



Epilepsy News

Celebrating 50 years in 2016

Shining a light on epilepsy

Epilepsy Ireland Issue 73 Summer 2016

Are students with epilepsy getting enough exam support?

IN THIS ISSUE:

- **Let's talk about stress**
- **Medicinal cannabis for the treatment of Epilepsy**
- **Talking about Epilepsy**
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NOTE FROM THE EDITOR

Welcome to the summer edition of Epilepsy News. Hard to believe we are almost half way through 2016 and that our National Conference is only round the corner. As this is Epilepsy Ireland's 50th anniversary, the conference is somewhat different from past years. There will be an evening session on Friday October 7th and the usual full day's programme on Saturday October 8th. Please see the back cover of this issue for full details. It promises to be a very interesting and informative conference and we hope to see as many of you there as possible.

This summer edition of Epilepsy News includes some very interesting and topical pieces:

Maria Carty-Mole tackles the issue of whether students with epilepsy getting enough help for the leaving cert (page 4). This is unfortunately the last Yay or Nay article from Maria. I am sure I speak for all our readers when I thank her for her very valuable contribution over the years and wish her well.

For those planning holidays – Travelling with Epilepsy – Sun Sea and Seizures (page 6) by Sarah Holden will prove of particular interest especially her personal travel tips.

Talking about epilepsy: Challenges parents face when communicating with their child about epilepsy and epilepsy-related issues is the title of a piece explaining the EI-funded research project exploring how families

talk about epilepsy which was carried out by a team of researchers at Dublin City University. We thank DCU for their permission to publish the piece (page 7).

Stress can be a major factor for many and for those with epilepsy it can prove a particularly annoying seizure trigger. Maria Keegan, Paediatric Neurology Clinical Nurse Specialist, Our Lady's Children's Hospital, Crumlin presents her first article for Epilepsy News – "Let's Talk About Stress" (page 8) in which she provides food for thought and some practical advice which I'm sure will prove helpful to many.

We also thank Dr Colin Doherty, Consultant Epileptologist, St James's Hospital, for his very timely article Medicinal Cannabis for the treatment of Epilepsy (page 10). He covers the use of medicinal cannabis in epilepsy treatment; its efficacy and the implications of the availability of the drug here in Ireland. It should prove a very interesting read for many.

Finally to Kate Maher for the first part of her personal story, Kate from Cork has written a series of pieces telling her epilepsy story up to her epilepsy surgery and we will be publishing these as a series over the next number of issues. As with all our personal stories we thank Kate for her contribution and I am sure hers will prove inspirational for many of our readers. The first part is on page 13.

HAS EPILEPSY LEFT YOU FEELING ADRIFT?

Training For Success (TFS), Epilepsy Ireland's pre-employment training programme, based in Sligo, is currently recruiting for its 2016/17 term. Places are limited so if you or anyone you know might be interested in further details, please contact Honor Broderick or

Marie Tansey on 071 9155303 to arrange an interview.

TFS students earn as they learn and receive a FETAC Level 4 Major Award in Employment Skills.

ONLINE SUPPORT GROUPS



June

15th June, 11am, General Support Group
21st June, 7pm, Parents Support Group
28th June, 7pm, General Support Group

July

5th July, 7pm, General Support Group
13th July, 11am, Parents Support Group
19th July, 7pm, General Support Group

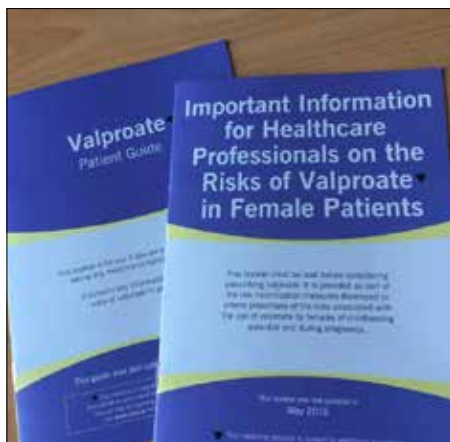
Top award for Cork epilepsy outreach service



The Cork University Hospital epilepsy team has taken one of the top honours at the annual HSE Health Excellence Awards in April. The Community Epilepsy Outreach Service led by Dr Danny Costello and Dr Ronan McGinty won the prestigious Popular Choice Award for providing a high-quality specialist epilepsy care service to people with an intellectual disability and living in residential care. The innovative service was established two years ago. The service now visits more than 200 clients in their homes rather than in the hospital environment and provides on-going telephone-based care between visits. Congratulations to all the team in Cork on their success.

goo.gl/UDGxzW

Updated information materials on valproate distributed



Sanofi and the Health Products Regulatory Authority (HPRA) have recently updated and redistributed important information booklets on the use of valproate (e.g. Epilim) in women and the risks associated with the drug in

pregnancy. In 2014, the European Medicines Agency strengthened its warnings on the use of valproate in women and girls due to the increased risk of developmental problems, autism and malformations in children exposed to valproate in the womb. The new booklets (pictured) for patients and healthcare professionals, along with instructions for prescribers are being re-distributed nationally to GPs & specialists while pharmacists are being asked to distribute a new information card to patients with their medications. During 2016, the outer packaging of Epilim will also be updated to reinforce the risks associated with the drug. PDFs of these booklets are now available on epilepsy.ie.

goo.gl/QBfO5E

New data on Lamotrigine & Pregabalin in pregnancy

New data on two other common epilepsy drugs has also been published in recent months. Dr Helen Dolk of Ulster University published findings in the journal *Neurology* showing that babies born to women who are taking the drug lamotrigine (e.g. Lamictal), do not have a significantly increased risk of birth defects such as cleft lip, cleft palate or club foot. The study analysed data for more than 10 million births over 16 years and the findings are contrary to earlier, smaller studies. Dr Dolk concluded that more studies need to be carried out to see if exposure to high doses of the drugs has any effect. Meanwhile, Swiss research also published in *Neurology*, found that pregabalin (e.g. Lyrica) is associated with a three-fold increased risk of major birth defects after first trimester exposure. The study, while small, found that pregabalin "should be prescribed for women of childbearing age only after making sure that the benefits of the drug outweigh the risks". These and other studies continue to highlight the importance of close communication with your medical team before and during pregnancy regardless of which AED(s) you are taking.

goo.gl/EoG9FP and goo.gl/r9g078

New findings on SUDEP

A number of new studies on sudden unexpected death in epilepsy (SUDEP) have emerged this year. Among these

is a long-term study from Switzerland suggesting that patients with drug-resistant epilepsy treated with vagus nerve stimulation (VNS) have a reduced risk of SUDEP. Reported at the 2nd Congress of the European Academy of Neurology, the researchers conceded that their study was limited by the quality of the available data, but stated that "we can assume that maybe we saved one in 40 patients from SUDEP" through the use of VNS. Meanwhile, an Australian study of DNA from over 60 people who died from SUDEP has found that one in four carried mutations linked to cardiac sudden death, suggesting that irregular heart rhythms may play a role in a significant number of epilepsy deaths. A major conference on mortality in epilepsy (PAME conference) is to be held in Washington DC from June 23rd – 26th. Follow the latest research presented at the event at pame.aesnet.org.

goo.gl/IWHSN7 and goo.gl/DnXe2X

Tegretol Retard becomes Tegretol SR

Novartis, the manufacturers of Tegretol Retard have changed the name of the medication in Ireland to Tegretol SR (Slow Release). This name change is in response to a request from Epilepsy Ireland, on foot of a concerns raised by parents of children taking the drug about the connotations and stigma associated with the name. While both names have the same scientific meaning, the original name has led to some unfortunate instances where children have been teased, bullied, even humiliated by other children when their medication became public knowledge. It is important to emphasise there is no change to the medication, and the change has been notified in recent months to all pharmacists and healthcare professionals.

YAY OR NAY: ARE STUDENTS WITH EPILEPSY GETTING

ENOUGH HELP FOR THE LEAVING CERT?



For most of us the Leaving Cert is great, because it means at least one week of nice weather. But for students who get daytime seizures, the setup of the Leaving Cert could ruin their chance of getting into third level education. Epilepsy News columnist Maria Carty-Mole debates whether or not enough help is available for students with epilepsy who are taking these exams.

YAY

Right, here it is! Your 13 years of full-time education have led to these exams, the most important ones you will ever take. After listening in class, doing (most of) your homework and getting reasonable results in your mocks, you should be ok, except for one thing: your chance of having a seizure is very high. Several days of last-minute study mean that you're tired and you're stressed, and as we all know, both of those can trigger seizures.

Right, so it happens! You're 20 minutes into English, an essential subject that you will need to get into almost any course, and suddenly you feel an aura. You slip away into unconsciousness and have a complex partial seizure that means you're unable to read and write properly for the next two hours. That's it, there's nothing you can do. You'll just have to fail the exam and take it again next year, praying that the same thing doesn't happen again. Right?

Wrong! When I contacted The State Examinations Commission (SEC), a representative assured me that the organisation recognises that people can fall ill during an exam. All the student

needs to do is apply for 'Reasonable Accommodations' beforehand:

In circumstances where a candidate suffers an event such as an epileptic seizure which renders them unable to continue with an examination, the examination may be suspended at that point and restarted when the candidate is able to continue provided that the candidate was under the supervision of the school authority at all times. The time lost to the candidate during the event is added on at the end of the examination.

Provided that the exam is finished by midnight of the same day, the student can take as long as they need to recover. In fact, the test can even be delayed if the seizure happened before the exam. And all of this can be carried out in a separate room and with an individual supervisor, away from the judging eyes of peers. Sorted.

NAY

It's not that simple. The Leaving Cert timetable is intense and often a student will have two exams a day, meaning that they can't afford to postpone the morning one if they want to sit the afternoon one at the right time. Plus it can take a lot longer than a couple of hours to fully recover from a heavy seizure – it can take a couple of days. Two days means four exams would suffer.

Unlike in the accommodating colleges, it is not currently possible to repeat any Leaving Cert exams. Some would say this is reasonable, as it clashes with the SEC's anxious determination not to give students with disability "an unfair advantage over other candidates in the same examination". Students would know what questions they are going to get in the repeat, and they could even fake a seizure in the first exam so that they could have a resit and get a second chance.

The solution? To make the repeat exam, taken a few weeks later, a different one. The SEC is reluctant to do this, but as Epilepsy Ireland's CEO Peter Murphy explains, it wouldn't be too difficult when an alternative exam already exists:

Each year, for every subject at least one backup paper is prepared in case an emergency makes it impossible to use the first paper, e.g. the first one leaks. The SEC has pointed to the cost/logistics of having a second exam set and all that needs to go into that behind the scenes – marking schemes, examiners' meetings and the like... my point is that surely much of this work is already done given that a backup paper is already prepared.

He also points out that if the repeats were to be kept to a maximum of two papers per student, available on one day in five main cities around the country, then costs would be minuscule. It wouldn't solve things for students who had missed all or most of their exams, but it would help many.

Of course, all of this is based on the theory that the Leaving Cert is a realistic representation of a young person's intelligence, when actually much of it is just testing a student's ability to absorb thousands of facts and figures and give them back in a stressfully short amount of time on a particular day – not fair when memory loss is a common side effect of anti-epileptic drugs. A CAO process which included more continuous assessment would be fairer for those students whose medical conditions mean that they are at a disadvantage during exams, and might actually be a more accurate indicator of how well a student would do in college and in the world of work.



REASONABLE ACCOMMODATIONS IN CERTIFICATE

EXAMINATIONS (RACE)



What is RACE: This is a special arrangement put in place by the State Examinations Commission (SEC) at Junior or Leaving Certificate for students with a range of long term conditions which may affect their performance in a state exam and to facilitate the student to take the exam.

What is it for: According to the State Exams Commission the purpose of RACE is "to remove as far as possible the impact of the disability on the candidates performance and thus enable them to demonstrate his or her level of attainment" and "ensure that, whilst giving candidates every opportunity to demonstrate their level of attainment, the special arrangements will not give the candidate an unfair advantage over other candidates in the same examination".

How does RACE do this: There are a range of provisions whereby RACE can support candidates with a range of conditions and disabilities. Here, we will only concern ourselves with those supports available to students with epilepsy who do not have other qualifying conditions or disabilities for which they might also receive support. In the main, with regard to students with epilepsy, the supports they can apply for are typically limited to the following:

Separate Room: Some students may worry about having a seizure in the setting of a large exam hall. Students may

apply for a separate room in which to take the exam. A separate room can afford a candidate more privacy in the event of a seizure during the exam. Others may not wish to opt for the separate room.

Opportunity to complete exam later the same day: In the event of a seizure during or around the time of an exam how the provision works may depend on how the candidate is affected. Some seizures are brief and the student will be able to resume the exam when recovered. In this way, they may have the opportunity to complete the exam later on the same day if they recover sufficiently to complete it, though the question of remaining under supervision has arisen previously. Other students however, might not recover quickly, and their seizures might cause tiredness, disruptions to memory and information processing and overall functioning for an extended period. Such students may not be able to complete the exam within the same day. Unfortunately, in such cases there is no opportunity to retake the exam on a different date.

What can the school do?

- Based on their knowledge of the student the school has the authority to make some arrangements of its own and they do not need to seek permission from the SEC to do this but the SEC site states the Examination Superintendent should be advised by

the school in writing that the school is satisfied these arrangements are warranted. The kinds of arrangements schools can make include

- Granting of rest periods or breaks and the time taken is added on to the end of the exam up to a maximum of 20 minutes.
- Allowing students to take medicine, drinks or food to the exam centre where there is a known medical need.
- Allowing the candidate move around within the centre. There may be other arrangements the school can make which have less relevance to most students with epilepsy.

Applying for RACE: Students need to apply through their school for RACE provision using the application form supplied to schools or from the SEC website and the closing date is usually in November before the exam. Students will be notified of the SEC decision in April just prior to the exam. A student or parent who is unhappy with a decision of the SEC regarding the granting of RACE can appeal the decision to an external appeals group.

For more information contact your school or the SEC through their website www.examinations.ie



By Sarah Holden – check out www.destinationanywhere.org

I've had epilepsy for five years now. It causes memory blackouts – sometimes I'm missing entire days. I can watch a movie and watch it again the next day only to remember half way through that I've already seen it, if I remember at all.

I found out I had epilepsy just after my 19th birthday. My friend came to visit me so we could celebrate but, due to untreated seizures, I had forgotten.

Two weeks later, I called her asking why she hadn't come to visit. She must have thought I was crazy and told me to check the pictures on my Facebook. I checked and sure enough there was a photo of both of us taking silly pictures while having birthday lunch in my favourite restaurant. That week she made her way back to my house, helped me pack my things and off I went to the hospital where I would spend the majority of that year.

It took four years to find a medication that would have much of an effect on my seizures. At one stage I was having up to twenty a day. I'm grateful that I have finally found one that works pretty well and now I only occasionally get partial seizures.

What happens when I have a partial seizure?

I'm one of the lucky ones, I get a warning beforehand and have time to put myself in a safe position and let someone know what's happening. It's always the same; I get the smell of chicken, get déjà vu, feel a euphoric rush through my body followed by a sickness that feels like it's dragging my consciousness into the ground and then I trip out for a few minutes. During this time I feel like I'm out of my own body and can control senses that I didn't know I had before. I also visualise talking to people and have a sense that I know what the meaning of life is about. Strange, I know, but that's what happens!

Despite all of this I have never let my epilepsy hold me back. I'm currently in Brazil where I have spent the last five months soaking up the sunshine. Next month I'm beginning my backpacking adventure around the rest of South America, first stop; Argentina.

Of course I take precautions. I travel with my boyfriend who knows exactly what to do when I get a seizure. I don't go into

the sea alone, I try not to take long bus journeys during the day because the sun flickering through the trees can act as a trigger and I always make sure to have enough medication with me.

Sometimes the fear of having a seizure is worse than the seizure itself but epilepsy shouldn't hold you back in life. In fact, I would say that it has made me a more confident and outgoing person because I know I have conquered an illness and now I am fully capable of conquering the world.

Some travel tips for people with epilepsy

Always let the people you are travelling with know that you have epilepsy, especially if you are feeling unwell. Let them know what to do if you have a seizure. This will minimise panic in the event of a seizure and you will feel a lot safer knowing that you will have someone to look after you.

Before you travel, book an appointment with your doctor. They can give you a check-up and give you notes on your medical history in case you need to go to hospital while travelling. You will also need a letter for customs stating what medication you have been prescribed. I haven't had any problems with my medication so far.

Always carry emergency contact details with you. It's a good idea to have them translated into the language of the country you are in. On mine I have details of the type of epilepsy I have, what medication I'm on and details on what to do if you find me unconscious. It's a common misconception that people can swallow their tongue during seizures so I also include instructions NOT to put a spoon or other object in my mouth. In Ireland, you can get a free ID/ emergency contact card from Epilepsy Ireland.

Don't take stupid risks. For me, things like cliff diving are completely off the cards. If you are prone to having seizures it's probably not a good idea to swim in deep water or go hiking alone. In saying that, you can't always let your epilepsy hold you back, we all need our moments of independence. If you feel like your epilepsy is under control and you are in the company of people who can look out for you then go for it, just don't do it irresponsibly.

Have fun! Don't let the fact that you have epilepsy hold you back. People use enough excuses not to travel the world. Epilepsy shouldn't be one of them.

Challenges parents face when communicating with their child about epilepsy and epilepsy-related issues.



A research project exploring how families talk about epilepsy has been carried out by a team of researchers at Dublin City University. The research is funded through Epilepsy Ireland and the Health Research Board and took place in collaboration with Temple Street Children's University Hospital and Epilepsy Ireland. The overall aim of this research was to find out how children who are living with epilepsy and their parents communicate about epilepsy and the challenges they may face in doing so. It is hoped that this project may provide valuable information for improving the wellbeing for children with epilepsy and their families.

The first phase of this study involved interviews with 30 families (i.e. - 29 children with epilepsy and 35 parents) throughout Ireland. During these interviews, children and parents were asked how they talked about epilepsy, or not, within their family. Findings from this study reveal that although many families talked openly about epilepsy, some chose to not talk about epilepsy within the family home. In many cases this silence surrounding epilepsy was as a result of the challenges parents faced when talking to their child about epilepsy. A number of these challenges were highlighted by parents during interviews. The five main challenges recalled included: the challenge of making their child feel 'normal' despite their epilepsy, the 'invisibility' of epilepsy (the possibility of hiding their child's epilepsy) and a lack of awareness about epilepsy, the need to conceal certain information from their child with epilepsy, fears about misinforming their child, and difficulties in discussing particular epilepsy-related issues.

Parents believed that they played an important role in encouraging their child to view epilepsy as a normal part of their everyday family life. This created a challenge for parents when seeking to ensure that their conversations with their child did not make them feel different in any way. The invisible nature of epilepsy also created a difficulty for parents when discussing epilepsy with their child. As epilepsy is an often "invisible" condition (i.e. - not always apparent during times of seizure freedom), parents faced challenges in terms of choosing when to talk about epilepsy within the home, and also when discussing instances of telling or not telling others about their child's epilepsy. Some parents spoke about how they limited the amount of information relating to epilepsy that they made

available to their child. Many parents felt that some information, often relating to medication side effects and sudden unexpected death in epilepsy (SUDEP), was inappropriate for their child's age (particularly in the case of younger children) because it would cause their child worry and cause him/her to think about their epilepsy more. This presented a challenge for parents when balancing the level of information they gave to their child.

Parents also held concerns about their own lack of knowledge about epilepsy. Children with epilepsy often turn to their parents for information and guidance in how to manage their epilepsy. A number of parents spoke about their fear of misinforming their child when faced with explaining aspects of epilepsy to them. This challenge came from not receiving adequate information relating to their child's epilepsy at the time of diagnosis. As a result of this lack of information, parents felt largely under-informed about their child's specific epilepsy type and seizure types. Finally, parents of older children (particularly teenage children) found a number of topics especially difficult to talk about with their child. These difficult topics included; the amount of time since their child's last seizure, the possibility of their child growing out of epilepsy, and telling others outside the family about their epilepsy. In many cases parents spoke about how these challenges prevented them from talking openly to their child about epilepsy.

This research study is the first of its kind to investigate how families living with epilepsy in Ireland talk about the condition and the challenges they may face in doing so. This study highlights the unique challenges that parents of children with epilepsy experience when talking about epilepsy. Further research is currently ongoing to assess what might be done to alleviate these challenges for parents and allow for a greater ease of communication about epilepsy within the family. The role that healthcare professionals play as educators of parents of children with epilepsy in relation to their child's condition also warrants attention. Healthcare professionals who work closely with families living with epilepsy should remain mindful of the importance of discussing family communication surrounding epilepsy, and the challenges parents of children with epilepsy face when talking about epilepsy within their child.

We live in a time when people are regularly using the word stress. Regardless of age, we all seem to be affected by it in some way, right? Even children, babies included, cannot escape the effects of stress.

But what exactly is stress? What does it do to our bodies? What purpose does it serve? Is it always bad? Is there such thing as positive stress? And especially, what impact does stress have on seizures?

This article will look at answering these questions, give you a little insight into what stress is, identify possible stressors (the word that is used to describe the cause of stress), and look at the relationship between stress and seizures. Paying special attention to the possibility of stress causing increased seizures in children.

You will get some practical suggestions on how best to help your child manage stress effectively, especially important if stress is one of the triggering factors for your child's seizures.

The Origin of Stress

Though it feels like it has been around forever, the term stress in fact, is relatively new. The use of the term originated a little more than 60 years ago. Dr Hans Selye (1907-1982), a Hungarian doctor was so intrigued by it, that in 1950 he wrote a book entitled: The Physiology and Pathology Of Exposure To Stress.

He learned how the body behaved in response to the demands it was placed under. And that unconscious or involuntary hormonal changes occur in the body, when it is under pressure. So, what exactly does this mean?

Fight or Flight

I'm sure you've heard of the "fight or flight" response. This is what happens in the body, when confronted by a perceived harmful threat to one's self or someone close to us. A whole lot of physiological and emotional changes occur, increasing the body's strength and speed to protect itself. This is nature's way of keeping us safe. When the perceived threat is gone the body settles back into its normal balance. This is normal and happens to everyone.

Positive and Negative Stress

Believe it or not, you need a bit of stress! In normal everyday life, stress can help you stay focused and alert. It can even help save your life! For example, it's a stress response that spurs you to slam on your brakes to avoid a collision. It can keep you focused and on your toes when facing deadlines. Students, preparing for exams are helped by a bit of stress, driving them to study when they would prefer to veg out and watch TV! In other words, stress can encourage you to act. It helps to keep you motivated.

And the feeling of butterflies in your tummy when you're excited about something, this is a stress response, one of the good ones! Yes, positive stress or eustress is real.

Bear in mind of course, what may be a positive stress to one person, can result in a negative stress response in someone else. An example of this is how one person may feel as they plan a trip or holiday. They buzz with excited anticipation, otherwise known as, positive stress! To another person, this

may represent an absolute nightmare situation, a cause of much unwanted stress and anxiety. This is negative stress or distress.

So, if stress is a natural body response, how does it become negative? Well, this can happen when you're under a lot of pressure. You might not even be aware of it. Over time it becomes too much for your body and mind to handle, resulting in unpleasant effects. These unpleasant effects or signs of stress present differently in everyone, as no two people will show the same signs or respond to stress in the same way. And how an adult reacts to stress is slightly different to how a child reacts.

Some common physical signs of stress

- headaches
- neck or back pain
- stiffness in your back or joints
- trouble sleeping
- feel unmotivated.
- lack energy
- feel more tired
- seem to sweat more
- feel like your heart is racing
- find it difficult to relax
- seem to get more colds

Some common emotional signs of stress

- easily irritated become irrational
- experience mood changes
- feel down in yourself
- feel like you can't think straight
- feel overwhelmed
- feel like crying a lot of the time
- lose focus and lack clarity
- feel anxious or worried

REMEMBER: There are often other reasons for some of these signs. If you're at all concerned about yourself or your child, it is always advisable to have a chat with your family doctor.

Children and Stress

As parents, we'll always want to see our little ones happy and stress free, but realistically we know this can't always be the case. It's a fact of life, children including babies and toddlers get stressed too. Children are very sensitive to changes around them and can be affected by exciting and/or stressful situations. This has actually been proven by research. Babies are very quick to sense a change in mood or behaviour of their parent or carer and be stressed by this. Also, being hungry, tired, too hot or too cold can stress babies and toddlers. And of course being scared or frightened for example in a new or unfamiliar environment can result in stress.

Good stressors

We're often more aware of the not-so-good or negative stressors, but have you ever thought about good or positive stressors?

These are things that excite children, like the excitement they feel coming up to important occasions in their life. Things like birthdays, sleep-overs, play dates, holidays, starting school

(this can be a mixture of excitement AND anxiety), Christmas, their First Communion, Confirmation etc., the list goes on. As children get older they will have a variety of positive stressors at different stages. And of course, as every child is different, their response to stressors can vary.

Stress and Seizures

Being aware of the impact stress may have on any child is important of course. This is more important to the parent or carer of a child with epilepsy. Why is this? Well, as you will have seen from the information above, any stress or strain upon the body upsets its natural balance and ability to cope. You also know that anti-epileptic medication is there to control the seizures. So, why would stress, even the 'good stress' have such a negative impact? You may feel that the medication is working away controlling your child's seizures. And of course it is, until something happens to throw the body off kilter. If the stressor isn't removed or managed in some way, this may become too much for the body and brain to handle, resulting in possible loss of seizure control. This is why your nurse specialist or doctor may ask about stress.

Would you know if your child was stressed? Here are some of the signs:

Some common signs of stress in babies or toddlers

- Crying more than usual
- Difficulty sleeping
- Not feeding great
- Nothing seems to comfort them
- Appears frightened/scared
- Tending to have more tantrums
- More clingy than usual
- Anxious body movements
- Appears more fidgety than normal
- More thumb sucking or self-stimulation

Some common signs of stress in older children

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

REMEMBER: As stated before, there are often other reasons for some of these signs. If concerned about your child, it is always advisable to have a chat with your family doctor.

Causes of distress in Children and Teenagers

We've talked about some of the good stressors that affect children of all ages, let's look briefly at some of the not-so-good, though I'm sure as parents you will be aware of these upsets. Do keep in mind that every child is different in how

they react to stressful situations. It's all about being aware and watching out for possible stressors, especially if seizure frequency increases or there's a change in the seizures themselves.

Things like bullying - this can be in person or via social media. Struggling with school work and not even being aware of this themselves. Home upsets, death of a loved one including a family pet, illness, family disharmony, parents separating or fear of parents splitting up. Peer pressure and fear of not fitting in. Fear of failure, this can be in school, at home or on the sports field, etc.

What to do to help your child

Recognise the early signs of stress in your child. Spend time with them and depending on their age or understanding, gently encourage them to express their feelings. "A problem shared is a problem halved". Let them know you care and even more importantly, let them know you believe them. Reassure them that stress is actually normal. And show them practical ways to manage it. For example:

- Exercise/sport
- Laughing – having fun and playing, as a family or with their friends
- Breathing techniques
- Meditation – see www.teachchildrenmeditation.com.
- Yoga – there are practitioners who specifically run classes for children and teens (be sure to let them know about your child's seizures)
- Proper nutrition
- Listening to music
- Drinking water – helps keep body's natural balance
- Good sleep routine and proper night's sleep

No parent wants to see their child stressed or upset. But if you know that stress can upset seizure control (even the 'good stress') and are aware of the signs, you may be in a position to do something about it before it gets out of control.

Successfully managing stressful situations as a child will help them to cope better in the future. Learning to manage their stress can give them a feeling of control on their seizures, rather than feeling their seizures control them.

Be proactive, look for support from friends, family members, school teacher/guidance counsellor etc. Also, speak with your family doctor, paediatrician, nurse specialist or anyone who you feel might guide you in the right direction when concerned.

"The doctor of the future will give no medicines, but will interest his patients in the care of the human frame, in diet, and in the causes and prevention of disease." ~Thomas Edison

Some helpful reading:

- The American Institute of Stress (www.stress.org)
- Parenting Your Stressed Child by Michelle L Bailey
- www.kidshealth.org



Colin Doherty MD
Consultant Epileptologist,
St James's Hospital, Dublin 8

'The narcotic effects of hemp are popularly known in the south of Africa, South America, Turkey, Egypt, Asia Minor, India and the adjacent territories of the Malays, Burmese and Siamese. In all these countries hemp is used in various forms, by the dissipated and depraved, as the ready agent of pleasing intoxication. (However) in the popular medicine of these nations, we find it extensively employed for a multitude of affections, especially those in which spasm or neuralgic pain are the prominent symptoms'

So opens the now celebrated text of Irish Physician W.B. O'Shaughnessy's famous paper in the 'Provincial Medical Journal' published on 28th Jan 1843, called 'On the preparations of the Indian hemp or Gunjah (Cannabis Indica). Their effects on the animal system in health and their utility in the treatment of tetanus and other convulsive diseases.'



O'Shaughnessy, born in Limerick in 1809, moved to Calcutta where learned of the myriad uses of cannabis, is now considered the father of the medicinal cannabis movement. So much so that the name of the premier journal for medical use of cannabis is called after the physician. In the following I will give a brief review of the history of cannabis use for epilepsy and describe the science underlying its potential use in the future as a prescribed treatment. Finally, I will give the latest update on the scientific trials of the drug and its potential availability for Irish patients.

History of Cannabis use for Epilepsy

O'Shaughnessy's paper is generally accepted as the first modern scientific text regarding the use of cannabis for human ailments and gave rise to the extensive spread of medicinal cannabis use in Europe and the United States. The so called Modern World was way behind the ancient in knowledge of this topic and in fact the first description of the use of the drug goes back 10,000 years ago to ancient China when it was used as an anaesthetic agent.

Probably the first description of the treatment for epilepsy was recorded on a Sumerian cuneiform Tablet (2200 BC) with a description of the treatment of nocturnal seizures. The first paper written account was by the famous Muslim physician Al-Majusi who in 1100 AD described nasal treatment with cannabis leaf for seizures: The East continued to produce written records on cannabis use and famously Ibn al-Badri noted in 1500 AD "the epileptic son of the caliph's chamberlain" was treated with cannabis and "it cured him completely, but he became an addict who could not for a moment be without the drug".

In 1851, the US Dispensary classified cannabis compounds as useful treatments for neuralgia, depression, hemorrhage, pain relief and muscle spasm, convulsive disorders and other ailments. By 1860 the Ohio Medical Society Committee on Cannabis declared efficacy for infantile convulsions, epilepsy and many other disorders. With increasing use by western doctors from the middle of the 19th century onwards the value of the drug for treating epilepsy came under the scrutiny of one of the so called

fathers of modern Epileptology. In 1881 William Gowers in London reported that cannabis was "sometimes, though not very frequently a useful drug with small value as an adjunct to the bromide, but is sometimes of considerable service given separately..."

However, the narcotic effects of some varieties of cannabis led to unregulated recreational use and in 1911 Massachusetts became the first state to outlaw cannabis (in setting of prohibition of alcohol) Other states quickly followed with marijuana prohibition laws which persisted throughout the 20th century such that by 1970 the US Controlled Substances Act was passed, classifying marijuana as a drug with "no accepted medical use". Countries throughout the world now have stringent laws and punishments for the possession and distribution of cannabis. To understand how what was potentially the first useful treatment for epilepsy, became a by word for the drugs trade, one must understand some basic aspects of the chemistry of the cannabinoids as the active drugs in cannabis are called.

Botanical and chemical aspects of Cannabis use

To start is is worth going back to O'Shaughnessy's botanical description of the two main cannabis plants cannabis sativa and cannabis indica:

Cannabis sativa and Indica look identical, we find that the plant is dioecious, annual, about three feet high, covered over with a fine pubescence; the stem is erect, branched, bright green, angular; leaves alternate or opposite, on long weak petioles; digitate, scabrous, with linear, lanceolate, sharply serrated leaflets, tapering into a long, smooth, entire point; stipules subulate; clusters of flowers axillary, with subulate braces; males lax and drooping, branched and leafless at base; females erect, simple and leafy at the base.

The herb and its extracts contain more than 100 chemically similar compounds (called cannabinoids). It also contains over 400 other non-cannabinoid compounds. The cannabis plant's closest relative is the hop which is used to make beer and other ferments.

As we know, cannabis remains best known as a drug of recreational use and is



consumed by approximately 150 million people around the world each day. The recreational use is due to the creation of leaves, resin and oils of the Cannabis Sativa plant which has large amounts of the psychoactive form of cannabinoid THC (Tetrahydrocannabinol). It is cannabis rich in THC that causes the 'high' people commonly associate with the drug. However, the Indica plant produces a more fibrous compound that has no psychoactive effects and this was probably the first non-food crop grown by man with evidence of its use for fibers such as hemp rope and sacks dating back to 8,000 BC. This fibrous compound is rich in CBD (Cannabidiol) which as it turns out is the form that appears to be useful for treating convulsive disorders.

Over the last 50 years the alleviation of various ailments by the illegal use of certain cannabis formulations by patients around the world has led to a growing community of campaigners for more widespread and regularised use of medicinal cannabis. Amongst the most popular indications are for chemotherapy induced anorexia and chronic pain in cancer and multiple sclerosis. Of course there have also been reports of spectacular reversals in the treatment of epilepsy leading to a chorus of calls from patients, carers and parents for more thorough evaluation of the

drug for epilepsy and if proved useful, its legalisation.

In 1996, California became the first state in the US to legalise for medicinal use only. Now cannabis is legal in 23 states. In the UK, CBD, the version potentially useful for epilepsy has now been classified as a food supplement and can be bought openly in health food centers and on-line.

Growing Evidence for the efficacy of CBD in Epilepsy

While there have been a number of high profile stories in the popular media of improvements in severe refractory epilepsy going back to the 1990s, the first scientific reports did not appear until the early 2000s. In 2004 a telephone survey of patients in a Canadian tertiary epilepsy centre showed that 21% had used marijuana during past year. The majority reported positive effects on seizures while 24% believed marijuana was an effective treatment for their epilepsy. In 2007 there appeared a Case report of a 45-year-old man with cerebral palsy who had refractory partial seizures that demonstrated a significant reduction in seizures after marijuana use. In 2013 solicited data from an online Facebook survey of 150 families whose children were using cannabidiol (CBD)-enriched cannabis to treat drug resistant seizures, only received 19 responses (12.7%). 13 had Dravet's syndrome, 4 Doose syndrome, 1 Lennox-Gastaut syndrome, 1 idiopathic epilepsy: all were severe forms of epilepsy and the children had previously used an average of 12 AEDs. Overall, 84% noted decreased seizure frequency on CBD:

- 2 (11%) had complete remission
- 8 (42%) had >80% reduction in seizure frequency
- 6 (32%) had 25-60% reduction

CBD was associated with adverse events including drowsiness in 37% and fatigue in 16%. On the other hand, there were some side benefits including better mood in 79%, increased alertness in 74% and better sleep in 68%.

Despite studies like this in 2012, a literature review of clinical studies on CBD for epilepsy could not give a reliable conclusion about the effectiveness of cannabidiol. Yet in the 48 people included in these reports, no side severe effects were noted.

Then in 2013, all hell broke loose with the broadcast of Dr Sanjay Gupta's two-part documentary on cannabis on CNN use called 'Weed'. The series opens with a description of Charlotte Figi, a young girl from North America with Dravet's syndrome, a severe genetic form of epilepsy that is often resistant to anti-epileptic drugs and which puts most sufferers at risk of sudden unexpected death (SUDEP). Charlotte began to have seizures at the age of 3 months and by 3 years she was having more than 300 per month. She was wheelchair bound, fed by a tube and barely conscious, such were the doses of medication required. She spent 3 years in and out of intensive care units. Her parents, at their wits end, would try anything. They moved to Colorado having researched cannabis and were prescribed a high content CBD oil which had a sudden and dramatic effect on the seizures. The Figis noted that the amount of CBD in each preparation was important and they worked a local grower family, the Stanley brothers, to perfect the strain that worked best. This has become known as Charlotte's Web.

This and other stories like this have led to unprecedented cooperation in open-labeled studies in the U.S. of Epidiolex (a drug derived from CBD in the UK), which is produced by a local pharmaceutical company (GW Health). Epidiolex is a purified, 99% oil-based extract of CBD that is produced to give known and consistent amounts in each dose. The U.S. Food and Drug Administration (FDA) has given some epilepsy centres permission to use this drug as "compassionate use" for a limited number of people at each centre. Such studies are ongoing for difficult epilepsies such as Lennox-Gastaut syndrome (in children and adults) and Dravet syndrome in children.

Results from 213 people who received Epidiolex (99% CBD) in an open label study were presented at the American Academy of Neurology meeting in April 2015 in Washington DC. Data from 137 people who completed 12 weeks or more on the drug were used to look at how helpful or effective the drug was. People who received the Epidiolex ranged from 2 to 26 years old with an average age of 11. All had epilepsy that did not respond to currently available treatments. 18%

had Dravet Syndrome (DS) and 16% had Lennox-Gastaut Syndrome (LGS). The main findings of the study so far are:

- Seizures decreased by an average of 54% in 137 people who completed 12 weeks on Epidiolex and this was largely sustained for those who completed 24 weeks
- Patients who had DS responded more positively with a 63% decrease in seizures over 3 months.
- The responder rate (the number of people whose seizures decreased by at least 50%) was also slightly better in patients with DS (about 55% at 3 months) as compared to patients without DS (50%).
- People who were also taking the anti-seizure medication Clobazam (Frisium) seemed to respond more favorably to the Epidiolex with a greater improvement in convulsive seizures than in patients who were not taking Clobazam.
- 14 people withdrew from the study because the drug was not effective for them.

A controlled study on Epidiolex involving many epilepsy centres is now being done that will compare children with Dravet's syndrome or Lennox-Gastaut syndrome taking the active drug with children not receiving the drug.

Issues for the availability of CBD in Ireland

Under Irish law cannabis is not recognized as having any medical benefits. The most recent Misuse of Drugs (Designation) Order (S.I. No. 69/1998) lists cannabis, cannabis resin, and most of its derivatives as Schedule 1 drugs under the Misuse of Drugs Acts of 1977 and 1984. As a consequence, manufacture, production, preparation, sale, supply, distribution and possession of cannabis is unlawful for any purpose, except under license from the Minister of Health for the purposes of research. The availability of various formulations for use in cancer, MS and epilepsy has led to calls for a liberalisation of the law in relation to medicinal use. Currently Sativex, a drug containing a currently illegal derivative of cannabis (THC) specially licensed for Multiple Sclerosis is listed as an authorised medicine for this condition on the National Health products Regulatory Agency (HPRA) website. This formulation

however would likely make epileptic seizures worse.

The particular form of cannabis derivative, cannabidiol (CBD) that is proposed for epilepsy treatment is not specifically listed as controlled and so long as it is pure (uncontaminated with controlled substances) is not illegal but it is not currently authorised. However, it appears that an unauthorised medicine can be prescribed under Irish legislation which recognizes the possibility for registered doctors and dentists to access unauthorised medicines for patients under their care. This is addressed in the Medicinal Products (Control of Placing on the Market) Regulations, 2007, (SI No 540 of 2007) as amended.

"An unauthorized medicine is considered 'exempt' from authorisation when it is supplied to the order/prescription of a registered doctor or dentist for use by his individual patients on his direct responsibility in order to fulfill the special needs of those patients. The HPRA does not issue approvals for use of exempt medicines as they have not been assessed against the criteria of safety, quality and efficacy. Wholesalers and manufacturers based in Ireland are required to notify the HPRA when they are importing exempt medicines for the purposes of supply in Ireland. This permits the HPRA to track availability of exempt medicines and to assist in a recall if this is necessary. The wholesaler or manufacturer is required to have processes in place to capture and record any adverse reaction notified in relation to an exempt medicine and to report this to the HPRA. (www.HPRA.ie)"

The HPRA does not keep records of patients that are being treated with exempt medicines. The difficulty here is that practitioners are being asked to prescribe a medication that has not yet reached the usual level of scientific evidence of value and safety to patients who are desperate for a remedy.

Another difficulty is that exempt products need to be supplied through a legitimate supply chain, which means that manufacturers, wholesalers and brokers involved in the production and supply of the product must be authorised or registered as such. Our current understanding is that GW Health are the only authorised manufacturers, and their Epidiolex product appears to

be unavailable at present outside of the ongoing clinical trials.

Conclusion

The use of cannabis to treat epilepsy offers a tantalizing new horizon for severe disabling seizures. What differentiates this from other new drugs that have become available in the last few years for epilepsy is the long social and medicinal history of the drug going back over 150 years. There is an urgency created by the community of families with severe epilepsy to complete the proper, sober and reflective scientific evaluation of the efficacy and safety of this drug. Initial studies are encouraging but not definitive. Already it is possible to state with confidence that this drug will not work for everyone and will cause intolerable, but probably not dangerous, side effects in a few. But for those for whom it will work it may be lifesaving, given that the risk of death with severe intractable epilepsy may be as high as one in a hundred per year. I know personally a number of families who are sourcing the CBD rich oils online and importing them to get by the prescribing restrictions and possibly the wariness of prescribers.

The legal position regarding the prescribing of pure CBD oils needs clarifying. Currently, as long as a CBD derivative can be proven not to contain illegal elements and there is a proper overview of the risks of taking the drug, it appears that it can be prescribed. However, regulations around the supply chain as well as the currently unavailability of Epidiolex on an exempt product basis means it is virtually impossible for patients to access any form of CBD medication, whether the pharmaceutical product or the non-pharmaceutical 'oils'.

The long history of anecdotal use, the regular case reports and series in the scientific literature over the past 12 years and the most recent open label studies may be enough to convince prescribers that medically monitored trial of treatment for extremely resistant cases is not only reasonable but highly rational. Clearly, more information will come with the controlled trials but the question for the epilepsy community is whether there is a role for this drug now based on the data we have in advance of definitive trials.



This is the first in a series of articles by Kate, charting her personal journey from diagnosis through to epilepsy surgery

I was diagnosed with epilepsy aged five. I had had a convulsion at seven months of age due to a high temperature, and this doctors believed had caused the onset of my epilepsy. So epilepsy has been something I've lived with all my life. As a child I have clear, vivid memories of sitting in a dark, musty and gloomy doctor's waiting area. Upon entering his office, I wouldn't have a clue what was going on, however as an eight year old, I would endlessly gaze around me. Soaking it all up. Sitting up on the surgery bed, he would tap my knee and elbow joints.

He spoke very little, so as a young child, I used to wonder "What are you hitting me for? Ow!"

Nevertheless, growing up epilepsy affected me very little. I would have mild simple partial seizures 2-3 times per week. To some degree the seizures blurred into my life, because at such a young age you think it's just a "normal" feeling and that everyone feels it. Occasionally at this age, a seizure could cause me to be incontinent, which would feel quite embarrassing. One thing I hated though was white metallic tasting Tegretol being shovelled down my throat morning and night. It was being shovelled down as I would try my utmost as a young child to avoid it, thankfully my mother knowing better. During seizures I'd stare blankly and if I spoke, my words would come out mixed up. As I grew older, and my knowledge expanded, I became more aware of my seizures, primarily due to the aura I would feel prior to having one.

Seizures continued as such throughout my teenage years. Only my immediate family and two close friends were aware of it. Otherwise I remained private and silent about it. In the late eighties and mid-nineties, epilepsy had quite a stigma attached to it. I enjoyed my teenage years with great family and friends around me.

Yearly I would visit my neurologist who continued me on Tegretol. He would tell me that, most likely, by the age of 18 or 19 my epilepsy "will have fizzled out". Which can be the case for a lot of people, but unfortunately was not to be the case for me. His words released a false sense of hope and recovery within me. Reflecting back, I now realise, one must only live, minute by minute, hour by hour, day by day and seizure by seizure. We may not have control, but we do have strength.

I have always been a very strong and determined character, and never wanted to be defined by epilepsy. Within me however, epilepsy released an innate interest in the human body. So I applied to university after school and received a place in a general nursing degree course. In order to commence it, I had to undergo a medical. A fear grew within me though that they would refuse me entry into the course due to having epilepsy. Therefore I denied I had any epilepsy issues, ticking "no" to the epilepsy box. My spiral down into epileptic denial was to begin at this point. While I was disciplined with regards taking my medication every day and attending doctor's appointments, my denial came from a reluctance to accept being epileptic and having epilepsy.

UCD HOST EPILEPSY AND INTELLECTUAL DISABILITY

WORKSHOP FOR HEALTHCARE PROFESSIONALS AND FAMILIES



Epilepsy and Intellectual Disability

On Friday 15th July, the UCD Centre for Disability Studies will host a workshop entitled "Epilepsy and Intellectual Disability; Reducing risk, improving quality of life" for healthcare professionals and families.

The event is part of the Centre's series of events marking their 20th anniversary this year. The venue is the George Moore Auditorium in the UCD O'Brien Science

Centre on the Belfield campus.

Prof Mike Kerr, clinical professor at the Institute of Psychological Medicine and Clinical Neurosciences, Cardiff University will deliver the workshop. Prof Kerr is a world renowned expert in the field and among his many roles, he is Chair of the International League against Epilepsy's Intellectual Disabilities in Epilepsy Task Force.

In 2015, Prof Kerr's expertise in the epilepsies among people with intellectual disability was recognised by the International League against Epilepsy who awarded him the prestigious honour of 'Ambassador for Epilepsy'.

The workshop is aimed at a broad audience of those involved in supporting individuals with intellectual disability who have epilepsy. The workshop will comprise interactive discussion with attendees to understand the assessment of individuals with intellectual disability who have epilepsy, how epilepsy impacts on quality of life, the reduction of risk, and how to achieve best outcomes from treatment.

For further information and to register for this event (€40) visit:

 goo.gl/yHNuSg

REGIONAL EVENTS

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

Epilepsy Ireland Killarney Office
Wednesday 22nd June &
Wednesday 24th August
10.30am

Killarney: Parent support group

Epilepsy Ireland Killarney Office
Tuesday 28th June & Wednesday
7th September
10.30am

SOUTH EAST

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

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

Upcoming Events

Kilkenny: New Diagnosis Toolkit Group Session - For parents of children with epilepsy

Epilepsy Ireland Kilkenny Office
Thursday 22nd September
10.30am - 1.00pm

Places are limited and must be reserved by contacting Joan

Kilkenny: New Diagnosis Toolkit Group Session - For adults with epilepsy

Epilepsy Ireland Kilkenny Office
Thursday 29 September
10.30am - 1.00pm

Places are limited and must be reserved by contacting Joan

EAST

(Co's Dublin, Kildare, Wicklow)
Address: 249 Crumlin Road, Dublin 12. Tel: 01 4557500.

Ina Murphy, Community Resource Officer Epilepsy Ireland, Email: imurphy@epilepsy.ie

Office hours: Mon, Tue & Wed, 10am - 6pm; Thur 1.30pm - 6pm

Carina Fitzgerald Community Resource Officer cftzgerald@epilepsy.ie Office hours Mon, Tue & Wed, 9am - 5pm Thur 9am - 1pm

Upcoming Events

Kildare: Seminar for Parents of Children with Epilepsy & Professionals Caring for Children with Epilepsy

Keadeen Hotel, Newbridge, Co. Kildare
Tuesday 21st June, 2016
10.00am - 12.00pm

Topics Covered: Emergency Medication for Epilepsy; Information and Demonstration followed by Q & A Session with Epilepsy Paediatric Nurse

Session is free to attend but places must be reserved by phoning Ina or Carina

Dublin: New Diagnosis Toolkit Group session for Adults with Epilepsy

Carmelite Community Centre, Aungier Street, Dublin 2
Monday 4th July
6.00pm - 9.00pm

CORK

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

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

North Lee & North Cork: Loretta, Community resource Officer. email: lkennedy@epilepsy.ie. Office hours: Monday, Tuesday and Wednesday: 9-5 Friday: 9-1

MIDLANDS

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

Contact: Margaret Bassett, Community Resource Officer, The Charleville Centre, Church Avenue, Tullamore, Co Offaly. Tel: 057 9346790. Email: mbassett@epilepsy.ie. Office Hours: Mon, Tue, Wed & Fri 10am - 2.30pm; Thur 9am - 5pm.

MID-WEST

(Co's Limerick, Clare & North Tipperary)

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

Upcoming Events

Limerick: Group Toolkit Session

Limerick Education Centre, Dooradoyle.
Wednesday 8th June & Monday 8th August
Prior booking essential with CRO

Clare: Teachers and SNA Awareness Information Morning

Clare Education Centre
Wednesday 31st August
10.00 am - 11.00 am.
Contact Anna to reserve a place

Limerick: Teachers and SNAs Information Evening

Limerick Education Centre
Monday 5th September
4.15 pm - 5.15pm
Contact Anna to reserve a place

NORTH WEST

(Co's Donegal, Sligo & Leitrim)

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

Upcoming Events

Sligo: Women and Epilepsy

Clarion Hotel, Clarion Road, Sligo
Monday June 20th
11.30am to 1.30pm
Guest Speaker: Sinead Murphy, Clinical Nurse Specialist for Epilepsy, Msc. Epilepsy
Covering: Managing Epilepsy in Pregnancy; Effects of Medications; Sodium Valproate (Epilim) and women and the Need for Folic Acid
Places are limited so please book early

Sligo: Outreach Service

Epilepsy Ireland Sligo Office
Tuesday July 12th
11.00am - 12.30pm
Please call to make an appointment and to confirm your attendance

Donegal: Epilepsy Awareness and Administration of Buccal Midazolam

Station House Hotel, Letterkenny, Co. Donegal
Morning Session for Parents of Children with Epilepsy
Afternoon Session for Professionals working with Children with Epilepsy, including Creche and Pre-school Staff
Friday 8th July, 11am
Guest Speaker: Maria Keegan, Paediatric Neurology Clinical Nurse

Specialist, Our Lady's Children's Hospital Crumlin
Topics Covered: Epilepsy & Seizures explained; Recording Seizures; Medication Management; Administration of Buccal Midazolam and Educational and Behaviour Problems in Children with epilepsy
Places must be booked in advance.
To Book a place and confirm your attendance please contact Agnes

WEST

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

Upcoming Events

Mayo: Maximising Memory Information Session

Harlequin Hotel, Castlebar
Monday, 27th June
5.30am - 7.30pm

Roscommon: Epilepsy Support Group - -- Managing Stress & Anxieties

Abbey Hotel, Roscommon Town
Monday, July 4th 2016
5.30pm - 7.30 pm

NORTH EAST

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

Upcoming Events

Dundalk: Coffee Morning
Tuesday, 21st June
10am - 12pm
Venue: Dundalk offices. Contact Noreen for further details.

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

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

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

Benefits of Membership

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

MEMBERSHIP FORM



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

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

Membership Type

Renewal ☐ New ☐

Membership Category

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

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

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

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

Voluntary Donation

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

☐ €7.30 ☐ €20 ☐ €30 ☐ €50 ☐ €100

☐ own amount €_____ Total Enclosed €_____

Payment Method

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

Name of Person with Epilepsy Please use block capitals

Title _____ Name _____

Address _____

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

E-mail _____ Date of Birth _____

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

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

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

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

Card Payments

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

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

Name on Card _____

Card Number _____ Expiry Date (mm/yy) _____ CV 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 _____



NATIONAL CONFERENCE 2016



What's New In Epilepsy Care: Latest Developments for Adults and Children with Epilepsy

Friday October 7th **5.00 pm - 7.00pm** | Saturday October 8th **10.30am - 4.00pm**
Alexander Hotel, Fenian Street, Dublin 2

Introduction to Latest Developments in Epilepsy

Prof. Norman Delanty *Consultant Neurologist, Director, Epilepsy Programme, Beaumont Hospital*

Surgery, Devices and VNS Treatment

Mr. Gavin Quigley *Consultant Neurosurgeon, The Royal Victoria Hospital, Belfast*

Genomics - a New Era in Epilepsy Diagnosis and Treatment

Dr. David Goldstein *Director of Institute for Genomic Medicine, Columbia University, New York*

When One Becomes Two - AED's, Pregnancy and Epilepsy

Dr. John Paul Leach *Consultant Neurologist, Southern General Hospital & Hon. Associate Prof, Glasgow University*

Cannabis Treatment - Is it working for Epilepsy?

Dr. Colin Doherty *Consultant Neurologist, St. James Street Hospital*

Current Services and Developments in Epilepsy Ireland

Mr. Peter Murphy *CEO, Epilepsy Ireland*

The Importance of EEG in Management of Children with Epilepsy

Dr. Amre Shahwan *Consultant Clinical Neurophysiologist & Epileptologist, Temple St. Children's University Hospital*

Understanding the Ketogenic Diet for Children with Epilepsy

Ms. Eimear Forbes *Senior Paediatric Dietitian, Temple Street Children's University Hospital*

Medical Q&A for Parents of Children with Epilepsy

Ms. Maria Keegan *Paediatric Neurology Clinical Nurse Specialist, OLCHC & Ms. Yvonne Owen Epilepsy Transition Nurse Co-ordinator*

Understanding Cognition and Memory in Epilepsy - What can help?

Dr. Andrea Higgins *Senior Neuropsychologist, Bloomfield Hospital and Health Services, Dublin*

Managing Lifestyle, Stress and Epilepsy

Dr. Niall Pender *Principal Clinical Neuropsychologist, Dept. of Psychology, Beaumont Hospital*

Medical Q&A for Adults with Epilepsy

Ms. Sinead Murphy *Clinical Nurse Specialist, Beaumont Hospital and Epilepsy Ireland & Ms. Máire White Clinical Nurse Specialist in Epilepsy, Beaumont Hospital*

CONFERENCE FEE INCLUDES:

Full attendance at conference on
Friday 7th 5.00pm - 7.00pm &
Saturday 8th 10.30am - 4.00pm
with refreshments, lunch and
conference pack

BOOKINGS

To book please visit
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