cannabis and we agree with the path recommended by the HPRA in February's Report. We also fully support the position of the NECCP and with the need for further research. In recent months, we have discussed these issues with Minister Harris and with Minister for Drugs Strategy, Catherine Byrne, and we engaged with the HPRA's consultation process in developing their report.

More Information

Please see www.epilepsy.ie for more detailed information and links to reports, documents and studies referenced above.

ROAD TO RECOVERY

Yvonne Cahalane talks to Epilepsy News about her efforts to obtain medicinal cannabis for her son Tristan

It's been a whirlwind for Tristan Forde since he was born three years ago. In late 2015 he moved to Colorado along with his mother, Yvonne Cahalane to begin medical treatment for Dravet syndrome – a rare form of epilepsy. Shortly before Christmas last year the little boy from Dunmanway Co Cork, became the first person to be granted legal access for cannabis-based medication in Ireland.

Yvonne has been given special permission to obtain a THC-based product after Health Minister Simon Harris TD approved a licence application. Having begun his treatment in Colorado and with its effectiveness established, Tristan is now allowed to take the drug in Ireland under medical supervision.

The road to accessing this treatment was long and Yvonne is keen to share her experience with Epilepsy News.

"I buried myself in searching for and examining research documents relating to Medical Cannabis. We spoke at length to experts who were world leaders in the area of cannabis treatment. We spoke with one particular expert from Israel (Dr Raphael Mechoulam) who recommended other Medical professionals and researchers who could help us.We talked to other families in similar situations who spoke of great benefits and also side effects they had experienced with the treatment. We wanted legal access to the medicine and received crucial data for Tristan's participation in a Medical Cannabis study in Colorado which proved highly successful for him. His treatment plan was set up and overseen by all his Medical Team", she said.

After much research and consideration Yvonne decided to move to the American state in 2015 as she believed there was no other option. Tristan's seizures at this point would often last between 20 minutes to an hour. Since he was prescribed medicinal cannabis Yvonne says his seizures have dramatically reduced in frequency and duration and he has never been admitted to hospital since beginning Medical Cannabis in 2015.

Even though medicinal cannabis has been beneficial for treating Tristan, Yvonne feels it is not a cure for Dravet Syndrome or epilepsy but an effective treatment plan if overseen correctly. She urges families to be cautious when purchasing cannabis derived products.

Yvonne explains: "Many people pay through the nose for fake medication. There are products available to people both in stores and online that have the potential to be very different to what they promise."

She believes doctor's advice is imperative if a family is considering taking a similar route to Tristan.

"The use of medicinal cannabis is very new to doctors in Ireland and although more information is being sought, medical professionals have shown great interest in this new treatment option. It is important to be upfront and honest with your medical team and work together to achieve the best treatment plan for you. Be aware of new research and I don't recommend self-medicating as this can lead to further dangers with conventional drugs."

Yvonne concludes: "We believe we were successful in accessing medicinal cannabis as we followed a chain of medical expertise and did not self-medicate. Tristan's care was always overseen by medical professionals, which led to a license application approval from Minister Harris. The process was lengthy and worthwhile but we understand it may not be suitable to every family's circumstance. I have great hope that the Access Programme will be an effective one for everyone and hope it will begin as soon as possible for others to benefit"

"IT HAS NEVER HELD ME BACK"

Niamh Hegarty is a journalist and blogger who has learned to live with her epilepsy. In this piece she speaks candidly about how the condition has affected her life and the importance of openness.

The first time I noticed anything was wrong was when I was 15. I woke up in the middle of the night, tried to get back to sleep and when I did my body started shaking or jerking uncontrollably. It was like an electric jolt to my body, like someone had literally given me a few electric shocks. This started around the time of my Junior Cert results and around the time I lost my granddad. The loss of my granddad brought my world to a standstill as he was my hero and still is. It was a really tough time and following that series of events the seizures became more frequent.

I suppose I didn't want to believe it was happening or that anything might be wrong, I was afraid of the answer or possible diagnosis. At 15, and having just experienced my first big loss I assumed the worst. At the time, we had one computer in our house and dial up connection to the internet. I remember typing in my symptoms to Internet Explorer and the search returning some worrying articles. It made me more afraid to speak up. As I began to see trends in when these attacks would come on (like if I hadn't slept) I began to feel like I had it under control myself. Which couldn't have been further from the truth! I eventually got a part time job in music shop and I think having this outlet took my mind off the stress of what was going on at the time.

If I'm being honest, the hiding or denial on my part went on for years. At 21, I had my first tonic-clonic seizure in front of my parents on New Year's Day. This happened after being out all night at a party. Last thing I remember is trying to tell my mom something and not being able to. Like I was frozen in time, or paralyzed in the moment. When I came around, a paramedic was talking to me. Nothing like that had ever happened to me and it was really frightening. That night at the hospital felt like the longest night of my life as I waited to meet with the neurologist the next day. When I was diagnosed with epilepsy, it was actually a relief as I had an explanation and it wasn't that frightening. When the neurologist told me the type of epilepsy I had, Juvenile Myoclonic Epilepsy, I read about it and found other people's stories were similar to mine. I'd like to say that I took responsibility there and then and never had a grand mal seizure again but it wasn't until I was 28 that I decided to stay on medication full time. This was following a seizure in a supermarket. At this time, I also decided to give up alcohol to avoid having a tonic-clonic seizure again - as I know the effects of alcohol can be a trigger for me.

My experience of living with epilepsy is that you can try to hide it or live in denial but the sooner I confronted the situation and made health a priority, the sooner things improved. Speaking candidly, my decision to give up alcohol was harder socially than being diagnosed with epilepsy. I still find meeting new people and not being able to have pint with them a bit challenging because it's a social standard in Ireland. Epilepsy has never held me back. It has never held me back in education or employment anymore than anyone else might struggle in education or the workplace. Perhaps the main difference between people with a long term illness and people without is that we need to plan our days more.

Staying in touch with the neurology team at Cork University Hospital has been really helpful for me, as in a way it keeps me grounded in terms of the impact of epilepsy on my day to day. They've always been so understanding and help me see the wood from the trees in terms of the illness. Essentially helping me realise that my epilepsy won't hold me back as long as I'm responsible around it. I'm happy to say I'm now four years (and counting) without a tonic-clonic seizure. I try not to dwell on epilepsy any more as something negative in my life and instead treat it as something I need to plan for. At this stage, I've accepted it's just part of who I am.

> *"My experience of living with epilepsy is that you can try to hide it or live in denial but the sooner I confronted the situation and made health a priority, the sooner things improved."*

SEIZURES BECOMING OUT OF CONTROL

In the fourth part of her series of articles charting her personal journey with epilepsy, Kate Maher spoke about the discovery of her correct diagnosis. In this piece she reveals how her condition deteriorated and the affect it had on her career.

After my visit to London, I attended my own neurologist once again, armed with my scans. I told him I could no longer trust his care or judgement and enquired who would be the best Irish neurologist to attend for epilepsy, telling him I would go anywhere. He told me that a new specialist epilepsy neurologist had commenced in Cork University Hospital (CUH), Dr. Daniel Costello. In late 2012, I walked into his office along with my 2009 scan reports. After a chat he looked at my scans. I sat there, holding my breath as he examined them, before he pointed to my left hippocampus, revealing how it appeared scarred.

My seizures continued to worsen and in the summer of 2013, after commencing a new AED (Anti-Epileptic Drug), I was to have my first tonic-clonic seizure. The seizure came on in my sleep but thankfully my partner Joe was with me. He called an ambulance and acted very calm as I was not coming around from the seizure. I had a further tonic-clonic in the A&E but later that day was discharged home, with my medications readjusted. On a daily basis now I could have up to six seizures a day. I continued to work full time, however it was becoming ever harder to hide the seizures. In 2014, I had my first blackout seizure, where at its peak, my head would drop suddenly and I would lose consciousness for a few seconds. At this point, increased seizure numbers, seizure intensity and my need to mask it were beginning to have an emotional impact. So I began to visit a counsellor.

During this time, I started to realise that I had never fully accepted my epilepsy and that I had to do this for myself. At work I began to speak to my colleagues more openly about it. Blackout seizures were becoming more common for me now. One particular day at work I had to step aside, telling my boss "Right now, I do not feel confident or competent in my role". My vision had blurred, my speech had slurred. This feeling had very slowly built up over two hours until it reached a pinnacle point. I felt that life, and what was carrying on around me had gone into slow motion. My boss was worried so she brought me down to A&E. I felt like I was living in a dream. This time round, I was admitted onto the Neurology ward.

> *"During this time, I started to realise that I had never fully accepted my epilepsy and that I had to do this for myself."*

After two days I was discharged home and remained out sick for a further week. Early the next month however, I experienced my first panic attack. I believe the primary cause of this was due to my feelings of anxiety, worry and fear surrounding my epilepsy journey. Thankfully in early 2015 an Epilepsy monitoring unit opened in CUH. Six weeks after it opened, I was admitted into the unit and would stay there for 8 nights. The amount of seizures I had in that week shocked the doctors, primarily due to how quickly I would recover from each one. Typically, out of the unit, I would have more seizures though, so I wasn't one bit shocked. I also had a PET and MRI scan of brain carried out that week. Dr. Costello believed there was a good chance surgery could be an option as all my seizures were being triggered from the one focal point.

As the year progressed, my seizures continued to worsen. Routinely I would have 6 to 8 per day. They were now becoming much harder to mask in my role as a midwife. One summer evening I arrived home from work shattered. I had eight seizures that day. I felt whacked out and exhausted. So I rang in sick and attended my GP the following day. She emphasised that "I needed to rest" so I was put out on sick leave. Two weeks after this, I felt my seizures were lessening in number but not in intensity. Obviously my stressful work environment had not been helping me.

In the Autumn issue of Epilepsy News, Kate will reveal her brain surgery treatment in the final article of the series.

Dr. Daniel Costello, Cork University Hospital

HOW2TELL – TALKING ABOUT EPILEPSY

Trinity College Dublin has developed an educational resource for adults with epilepsy who want to learn how to tell others about their epilepsy. Professor Naomi Elliott and Dr Mary Quirke explain.

The purpose of the How2tell study was to design a set of educational tools to help people with epilepsy (adults aged 18+ years) learn about the best ways for telling another person 'I have epilepsy' across a range of situations that present in everyday life. The study first explored the concerns that people have when talking about their epilepsy and identified the strategies that they use in the process of telling 'I have epilepsy'. This information, based on the direct experiences of people with epilepsy, was then used as the evidence-base for the development of a multi-media educational resource.

This resource includes the How2tell smartphone app, website and booklet which are designed to support people in telling others that they have the condition. The How2tell study was funded by Epilepsy Ireland and the Health Research Board. The study was carried out by a team of researchers in Trinity College, healthcare professionals who work closely with people with epilepsy and importantly, people with epilepsy who had a key role in ensuring the design of the How2tell educational tools was user friendly.

Phase One set out to identify the common strategies that adults with epilepsy use in the process of telling people about their condition in everyday social, personal and work situations. Interviews exploring first-hand experiences of self-disclosure (or not) were carried out with forty-nine adults with epilepsy from around Ireland. People shared their personal experiences, explained what they found useful (or not useful) and how they adapted 'telling' in different situations.

People reported using a range of strategies that they found useful and they adapted depending on the situation in which they were talking about their epilepsy. Based on their experiences of telling in different situations, they gave practical advice about important issues including: becoming comfortable with 'my' epilepsy; decision-making for why to tell; weighing up who needs-to-know and when to tell; identifying opportunities for telling; how to construct the message for the moment of disclosure; tailoring the message to different audience needs; telling to make it 'ordinary' and dealing with other people's reactions.

For example, when identifying opportunities for telling:

1) Use opportunities – they respond to questions that come up in natural conversation, e.g. about driving or what they like to drink.

2) Wait for opportunities- wait until a relevant topic e.g. health/medication comes up in conversation.

3) Create opportunities - they take their medications openly in front of the other person as a prompt to start a conversation about telling.

If the person shows interest and asks questions, then they talk about their epilepsy; however, if the person shows no interest or doesn't ask questions, in those situations they do not tell.

People with epilepsy also reported on WHAT to say and how to construct the message for disclosure. They typically broke it up into three parts: 1) starting with a brief statement that they have epilepsy; 2) reassurance to the person being told, and 3) ending with practical information on what they want the person to do if they have a seizure. For example: "I have epilepsy, it's not a big deal, it will be grand, just do … if this happens".

This message can then be adapted depending on the situation and the other person's needs. In social situations, people with epilepsy used a casual approach, presenting practical information in a way to educate, reassure and also to maintain the relationship. Whereas in employment or formal situations, they used a structured, factual format that addressed work performance and safety information needs.

Phase Two of the study involved using the information given by people with epilepsy to develop a set of multi-media educational tools. These tools aim to support people to develop effective strategies, so it is less challenging to tell others that 'I have epilepsy'. Using the experiences of adults (aged 18+ years) with a range of forms of epilepsy and personal backgrounds, the How2tell tools are designed to provide information to people with epilepsy who want to learn how to tell others about their epilepsy. How2tell gives practical information about 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; make the message ordinary and deal with people's reactions.

How2tell educational tools feature the 'voices of real people with epilepsy' and use videos and quotes to present their voices. It is hoped that How2tell will support people newly diagnosed with epilepsy and healthcare professionals and community care staff who support them as they adapt to living with epilepsy.

The How2tell app (both for iPhone and android phones), booklet and website will be available shortly on the Epilepsy Ireland website www.epilepsy.ie.

EPILEPSY PARTNERSHIP IN CARE (EPIC)

Last year Epilepsy highlighted a unique piece of epilepsy research that was due to start in Ireland and we're delighted that John Paul Byrne (Royal College Of Surgeons in Ireland) is now giving an update on the work to date.

Epilepsy Partnership in Care (EPiC) examines

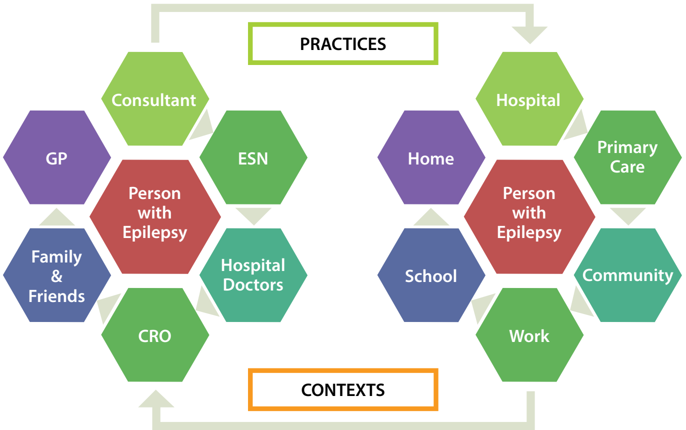
- *What counts as patient-centered care for people living with epilepsy*
- *If clinicians providing care and people who live with epilepsy share the same understanding of what matters*
- *Opportunities for improving the quality of epilepsy care*

Patient-centered care (PCC) is about creating a balanced partnership between people who use and people who provide healthcare services. Traditional healthcare often sees patients as people who receive treatment, rather than people who make decisions in partnership with the clinician. For people with chronic conditions like epilepsy, a PCC partnership can ensure that the right healthcare decisions are made for each individual, therefore enhancing well-being and quality of life.

Looking, Thinking, Acting

Funded by the Research Collaborative in Quality and Patient Safety (RCQPS) in December 2015, EPiC is a 2 year project researching epilepsy care services in Ireland. EPiC researchers are capturing viewpoints of patients, families, healthcare and community-based service providers using three methods: looking, thinking and action. This 'on the ground' approach highlights the variety of people, practices and contexts that matter for the delivery of PCC in epilepsy. It highlights four simple but important questions;

- Who is involved in care?
- Where does care take place?
- What spaces and places are involved in care?
- How does care happen in practice?



Looking

Ethnography is the study of people and their customs through observation. EPiC has conducted more than 40 observation sessions in a variety of settings across the country to "see" people with epilepsy and their families engaging with different healthcare and community services.

Thinking

EPiC researchers have met with over 35 individuals to carry out one-to-one conversations with people who live with epilepsy, parents, epilepsy specialist nurses (ESN's), consultants, Epilepsy Ireland community resource officers (CROs), healthcare managers, and GPs.

6 focus groups have also been conducted. These involved small groups of people with epilepsy coming together to reflect and share their experience of epilepsy care in Ireland.

These interviews and focus groups add to the information captured in the observations to depict the experience of PCC in epilepsy.

Taking Action

Through looking at and thinking about epilepsy care, a number of significant themes and opportunities for taking action are emerging, including; telephone based care, care in the community, and transition services. EPiC is using participatory action research (PAR) to bring groups of people together regularly to better understand these issues, and collaborate to improve the quality of epilepsy care and services.

Telephone Advice Line (TAL) Group

Epilepsy Specialist Nurses (ESNs) provide a telephone advice line as a point of contact for people with epilepsy. Telephone encounters are an increasingly large part of an ESN's workload. The TAL group - made up of ESNs from across the country - meets to reflect on the key goal of the telephone service, current practices and outcomes, and work together to continuously improve its quality and patient-centeredness.

Care in the Community Group

Epilepsy has a complex impact on people's lives and is about more than seizures and hospitals. Dealing with this complexity involves co-ordination of a range of services from those based in the community to those based in specialist hospitals. Epilepsy care co-ordination is the focus of the Care in the Community group. Made up of ESN's and Community Resource Officers (CROs) from Epilepsy Ireland, this group meets to learn about each other's job and identify ways to work together to provide better continuity of care for the benefit of people with epilepsy.

The Transition Workshop

A third theme emerging from observations and interviews centres around the needs of young people with epilepsy as they transition from pediatric to adult care services. On June 9th, a full-day workshop was held at the Royal College of Surgeons in Ireland (RCSI) which brought together healthcare professionals, community workers, policy makers, people with epilepsy and their families, to further explore what matters during transition care and to work in partnership to design improved services.

The EPiC project is creating the conditions that will allow people with epilepsy to work together with health service personnel to co-design services which meet patient needs and get the best value from healthcare resources.

EPiC is conducted by the HSE National Epilepsy Care Programme, in conjunction with Maynooth University, Dublin City University and RCSI. The team acknowledges the support and participation of Epilepsy Ireland in this research.

EPILELPSY QUESTIONS OFTEN ASKED BY PARENTS

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

As parents, you are constantly listening to your children and their endless string of questions - about everything! You do your best to answer truthfully in a manner they will understand. So when you have questions yourself, particularly relating to your child's epilepsy, where do you go for answers? You may have found the written materials you received from your child's neurology team or from Epilepsy Ireland, at the time of diagnosis helped answer many questions. But there may be some questions you might like practical answers to. Here are some questions parents ask.

Is it possible for seizures to change as my child gets older?

Yes, this often can happen, particularly if the seizures started early in your child's life. Remember, as your child grows and develops, his/her body is changing and the brain is growing too. These natural changes may affect how seizures present.

In some children their epilepsy can 'go away' as they grow up (e.g. benign rolandic epilepsy of childhood), whereas in others it continues into adolescence and adult life (e.g. juvenile myoclonic epilepsy/JME). But in all cases the change in seizures may be due to some of these factors:

- The type of epilepsy your child has been diagnosed with, for example some epilepsy syndromes follow a similar course as a child gets older
- Hormonal changes at puberty may cause a change in seizure pattern, usually related to the menstrual period
- And sometimes a new anti-epileptic medication (AED) can change the way a seizure presents. For example, following the introduction of a new AED, parents often report that the seizures look different, or appear to be a milder version of the original seizure. This is normal and can often be a sign that the new medication is working.

As always, if you're ever concerned about changes in seizure pattern or presentation, have a chat with your Advanced Nurse Practitioner or Clinical Nurse Specialist.

Can illness or infections increase the chance of having seizures?

Yes this is possible. It is not unusual for your child's seizures to increase in number or severity when they have a cold, 'flu, tummy bug, and ear or throat infection. In some cases it is possible that a high temperature (fever) may well be a triggering factor. In situations where a child has a gastro-intestinal upset (vomiting and/or diarrhoea) there may be reduced absorption of the anti-epileptic medication (AED). This means that the drugs won't work as well as usual, therefore increasing the risk of having more seizures. Often the best advice is to let the illness run its course and manage symptoms as they appear. Usually, seizures settle down again in a week or two, once the illness has passed.

Can other medicines be given to my child?

So, your child has taking the anti-epileptic medication and thankfully there are no unwanted side effects. Then wakes one morning with a fever, and complains of an earache. Your first thought is to give some paracetamol (CALPOL®) or ibuprofen (NUROFEN®), but then you're not sure if they can be given to a child who is taking AEDs. What to do?

The general advice is always to check with your pharmacist, or neurology team. Pharmacists know what medications are safe to give together and are aware of possible drug/drug interactions. This includes over-the-counter products, like CALPOL® and/or NUROFEN®, or cough and cold medicine. The same advice applies to any vitamins, fish oils or food supplement you are considering giving to your child. "If in doubt, check it out"!

What do I do if my child vomits after taking a dose of medication?

If your child is taking his/her drug in tablet form, it may be possible to see the tablets in the vomitus. In this situation it is safe to repeat the dose once the tummy upset has settled. In cases where the anti-epileptic medication is in a coloured liquid form, it too may be quite obvious in the vomit and likewise can be repeated. If however your child vomits an hour or more after taking the drug, it would not be advisable to repeat the dose. In this situation be aware that there may be some break-through seizures and you might have to give rescue medication.

Is it necessary for my child to have regular blood tests to monitor the anti-epileptic drug treatment?

A blood test may be used to measure the amount of an anti-epileptic drug in your child's blood, but not all children taking these drugs need to have the blood levels measured. However, there are some situations when it may be necessary to perform this test:

- If seizures are not being controlled despite high doses of medication.
- If the doctor/paediatrician/neurologist thinks that a child might not be taking or is not being given the drug(s).
- If a child has an episode of status epilepticus i.e. a seizure lasting for at least 30 minutes, or repeated seizures from which the child does not regain consciousness between each seizure.
- If a child appears to be toxic (i.e. excessively drowsy or lethargic) on even a small amount of their medication.

Who needs to be told that my child has epilepsy?

To be told your child has epilepsy can be a shock for parents/carers and needless to say a lot of emotions are felt, from worry and helplessness to anger or guilt. How people deal with this news differs from person to person, and parents worry about who they can tell and how other people will react to this news. It is up to the parents themselves to whom they disclose this information, but of course there are situations when it is vital for your child's' safety that certain people be informed, for example:

- Crèche or Montessori staff, school teachers and school staff, as they are responsible for your child's wellbeing in your absence. Epilepsy Ireland has informative booklets and packs specifically designed for teachers and schools explaining everything about epilepsy. One very helpful document is called Managing Chronic Health Conditions at School. Have a look at it online yourself. You will find it on www.into.ie and of course on www.epilepsy.ie
- All sports coaches need to be told and especially swimming instructors, so they can be vigilant. Therefore, in the event your child has a seizure in the swimming pool, prompt action can be taken.
- Baby sitters/child minders, again for same reasons as above.

There are helpful leaflets available to support parents when imparting this information.

When telling these people, exactly what should they be told?

You may be surprised how much some people know already, so tailor the information to your child specifically and make allowances for the persons understanding. For example it is important for teachers, childminders etc. to be made aware of:

The type of seizure your child usually experiences

- How it starts,
- How it progresses,
- Parts of body involved etc., so as they know what to expect

TIP: It's often quite helpful to show a video of the seizure to anyone who is responsible for your child in your absence.

- Whether or not your child gets an 'aura' or warning
- How the seizure is normally managed
- How and when to administer first aid
- How long the event may be likely to last
- How long your child needs to rest after the event
- How frequent the seizures are
- Is there a pattern to them
- What the possible trigger factors are e.g. flashing lights, certain computer games, stress, excitement etc.

In case of emergency;

- What action must be taken
- Who should be informed/contacted
- Where emergency medication is located
- How and when to administer it?

I have been given a diary in which to record my child's seizures. Is it necessary to keep this record?

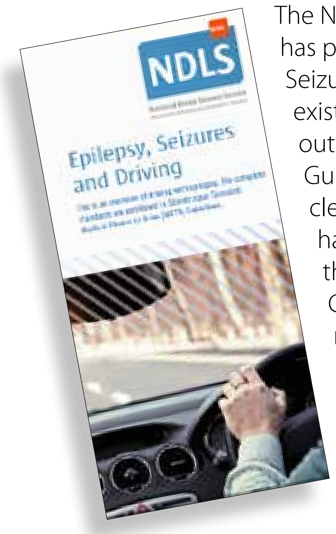
With the best will in the world, it's not always possible to remember all the details of seizure events, or how often they occurred, especially when it comes to sharing these details at each clinic visit. So, keeping a seizure diary is a good routine to get into for many reasons:

- Sharing the information recorded in the diary with the medical team, helps them assess the effects of the medication and changes can be made accordingly. This is particularly true if a new drug has been commenced
- If changes in seizure pattern are thought to be linked to hormonal changes (with the menstrual cycle), then a three-month record of both seizures and periods can help the medical team decide on what medication adjustments need to be made
- It is important also to keep a record of possible trigger factors or events leading up to a seizure which may be significant, as this can assist future management

I hope this has helped answer some of your questions in a practical way. And remember; never be afraid to ask a question! As Albert Einstein said: "The important thing is not to stop questioning. Curiosity has its own reason for existing……... Never lose a holy curiosity."

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

NEW EPILEPSY AND DRIVING LEAFLET FROM THE NDLS


NDLS

Epilepsy, Seizures and Driving

The National Driver Licensing Service has published a new leaflet on Epilepsy, Seizures and Driving explaining the existing driving regulations as set out in The Medical Fitness to Drive Guidelines, April 2017. Just to be clear, the main epilepsy regulations haven't changed, it is just the leaflet that is new. The leaflet covers Group 1 drivers, for car, light van, motor cycle or tractor and Group 2 Drivers, for driving a bus or heavy goods vehicle. It covers an explanation of the importance of health for drivers and how it affects driving ability, the regulations as they apply to epilepsy, general advice about informing the NDLS of your epilepsy and how to apply for a licence when resuming driving after becoming seizure free for the required period.

For most people with epilepsy whose seizures occur in waking, the driving regulations require them to be 12 months free of seizures before resuming driving a car, light van, motorcycle or work vehicle. There are exceptions to the 12 month rule in cases of single unprovoked seizures, seizures that only occur in sleep, seizures that do not affect consciousness, provoked seizures, seizures associated with physician directed withdrawal of therapy and breakthrough seizures.

Some Frequently Asked Questions about Driving

Q : How do I know what applies in my case ?

A : Your doctor can explain how the regulations apply in the case of your particular seizures. It is important to follow your doctor's guidance on driving.

Q : Do I have to declare my epilepsy?

A. Yes. The Medical Guidelines require drivers with any medical condition, including epilepsy, to declare this to the National driver Licencing Service and you must also tell your insurer.

Q. Why do I need to tell my insurer?

A. Not telling them could invalidate a policy and make cover more difficult to obtain in future.

Q : Am I legally obliged to stop driving if my doctor tells me?

A : Yes. To continue to drive against medical advice is dangerous and against the law.

Q. Can my doctor report me if I continue driving against medical advice?

A : Yes. The Medical Guidelines require health professionals to do this.

Q: Can my licence be cancelled if I don't stop driving as advised?

A : Yes. The Gardai and the NDLS can take steps to cancel your licence in that situation.

Q : Can I appeal a decision on my licence?

A : Yes. The NDLS has an appeals process for drivers who are not satisfied with a licensing decision.

Epilepsy Ireland has summarised the main driving regulations in this chart below :

Driving and Epilepsy at a glance Group 1: Car, light van, motorcycle, tractor (Class A, B, EB, M, W)

Seizure type	Requirement	Licence conditions
Seizures affecting awareness in waking	1 year seizure free	1-3 yr licence up to 4 years seizure free 10 yr licence at 5 years seizure free
First unprovoked seizure	Stop driving until 6 months seizure free	1-3 year licence may be issued 10 yr licence at 5 years seizure free
Provoked seizure	Stop driving. Individual medical assessment	Doctor advice on period May be below 12 months
Sleep seizures only	Driving permitted after at least 1 year of sleep seizures only	1-3 year licence may be reviewed annually
Seizure without impaired consciousness/function	Driving permitted after at least 1 year of aware only seizures	1 yr licence/annual review
Withdrawal from AED's	Must stop driving from date of reducing AED's and for at least 6 months after stopping all AEDs	Medical certification of fitness to drive
Breakthrough seizures	Advised not to drive (unless sleep seizures applies)	Notify NDLS Exceptions may be allowed drive after shorter period

*AED's : Antiepileptic Drugs

Driving and Epilepsy at a glance Group 2: HGV, Lorry, Bus (Class C and D)

Seizure type	Requirement
Loss of awareness in waking	10 years seizure free and off AED's Appropriate medical follow-up Extensive neurological Investigation No relevant cerebral pathology established No epileptiform activity on EEG
First unprovoked	5 years seizure free and off AED's Recent neurological assessment No clinical factors or investigation results (EEG/brain scan) that indicate risk of more seizures is 2% or less per annum
Provoked	10 years seizure free and off AED's
Withdrawal from AED's	10 years seizure free and off AED's

To download the leaflet see www.rsa.ie or www.ndls.ie Printed copies are available from NDLS offices countrywide.

FUNDRAISING

Purple Power

Thanks to Faye Creedon and friends in Dublin who raised €931.12. Faye organised a 'Purple Power' event to raise funds. Aoife, Ava & Carrie set up a fundraising committee in their school and organised first aid demonstrations, seizure posters and talked to students giving presentations and vital info.

A mermaid with epilepsy

Congratulations to Aoife Dardis, Kate Grogran, Caoimhe Currie and Sarah Robinson TY Students from St. Josephs School, Lucan who wrote two fantastic fairy-tale books which featured a girl named Anna who is a mermaid with epilepsy. These amazing girls made it to the finals of the Student Enterprise Awards which took place in Croke Park. The girls also raised over €160 proceeds from the book sales. Well done all, a great achievement!

If you would like to raise money for Epilepsy Ireland please contact our fundraising team on 01 4557500 or email abutler@epilepsy.ie

Rose week donations

5th Year Students from Colaiste Ailigh, Letterkenny Co. Donegal handing over a cheque to Epilepsy Ireland CRO Agnes Mooney for a fantastic sum of €1,300 from their participation in Rose Week 2017. Well done and a very big thank you to all the students and their Teacher Siobhan Lynagh.

Well done also to Transition Year Students from the Sacred Heart Secondary school in Tullamore Co. Offaly who sold roses during Rose Week raising an amazing €520 in three hours.

Saddle Up For Epilepsy donation

Huge thanks to Brian McCaffrey and Team Lightspeed (pictured) who took part in the 2017 Saddle up for Epilepsy Cycle in Mayo and raised nearly €11,000 which included matched funding from Google.

Peaks Challenge

Huge thanks to everyone who took in Epilepsy Ireland's inaugural Ancient East Peaks Challenge where over €8,000 has been raised to date. Four mountains were reached in 36 hours with lots of new friends made along the way.

HSF donation

Huge thank you to Dave Thomas from HSF for their generous €3,000 donation

In memory donation

Many thanks to Kepak for their wonderful donation of €15,000 in loving memory of their former colleague and friend, Jim O'Neill.

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 2017, we hope that you will consider it good value for money and a worthwhile investment in the future of epilepsy services.

Benefits of Membership

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

MEMBERSHIP FORM

epilepsy Ireland

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

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

Membership Type
Renewal ☐ New ☐

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

Membership Category		**€**
1 Year Renewal membership subscription	☐	12.70
1 Year New membership subscription	☐	12.70
2 Year New membership subscription	☐	20.00

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

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

Voluntary Donation

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

☐ €7.30 ☐ €20 ☐ €30 ☐ €50 ☐ €100
☐ own amount €__________ **Total Enclosed** €__________

Payment Method

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

Name of Person with Epilepsy Please use block capitals

Title _______ Name ____

Address ____

____

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

E-mail ____________________________________ Date of Birth ____________________

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

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

Tick here ☐ if you would like to receive our regular e-mail newsletter. Clearly write your e-mail address in the space above.
Tick here ☐ if you would like to find out more about volunteering & fundraising for Epilepsy Ireland

Card Payments

I wish to pay by: ☐ Visa ☐ Mastercard ☐ Laser

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

Name on Card ____

Card Number________________________Expiry Date (mm/yy) ______________ CVV No ______________

Signature____ Date ____________________

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

Bank ________________________________ Branch ________________________________

Account No ________________________________ Sort Code ________________________________

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

Signed____ Date ____________________

REGIONAL EVENTS

EAST

(Co's Dublin, Kildare, Wicklow)
Contact: Carina Fitzgerald, Community Resource Officer, Epilepsy Ireland, Edel Curran, 249 Crumlin Road, Dublin 12. Tel: 01 4557500. Email: cfizgerald@epilepsy.ie and ecurran@epilepsy.ie.
Office Hours:
Mon, Tue & Wed, 10am - 6pm;
Thur 1.30pm - 6pm

Upcoming Events

Dublin: Film Summer Camp
for Young People Living with Epilepsy
16-21 years
IMMA – Irish Museum for Modern Art, Royal Hospital, Kilmainham, Dublin 8
July 3rd to July 7th

Dublin: Family Fun Day
Saturday 15th July
Save the Date - Venue and details will be posted on www.epilepsy.ie

Dublin: Support, Information & Toolkit Group for Parents of Children with Epilepsy

Carmelite Community Centre, 56 Aungier St. Dublin 2.
Monday August 21st
6.00pm – 9.00pm
For more information or to register please contact Carina or Edel

MID-WEST

(Co's Limerick, Clare & North Tipperary)

Contact: Veronica Bon, Community Resource Officer, Epilepsy Ireland, Social Service Centre. Henry St. Limerick. Tel: 061 – 313773.
Email: vbon@epilepsy.ie.
Office Hours: Mon 9.30am - 5pm; Wed 9.30am - 5.30pm; Thur 12.30pm - 5pm; Fri 11.30am - 4pm.

Upcoming Events

Ennis: Awareness Talk for teachers and SNAs
Ennis Education Centre, Government Buildings, Kilrush Road, Ennis
Thursday 31st August
4.15pm - 5.30pm

Limerick: Awareness Talk for teachers and SNAs
Kilmurry Lodge Hotel, Limerick
Wednesday 6th September
7.00pm - 8.15pm

Limerick: Toolkit Support Group For parents who have completed toolkits in 2016 & 2017
Limerick Education Centre
Thursday 14th September
10.00am - 12.45pm

Limerick: Epilepsy Awareness & the Administration of Buccal Midazolam
Kilmurry Lodge Hotel, Limerick
Wednesday 27th September
9.30am - 4.30pm

NORTH WEST

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

Upcoming Events

Sligo: Outreach Service

Sligo: Parents and Pre-School Epilepsy Awareness & Buccal Midazolam Talk & Demonstration
Clayton Hotel, Sligo
Friday July 7th
10.30am - 12.30pm
Guest Speaker: Maria Keegan, Paediatric Neurology Clinical Specialist Nurse, Crumlin Children's Hospital.
Places must be booked in Advance

Sligo: STEPS Self-management programme for Adults with Epilepsy
St Michaels Family Life Centre, Church Hill, Sligo
Monday 28th August, and for the following five Mondays
6.00pm to 9.00pm
To Book a place please call Agnes

Letterkenny: Seminar for Teachers & SNAs
Station House Hotel, Letterkenny, Co. Donegal
Tuesday 19th September
7.30pm - 8.30pm.
To Book a place please call or email Agnes

MIDLANDS

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

Contact: Cliona Molloy, Community Resource Officer, Epilepsy Ireland, c/o The Charleville Centre,
Church Avenue, Tullamore, Co. Offaly.
Tel: 057 9346790. Email: cmolloy@epilepsy.ie. Office Hours: Mon, Tue, Wed & Fri 10am - 2.30pm; Thur 9am - 5pm.

Upcoming Events

Tullamore: STEPS Self-Management Training Programme for Adults with Epilepsy
Charleville Centre, Tullamore, Co Offaly
Starting on the 13th of July one Morning per week for 6 weeks.
11.00am to 2.00pm

Tullamore: Epilepsy Awareness & the Administration of Buccal Midazolam
Charleville Centre Tullamore
October 9th
9.30am – 4.30pm

NORTH EAST

(Co's Louth, Meath, Cavan, Monaghan)
Contact: Mary Baker, Community Resource Officer, Epilepsy Ireland, Unit 1a Partnership Court, Park Street, Dundalk, Co Louth. Tel: 042 – 9337585 Email: mbaker@epilepsy.ie. Office Hours: Mon, Tue & Wed 9am - 6pm.

Upcoming Events

Swords: Group Toolkit Session
Carnegie Court Hotel, Swords, Co. Dublin
Monday 19th June
6.30pm – 9.30pm
An introduction to the toolkit resource for people with epilepsy or parents of children with epilepsy.
For more information please contact Mary

KERRY

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

Upcoming Events

Killarney: Support Group for people with epilepsy
Killarney office
Wednesday 21st June
Wednesday 23rd August
Wednesday 20th September
10.30am

Tralee: Support Group for parents of children with epilepsy
Manor west hotel Tralee
Wednesday 28th June
10.00am
Killarney office
Tuesday 12th September
10.30am

Kerry: Hospital Outreach
Appointments available at Kerry university hospital on the 1st,2nd and 4th Monday each month.

Tralee: Information evening for teachers and school staff
Kerry education centre Tralee
Monday 25th September
4.30pm – 6.00pm
For further information contact Kathryn.

WEST

(Co's Galway, Mayo, Roscommon)
Contact: Edel Killarney, Epilepsy Ireland, Westside Resource Centre, Seamus Quirke Rd, Westside, Galway, Tel: 091-587640. Email: ekillarney@epilepsy.ie.
Office Hours: Mon-Wed 8.30am - 4.00 pm; Friday 8.30am -4pm.

Upcoming Events

Roscommon Support Group
Cuan Aire Resource Centre
Monday 19th June
6.00pm – 8.00pm

Galway: Epilepsy & Educational Effects on the Child
Maldron Hotel, Oranmore, Co. Galway.
Tuesday June 20th
2.00pm - 4.00pm
Information session open to Parents & Professionals –contact Edel if you wish to attend

Galway: Support Group
Imperial Hotel, Eyre Square, Galway
Wednesday 21st June
11.00am -1.00pm

Galway: Effects of Epilepsy on a Childs Learning
Maldron Hotel, Oranmore, Galway
Tuesday 20th June
2.00pm – 4.00pm

Castlebar: Family Puppet Day
(For children with epilepsy, their siblings and children whose parents have epilepsy)
Mayo Education Centre, Westport Road, Castlebar
Monday, 24th July
11.00am – 3.00pm
Free to attend but booking is essential.
Food will be provided.
Run in conjunction with Helium Arts.

Mayo: Adults STEPS Self-management Programme
Mayo Education Centre
Monday Sept. 4th – October 2nd
10.00am – 1.00pm

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

SOUTH EAST

(Co's Kilkenny, Carlow, Waterford, Wexford and South Tipperary)
Contact: Miriam Gray, Community Resource Officer, Epilepsy Ireland, c/o HSE, St. Joseph's, Waterford Rd, Kilkenny. Tel: 0567789904.
Email: mgray@epilepsy.ie.
Office Hours: Mon, Tue, Wed 10am - 5.30pm; Thur 10am - 2pm

CORK

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

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

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

epilepsy Ireland

NATIONAL CONFERENCE 2017

What's New in Epilepsy Care:

Latest Developments for Adults and Children with Epilepsy

Saturday September 9th 10.30am - 4.00pm
Clayton Hotel Sligo, Clarion Road, Ballinode, Sligo

Conference Programme

Top 10 things parents should know about their child's epilepsy
Dr. Bryan Lynch, Consultant Paediatric Neurologist at Temple Street Children's Hospital

Top 10 things adults should know about their epilepsy
Dr. Kevin Murphy, Consultant Neurologist, Sligo University Hospital

Top 10 things you should know about memory, cognition & epilepsy
Dr. Andrea Higgins, Senior Neuropsychologist, Bloomfield Hospital and Health Services, Dublin

How families talk about epilepsy
Dr Veronica Lambert, Senior Lecturer (Children's Nursing) School of Nursing and Human Sciences Faculty of Science and Health, Dublin City University

Medical Q&A for parents
Maria Keegan, Paediatric Neurology Clinical Nurse Specialist Our Lady's Children's Hospital, Crumlin

Transition to adult services
Yvonne Owen, Epilepsy Ireland Transition Nurse Co-ordinator

Epilepsy: How to tell
Dr. Naomi Elliott, Associate Professor, School of Nursing & Midwifery, Trinity College, Dublin

Employment and Epilepsy
Paul Sharkey, Epilepsy Ireland Training Manager

Medical Q&A for adults with epilepsy
Geraldine O'Rourke
Advanced Nurse Practitioner, Sligo University Hospital

Cara Conway
Advanced Nurse Practitioner, Sligo University Hospital

CONFERENCE FEE INCLUDES

Full attendance at conference on Saturday 9th September (10.30am - 4.00pm) with refreshments, lunch and conference pack.

BOOKINGS

epilepsyconference2017.eventbrite.ie
OR
Email/phone to reserve and pay for your place: info@epilepsy.ie / 01 455 7500

CONTACT US

Head Office (Dublin)
01 455 7500

Cork	021 427 4774
Dundalk	042 933 7585
Galway	091 587 640
Kilkenny	056 778 9904
Killarney	064 663 0301
Letterkenny	074 916 8725
Limerick	061 313 773
Sligo	071 914 1858
Tullamore	057 934 6790

PQASSO QUALITY MARK level 1 Charities Evaluation Services

www.epilepsy.ie

Email **info@epilepsy.ie**