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National Conference 2015
Keynote Speakers:
Prof Joan K Austin; Dr Sophia Varadkar; Dr Helena Moore
Another busy year draws to a close and Christmas is here once again. Following numerous requests we are again including the top tips to stay safe and maintain a seizure free Christmas holiday (page 6 - 7). The festive season can be often tinged with sadness as we remember those we have lost and this year we lost one of epilepsy's greatest champions Hanneke De Boer. Mike Glynn pays fitting tribute to this wonderful epilepsy ambassador, while Training For Success students pay tribute to this wonderful epilepsy ambassador, while Training For Success students pay tribute to the great pal they have tragically lost (page 4 - 5). On a happier note, our story in this issue is from Eoghan Magennety who has overcome many a challenge to share with us his tale of triumph (page 10). We trust that this Christmas edition will provide much reading with plenty of food for thought over the holiday season. We would like to take the opportunity to say thanks you to all the volunteers, supporters and members around the country, your dedication and generosity is much appreciated.
Galway entrepreneur invents safety device for epilepsy

EpiSafe is a new epilepsy monitor and alarm system invented by Galway entrepreneur Audrey Holland. The device is worn on the wrist and gathers data related to the user’s blood oxygen level, heart pulse rate and movement to determine the factors that trigger a seizure. The device will then send an alarm to notify selected individuals or services if a seizure occurs. Audrey came up with the idea after her brother Trevor died from a seizure last year. The invention was one of the top ten finalists at the Irish Student Entrepreneur awards in 2015. The next step for Audrey is to seek funding to develop a prototype and conduct trials.

http://goo.gl/NL7t5b

RCSI findings on microRNA biomarker

New findings from researchers at the RCSI on the role of biomarker molecules known as microRNAs in epilepsy could be hugely significant. Dr Elaine Spain and colleagues, working with Prof Delanty’s team at Beaumont hospital have reported a rapid and simple method of detecting microRNA in the blood. If developed further, this could lead to a simple point-of-care device for detecting epilepsy biomarkers, a move that could potentially transform the diagnosis and treatment journey for many people with epilepsy. Meanwhile Dr Christina Ruedell Reschke and colleagues have found that neonatal seizures increase levels of microRNAs in the brain and that this is associated with a reduction of a protein responsible for controlling the growth of neurons. Blocking microRNA activity in the brain was found to reduce the development of epilepsy in experimental models, a finding that opens new avenues of understanding the impact of neonatal seizures and new treatment options.

http://goo.gl/1KSqlq

Whooping cough linked to epilepsy risk

A Danish study published in the Journal of the American Medical Association highlights that whooping cough (pertussis) may be linked to a slightly increased risk for young children to develop epilepsy. 4,700 Danish children with whooping cough were studied and compared against matched children from the general population. By the age of 10, epilepsy was diagnosed in 1.7% of children in the whooping cough group and 0.9% of those in the general population. Only children diagnosed with whooping cough before the age of three were at increased epilepsy risk. The link had previously been unknown and the study does not establish any cause and effect.

http://goo.gl/uovg3r

Long term outcomes following childhood-onset epilepsy

An interesting 45-year study of 179 individuals with childhood-onset epilepsy has just been published in Epilepsia, attempting to answer one of the most common questions parents have about their child’s epilepsy: “Will my child always have epilepsy”. The good news is that the study indicates patients’ long-term health is excellent, with over 60% attaining 10-year remission and over 40% were in remission without being on medications, which is the definition of resolved epilepsy. However, the follow-up EEG and imaging at age 50 also found that participants often have abnormal neurologic signs including markers of cerebrovascular disease that may be a risk factor for stroke and cognitive impairment as they age.

http://goo.gl/c5eVIX

Mindfulness-based therapy improves wellbeing, reduces seizures

A new Hong Kong study published in Neurology has found that short-term mindfulness-based therapy significantly improves quality of life in patients with drug-resistant epilepsy. 60 adult patients took part in the study, randomly assigned to a mindfulness group or to a group who received ‘social support’. Quality of life measures in both groups increased after the study but more patients in the mindfulness group had clinically important improvements (37% v. 13%). The mindfulness group also exhibited a greater reduction in seizure frequency and anxiety, and a greater improvement in verbal memory scores.

http://goo.gl/9Qp71J

Texting-induced seizures

Doctors attending the Irish Neurological Association annual meeting heard a case report on texting-induced reading epilepsy in a young Irish male. It is only the second such case recorded worldwide. Reading epilepsy usually starts in the teenage years and involves brief jerks (myoclonic seizures) around the jaw and mouth triggered by reading either aloud or silently. The jerks can lead to tonic-clonic seizures. It was suggested that using picture characters (emojis) instead of written words might be useful for those who experience texting-induced epilepsy.

The genetics of SUDEP

Researchers from the UK Epilepsy Society and University College London have discovered that an individual’s genetic make-up may contribute to the risk of sudden unexpected death in epilepsy (SUDEP). The researchers conducted genetic sequencing of 1,479 non-epilepsy controls, 18 people who died of SUDEP and 87 living people with epilepsy. They identified rare variants within the DNA and found an overrepresentation of particular variants in people who had died of SUDEP. The discovery hints at how the genetic make-up of a person with epilepsy might contribute to a person’s individual risk of SUDEP and may even open the door to personalising the prevention of SUDEP in the future.


http://goo.gl/9Qp71J

http://goo.gl/VgrwWh

http://goo.gl/105sZf
HANNEKE DE BOER, RIP - A PERSONAL APPRECIATION

Hanneke de Boer who was known by many as “the mother of epilepsy” died in October aged 69. Hanneke had had a long battle with cancer which she refused to give in to and had been working up until very recently.

I first met Hanneke more than twenty years ago. She was a key figure in the preparations for the 22nd International Epilepsy Congress held in Dublin in 1997. One of the key features of the Dublin congress was the launch of the Global Campaign against Epilepsy (GCAE) when the World Health Organization came together with the International Bureau for Epilepsy (IBE) and the International League against Epilepsy (ILAE) in a united front to tackle the global issues that epilepsy faced. Hanneke had just come to the end of her presidency of IBE at that time following many years during which she had held all the key positions on the Executive Committee of IBE and had also been the editor of International Epilepsy News, IBE’s newsletter, for many years. Dr. Ted Reynolds was the prime mover in getting the GCAE under way but Hanneke was involved from the very start of the Global Campaign and continued to work on it right up until her death. Without her guiding presence the GCAE would not have continued and the benefits of the campaign continue to be felt in countries such as Brazil and China and in many other countries through Africa, Asia and Latin America. This year saw the major step of the WHO’s Resolution on epilepsy which has the capacity to improve care in all countries of the world, not just poorer countries. Without the GCAE and without Hanneke de Boer, it is most unlikely that this could have happened.

Hanneke began working as an employment consultant at Stichting Epilepsie Instellingen Nederland (SEIN) as far back as 1965. Although she went up through the ranks at SEIN over the years, she never lost her interest in and passion for helping people with epilepsy with their employment problems. She worked at SEIN all her life (although she didn’t like it when we joked that she had always been inSEIN). In theory Hanneke retired a few years ago but she was back at her desk the following Monday and she continued to work up until a few weeks before she became too ill to continue.

Hanneke’s name is legendary in epilepsy circles and she has a huge number of publications to her credit – just google “Hanneke de Boer” to find them. In 2007 Epilepsy Ireland invited Hanneke back to Ireland to celebrate ten years of the Global Campaign and Hanneke charmed everybody at the event in the Mansion House with her presence. Hanneke could converse with anyone at any level and did so at every opportunity. She had been decorated by the Queen of her native Netherlands just a few years ago and had had many meetings with top politicians in different countries all around the world but Hanneke would happily sit down anywhere with a parent of a child with epilepsy or with somebody who had epilepsy themselves and offer any help she could to them.

Hanneke always arrived for meetings laden with gifts of Dutch cheese, wine, tulip bulbs or chocolate. She could work until well into the night but she always insisted on either eating or having a glass of wine afterwards no matter how late it was. She loved Ireland and used every opportunity to get over here and Epilepsy Ireland was very close to her heart.

I am sure that a great many people with epilepsy or working in the Epilepsy Community around the world will deeply miss this wonderful person who achieved so much for so many persons with epilepsy and their families and caregivers but who was also such a warm person and a friend to many.

Mike Glynn, Epilepsy Ireland CEO

NICOLA HEHIR RIP – A TRIBUTE FORM HER CLASS MATES

Kind, loyal, generous, competitive and loving - these are some qualities that spring to mind when fellow Training For Success students think of Nicola Hehir. Nicola, who died recently is remembered here by two students who were particularly close to her.

We were fellow classmates and soon became close friends. Nicola was sports crazy and was one of the most competitive people I know and her independence was admirable. She was a tomboy at heart, always competing against the men in all the sports we played - football, pool, basketball, badminton, golf, you name it.

Nicola loved all the latest gadgets, phones, laptops, tablets you name it. Nicola had it. She was also one of the biggest animal lovers having three dogs (Toby, Boris and Bonnie) that she absolutely adored.

Nicola was great at making friends wherever she went because she had a great personality that everybody loved.
She was extremely loyal and loving, always wanting to help you and everyone in the class. If you had a problem she would be at your side in a heartbeat ready to help in any way possible. Even after the course finished Nicola would always keep in touch to make sure you were fine and support you in whatever direction you were heading in your life.

After Training For Success she decided to stay and do another course in IT Sligo again gaining more friends and trying to expand her knowledge and progress through life living it to the full.

Nicola decided to move to New Ross where she joined a local rugby team; she was also studying and working part time. She was fantastic with children, she adored them and they adored her.

Nicola was always taking care of her neighbours and she loved visiting a family in Sligo that she loved with all her heart. Kindness and love were two of Nicola’s qualities that she used in abundance because she loved to see happiness wherever she was.

We have so many happy memories. Nicola was taken far too early and is dearly missed by many. Those we love don’t go away, they walk beside us every day. Unseen, unheard but always near, so loved, so missed, so very dear. As Nicola's favourite team’s motto goes “You’ll never walk alone”.

*A rdeis Dé go raibh a h-anam.*

*Natasha Brogan and Colm O’Connor*
Epilepsy Ireland’s 12 Top Tips.

Christmas can be a hectic, exciting and stressful time for everyone and people with epilepsy are no exception. Every year at the beginning of January Epilepsy Ireland receive calls from people who have had seizures over the Christmas period. For some it will have been the first ever episode and they will be concerned about whether they may go on to become diagnosed with epilepsy in the event of a subsequent seizure. For most though it will mean a recurrence of seizures within the context of diagnosed epilepsy. Often in discussing the events leading up to the seizure, it can emerge that a range of trigger factors may have been at play to reduce the person’s seizure threshold. With this in mind we are highlighting some ways of reducing the risk of breakthrough seizures over Christmas and trying to address some of the questions people ask.

1. **Start early and plan ahead**
   
   Last minute rushing around in the run up to Christmas is the norm for many people but can be very stressful for someone with epilepsy. You can reduce the stress factor by being organised and breaking the tasks up into manageable pieces that can be spread out over time. Keep lists and try to focus on doing a certain amount each week, whatever is feasible. Shopping online is increasingly popular and can help reduce the need to rush around the shops. This should mean you don’t have to overdo it at any point and give you free time to enjoy the atmosphere without the pressure.

2. **Transport and Travel**
   
   If you are unable to drive currently this may affect how and where you shop. You may have been used to going about doing all the shopping for gifts and trimmings before. Now you may need to consider whether to seek help with lifts from others or whether you can actually manage to get the groceries, gifts and the Christmas tree in one outing. Consider your energy levels and pace yourself. Public transport can be in great demand at this busy time so try to avoid rush hour in order to get a seat. Be realistic about what you can undertake and if someone offers to get something for you consider accepting the offer. Whatever makes life easier and less stressful is welcome. Shopping locally or online again can reduce the transport demands.

3. **Skipping meals**
   
   It might be tempting to pass by when you see long queues at restaurants when out and about but don’t be tempted to skip meals. During the holidays our patterns can alter so it’s good to ensure you get to keep to a regular pattern of eating.

4. **Sleep Debt**
   
   Regular sleep patterns are important for people with epilepsy. Over the holidays these can change due to the late night festivities or morning lie-ins. If you are planning a late night try to ensure you are well rested prior to going out and take your medication as normal. If possible have some extra sleep the following day also. This will reduce your sleep debt (the amount of missed sleep you owe yourself).

5. **Take your medication as normal**
   
   Ensure you have sufficient supplies of your prescription to last through the holidays.

6. **Relaxation**
   
   Take a few minutes of quiet time each morning and evening to listen to a guided visualization, soothing music or do meditation – whatever method works for you to unwind and take a break from the cares of the day.

7. **Alcohol**
   
   Whether at parties or in the home, everyone is potentially more exposed to alcohol over Christmas. Your doctor may have advised you on what is a safe limit for you. Stick to this advice, keep your intake moderate (typically 1-2 units) and avoid binge drinking. Don’t be afraid to say no to another one. If your friends have your interests at heart they won’t force the issue or encourage you to drink more than is safe for you. Consider having shandies instead or non-alcoholic beers and wines as options. Remember you don’t have to “keep up” with everyone else to enjoy yourself. You have the right to choose not to put yourself at risk.

8. **Other Stimulants and street drugs**
   
   Whether we are talking about high caffeine energy drinks or any kind of street drugs, these are all associated with increasing seizures and must be avoided.
Christmas lights and New Year Firework Displays

While flashing light is a trigger for a small number of people with photosensitive epilepsy the Christmas lights sold in stores here, should all meet the required health and safety standards for flicker. Risk factors for photosensitive epilepsy are flicker from 5-20 flashes per second (hertz) glare and strong contrast, and saturated reds. Christmas lights circuits should flicker at about 1 hertz (flash per second). However, there have been a few anecdotal reports of people who feel they were affected by faulty lighting. Also if several circuits are combined a photosensitive effect could be generated. If it is not possible to avoid the lighting the simple measure of covering one eye with one hand should be sufficient to prevent a seizure on exposure to the flashing lights. Firework displays are live events and it is difficult to predict the flash rates they might generate. These displays are often held in darkness and the contrast can enhance the dangers of the photosensitive effect. Again the measure of covering one eye with one hand is advised (closing the eyes is not effective as light can penetrate the skin of the eyelids).

Excitement

Particularly for the children the anticipation of Christmas can cause huge excitement which although it seems like fun is felt by the body in a similar way to a stress reaction. Keeping the atmosphere as calm as possible and maintaining a regular routine can help manage the excitement levels which sometimes lead to sleep problems.

Family Support (or lack of it)

Christmas is a time when many people expect to spend more time than usual with family and this can have both its joys and downsides. If your family is supportive that is a great bonus but if they have difficulties accepting epilepsy it can place a strain on relationships. If you lack a supportive family or network of friends this can leave you feeling isolated at a time of great emotional expectation. Consider in advance how you will obtain support to help you through the holidays whether through talking to your GP, Epilepsy Ireland, joining a support group, getting referred to counseling, or calling a telephone helpline like the Samaritans. Don't be afraid to ask for the help you need to cope.

Expectations

Keep your expectations for Christmas realistic. If you hope for perfection the likelihood is you will be disappointed at least some of that time. There is a huge emotional investment we can make in wanting Christmas to be a certain way and the reality may be less than perfect. If we can be flexible around this we can accept that the images we see in TV and advertising are idealised and that the rest of us live in the real world we will be taking a healthier approach. If we could be content with a "good enough" Christmas we might actually be able to relax and enjoy it more.

Epilepsy Ireland wish everyone a happy and safe Christmas.

This year's National Conference- “Embracing Epilepsy” was held in the Malton Hotel, Killarney on October 3rd. The central theme of the conference was to address current issues for adults, parents and families.

Videos of the keynote speakers' presentations are available to view online.

Dr Helena Moore, Consultant Neurologist, Bons Secours Hospital, Tralee who covered Current Issues for Adults with Epilepsy.

https://youtu.be/v56aQ_KwQyg

Prof Joan K Austin, Distinguished Professor Emerita, Indiana University School of Nursing who spoke on Epilepsy and the Family: learning from research with parents, families and children.

https://youtu.be/3SQ_HISP900

Dr Sophia Varadkar, Consultant Paediatric Neurologist, Great Ormond St Hospital, London whose presentation covered Epilepsy and the Adolescent.

https://youtu.be/0UWBWC3x6NM

All of the presentations were followed by a lively question and answer session and the busy day concluded with the usual very popular workshop feature. All of the workshops were very well attended. Epilepsy Ireland would like to thank all the speakers for their invaluable input, the various exhibitors and sponsors for their support of the conference.
Epilepsy Ireland is one of 16 charities partnering with the Royal College of Surgeons in Ireland on a new phone app called RCSI MyHealth.

The app offers easy access to credible health information, allowing users to discreetly search for information relating to specific health conditions. It also provides users with information on where to seek advice and support if they are living with a health condition.

With almost 90% of adults in Ireland having access to an online device, the number of people turning to mobile devices to manage their lives is soaring. Recent research conducted by Aviva found that one in 20 searches using Google was for health-related information and that 81% of Irish adults had gone online seeking to self-diagnose. The study also found that 46% of those who had self-diagnosed using online information had reported increased stress or worry as a result of their search, which can often draw up the worst-case scenario for medical symptoms.

RCSI MyHealth aims to relieve these worries. The app has four easy to use features which provides users with access to information about more than 800 specific health conditions, including epilepsy. It also provides a very helpful list of health services in Ireland ranging from emergency contact numbers to support organisations and hospital details. It also carries the latest health news, calculates your BMI and links to important services like the Irish Blood Transfusion Service.

Professor Cathal Kelly, RCSI Chief executive / Registrar said “Recognising signs and symptoms of disease is a very effective method of reducing morbidity and mortality. However when looking for health information, it is important for patients to seek information from a credible source. This app is useful for patients looking for health information and also for health professionals who are looking to provide supplementary information to patients on specific health conditions.”

RCSI MyHealth is available free of charge in the Apple App Store and in Google Play.

Watch this video to find out more:
https://youtu.be/sgxywFDLFrw

With funding from Epilepsy Ireland and the Irish Research Council, Dr Sinead Heavin (pictured) and colleagues at the RCSI are conducting a study to look at the genetic profile of patients who are taking the anti-epileptic drug, Levetiracetam (brand name Keppra). The team are currently recruiting people with epilepsy to take part in the study.

People with epilepsy respond differently to anti-epileptic medication. As yet, there is no way of predicting who will respond well to medication and who won’t.

The goal of the study is to identify genetic factors that might be useful in helping to predict which patients will respond well to particular treatments. In this way, treatment for epilepsy could be more personalised and precise in future.

The researchers would like to speak to people who are seizure-free while taking Keppra. Taking part is very straightforward and involves nothing more than providing a blood sample. Patients attending any hospital/ neurology team or under the care of their GP can volunteer.

If this is you, the team would love to hear from you! To find out more, please contact Sinead Heavin, at 01-4022102 or email sineadheavin@rcsi.ie.

Find out more about the study:
http://goo.gl/8fM7J9
International SUDEP Awareness Day took place on October 23rd. Some of the key awareness messages highlighted on the day are presented below.

For the full infographic, go to [http://goo.gl/bvyPw6](http://goo.gl/bvyPw6)

**SUDEP stands for SUDDEN UNEXPECTED DEATH in EPILEPSY**

It is when a person with epilepsy dies suddenly and prematurely and no other cause of death is found.

The best way to lower risks of SUDEP is by achieving seizure freedom.

**RISK FACTORS INCLUDE**

- Having Tonic Clonic seizures (sometimes called Grand-Mal or convulsive)
- Having seizures at night or seizures when asleep
- Not taking medication regularly and as prescribed
- Having had epilepsy for a long time (often starting in early childhood)
- You don’t have to be having frequent seizures to be at risk from SUDEP. Even if your seizures are controlled you should still take your medication & have a regular medical review
- It is important to speak with your health professional to understand your individual level of risk

**TAKE POSITIVE ACTION**

- **BE AWARE** of epilepsy risks – they don’t have to be scary
  - Knowledge & advice can help you put steps in place to help you stay safe
- **BE OPEN** about your epilepsy and your level of risk – talk to others about it
- **BE PROACTIVE** don’t ignore your risks, instead put positive steps in place e.g.:
  - Having regular medical reviews – discussing risk & any changes
  - Creating a care plan with your health professionals to show the best ways to help you stay safe
  - Self-monitoring your epilepsy in-between reviews
  - Use tools like seizure diaries, medication reminders & risk monitoring apps to help you stay aware and in control

For further information on how you can be aware of SUDEP, risk factors and steps you can take, visit: [www.sudepawarenessday.org](http://www.sudepawarenessday.org)

Since they were launched in October 2012 Epilepsy Ireland’s Online Support Groups have proven very effective in bringing people together to talk, share experiences and exchange information. The service is completely confidential, non-judgemental and offers practical support from other service users.

Each session is facilitated by one or more members of the Epilepsy Ireland service staff team. Days and times are changed weekly to ensure that everyone who wants to take part has an opportunity to do so. The scheduled sessions include a number of themed sessions.

To take part, you must register for the service and accept the Terms of Service and support group ground rules. Once you’ve registered, we’ll email you every time that a new group is set up and send a reminder on the morning of the group. Details will also be posted on our Facebook page.

Contact us at info@epilepsy.ie if you have any queries about the online support groups.

If you would like us to send you text reminders please send your mobile number to osg@epilepsy.ie

All the dates and times are regularly updated on epilepsy.ie

**January**
- 12th January, 7pm, Parents Support Group
- 19th January, 7pm, General Support Group
- 27th January, 11am, Parents Support Group

**February**
- 2nd February, 7pm, General Support Group
- 9th February, 7pm, General Support Group
- 16th February, 7pm, Parents Support Group
My mother Agnes Mooney will be very well known to many members of Epilepsy Ireland, particularly in the North West region as she is Epilepsy Ireland’s Community Resource Officer covering Donegal, Sligo and Leitrim.

I was diagnosed with epilepsy at nine years of age, and like so many others I have experienced my own share of difficulties over the years. My epilepsy was not well controlled, and after trying out numerous different anti-epileptic drugs, my neurologist decided that surgery might be an option. I went through a lot of tests before having the surgery in Beaumont in 1992, aged 15 years.

It took a few years before I noticed any improvements, and now I am doing a lot better. Up until two years ago, I was experiencing a lot of side effects, and I was not able to do much exercise, and my diet was not healthy. However after talking to a neuropsychologist and making a decision to buy an electric bicycle, I started cycling, walking and eating a healthier diet. This has resulted in a better quality of life for me. My seizures are better controlled, and I even find I sleep better and I don’t notice the side effects as much as before. I am now in a “good place” as my story reveals.

I am the first and only administrative person responsible for photocopying in Errigal College. I got the job initially through Doreen Henry, a Job Coach in the North West Supported Employment Partnership Programme. I started on the 15th of October 2001 and fourteen years later I am still here.

From 1996 to 1999 I attended and completed a computer course in the Sligo N.T.D.I. This course included advanced word processing; data base; spreadsheets and advanced computerised accounts.

In Errigal College I am known as “The Expert Photocopier”. When staff need photocopying in a hurry they ask me and it’s done right away; that’s why they often call me ‘a star’! As well as photocopying I also do set binding, paper shredding, laminating and word processing. Any staff member or students who need advice or help with these tasks, I am the first person they come to. I also maintain the photocopier on an ongoing basis.

I am a very enthusiastic photographer and I cover all school events including the staff parties. I started photography as a hobby encouraged by my dad Fergal who is a professional photographer.

Why do I love this job so much? It gives me the opportunity to get up early each morning and leave the house. I walk or sometimes cycle to work and I socialise with the staff. Working in Errigal College gives me a good quality of life. I exercise physically. I feel needed and wanted by the staff. It’s nice to be able to help as much as I can. I’m very lucky I got this part time job. I do get holidays but during the summer when students are on their holiday, I work in the Donegal E.T.B. Administration Office with Frankie Quinn. I’m very proud to be here for over thirteen years, saying goodbye to retiring teachers and hello to new teachers. I hope I am still here when it comes to my retirement, still a few years down the road.

My mum, Agnes Mooney, says that this job is a life saver for me. It gives me something to do each day and I am learning new skills all the time. I have lived with intractable epilepsy since I was ten years old, and it is not easy for people with disabilities to get work, so this job is even more important to me.

I would like to say a big thank you to all those people who throughout the years have been there to offer their support and encouragement.

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Intractable Epilepsy

About one-third of people with epilepsy will eventually develop intractable epilepsy.

Intractable epilepsy is a seizure disorder in which a patient’s seizures fail to come under control with treatment. These seizures are sometimes also called “uncontrolled” or “refractory.”

Frequently intractable epilepsy can interfere considerably with a person’s quality of life. People who are not seizure-free also need to be careful about possible accidents during a seizure.

People with intractable epilepsy may have trouble at school, i.e. not being able to attend school and the ongoing implications of possible interruption to their education. There may also be difficulties with employment, getting a job in the first place and then being able to continue in work if seizures become more frequent.
Hi I’m Noreen.

I was 59 when epilepsy first came into my life. At first I did not recognise it as such, as perhaps like many other people, I had preconceived ideas of what epilepsy was. My first episode was when driving from Limerick to my home in Nenagh. I saw this magic sale sign and like many other ladies had to go and investigate! Luckily I did as having parked the car, next thing I found myself lying in the middle of the road not knowing how I got there – I didn’t remember falling. After a rest I got in the car and drove home 20 miles – it’s amazing what you do when you don’t know any better! After a bit of pressure I went to the doctor and had some heart checks which all came back clear. A couple of weeks later I was driving to Dublin on the motorway and knew I was in trouble, luckily my husband was with me and got the steering wheel – it was time to get back to the doctor again – this time I was referred to my Neurologist. I still didn’t believe I had epilepsy as just falling down; feeling sleepy after etc didn’t fit into my idea of epilepsy. I needed to have it spelled out to me by the professionals.

When I had my EEG I was told I had photosensitive epilepsy and boy do I know it! The flash photography, the Christmas lights, the sun shining through the trees, leaving weddings early etc... sometimes a great excuse for an early escape. But I live my great life around it – it does not control my life.

All my family and friends know about it and that is right for me. Maybe it isn’t right for everyone but I found by telling my family and friends and being open about it that I got great support. It also gave me a great sense of freedom about it and put me in control. I also think that talking about it helps educate other people about epilepsy. I am involved in Water Safety and have opportunities from time to time to talk to people about this and they see that I can get on with life, give courses and it does not hold me back. I went through a stage where my confidence took a knock and before I would give a course I would get a bit anxious and worry that I would clam up half way through. During the Epilepsy Ireland STEPS programme I brought this up and one of my dear colleagues there said “the next time just ask yourself ‘what’s the worst thing that can happen”. She really put me back on track.

It is 11 years since epilepsy came into my life – I am seizure free now – taking my medication every day and avoiding the situations likely to bring on a seizure. I still feel very vulnerable in a flash photography situation and at Christmas time with all the flashing lights and of course the cinema is a long distant memory – but life is good.

Calling all keen photographers!

The international Bureau for Epilepsy (IBE) has announced a competition to coincide with International Epilepsy Day 2016 which will take place on Monday, 8th February next year.

The theme of the competition is "Yes I Can" and entries are welcomed which support this theme in terms of showing achievement in overcoming barriers and also achievement in the face of barriers.

The best photos from the competition will be chosen to form the International Epilepsy Day Exhibition which will run in the European Parliament in Strasbourg on the week prior from Monday 1st to Friday 5th February.

All entries will be place in a gallery on the website of the International Bureau for Epilepsy http://www.epilepsy.org

Entries will be accepted in two categories
1. Photos taken with smartphones or tablets
2. Photos taken with regular cameras

The winning entry in each category is $1000 USD

Closing deadline for entries is 10th January 2016 and all entries must be submitted electronically.

For full details http://bit.ly/1MYApAT
Christmas Cards
Please support Epilepsy Ireland and raise epilepsy awareness by sending our new Christmas cards this festive season. All proceeds from our cards go to maintaining our support services. A box of 12 with 6 different designs costs just €10 including postage. Order online at epilepsy.ie or call us at 01 4557500.

Epilepsy Ireland calendar 2016
Epilepsy Ireland and The Dublin Photography School have teamed up once again to produce the 2016 EI charity calendar. The stunning images featured are the winners of the nationwide ‘Home & Away’ travel photography competition. At just €10 including postage, the calendar makes an ideal stocking filler this Christmas. So order your 2016 calendar today from epilepsy.ie or call us at 01 4557500. Our thanks to the Dublin Photography School for supporting Epilepsy Ireland once again this year!

Saddle Up for Epilepsy
The 2nd annual Saddle Up for Epilepsy leisure cycle takes place in Castlebar, Co Mayo on Saturday February 27th 2016. Join us for Ireland’s only epilepsy awareness cycle raising funds to support Epilepsy Ireland’s services in the west. See the back cover for details and register online at www.saddleupforepilepsy.com.

Rose Week 2016
Rose Week 2016 will take place in the run up to Valentine’s Day. As ever, the success of the annual rose appeal relies on volunteers around the country selling pins and flowers (on streets, in businesses and in shopping centres) to raise money for Epilepsy Ireland’s work. If you are in a position to volunteer for a few hours in early February, please give us a call on 01 4557500 or email us at fundraising@epilepsy.ie.

Annual raffle raises over €19,000
A massive thank you to all our members and volunteers who bought and sold raffle tickets for the annual All-Cash raffle. Over 6,000 tickets were sold and your outstanding support this year has raised over €19,000!

Pictured right, Epilepsy Ireland’s Peter Murphy draws the winning tickets, witnessed by Stephen Bradley, solicitor. Congratulations to all the winners: M. Graham (£2,000), A. Timmins (£1,000), G. Nash (£500) and Seller’s prize winner, C. Graham (£250).
A Marathon Effort

Thank you to Geraldine Lynch (pictured on the right with EI’s Niamh Jones) who raised an outstanding €6,319 in just ten weeks this summer by organising the Toonsbridge 10 Walk Challenge, a series of walks around stunning West Cork, all for Epilepsy Ireland.

Irish Tree Centre supports epilepsy

The Irish Tree Centre in Kildorrery, Co Cork celebrated its 20th anniversary in style this August, hosting a spectacular open day that raised €2,257 for Epilepsy Ireland. The event was a huge success with hundreds of people and families from all over Cork and beyond enjoying great music, food and chat. A big thank you to Peadar Collins and family for their amazing support. Peadar is pictured below left, with Epilepsy Ireland’s Bernard Hughes at the open day.

Gala Ball in Cork for Epilepsy Ireland

Thanks to everyone who attended the Gala Ball for Epilepsy Ireland in the Montenotte Hotel, Cork on 28th November. We also want to thank the Lord Mayor of Cork, Cllr Chris O’Leary for his support. But most of all we want to thank Annette, Stephanie, Ciara and all the Murphy family who organised the whole evening and made sure everyone had a great night! All the funds raised will support our services in Cork.

Walking for Epilepsy

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The Bearded Irishman

In December 2014 I was with work colleagues in New York where we attended a dinner and were served by a super-efficient waiter who happened to have a bald head and a substantial jet black beard. I had one thing in common with him, I sport a bald head too! A very persistent friend and colleague, Drew, was sitting beside me and was at me all evening: ‘Joey, that’s a great look that guy has… you’d look great with one of them’. I wasn’t taking the bait as despite the current beard trend, I had not been a fan of facial hair and was always clean shaven… until Drew rolled the dice.

“Ok” he said, “what if I raise €10,000 for a charity of your choice, would you grow a beard for a year?” He had finally succeeded in getting my full attention. Money talks! We compromised on me growing the beard from St Patrick’s Day to my big birthday (50th!) on November 19th. Drew started taking pledges there and then and within two days he had almost €5,000 raised. I knew at that point he would keep his side of the deal and I was now fully committed to mine.

It was an easy decision to raise the money for Epilepsy Ireland as my godson, Ross, had his first seizures almost three years ago at the age of 10. He has coped brilliantly during a difficult time. Finding the right medication however is not always straightforward, particularly for a growing boy. That was something I had not appreciated when he was first diagnosed. Epilepsy Ireland funds a number of research projects each year, some of which focus on identifying the right drug for a particular patient. More research in this area is needed to help kids like Ross find medication that works more quickly, reducing the anxiety and uncertainty surrounding seizure frequency and improving their quality of life.

In the past nine months, thanks to the inspiring idea by Drew and the incredible generosity of colleagues, friends and family, we have raised over €16,000 for Epilepsy Ireland’s research. Ross and I are overwhelmed by the support… sincere thanks to all! You can support Joey’s beard initiative by clicking www.mycharity.ie/event/joey_odea_event/
**REGIONAL EVENTS**

**EAST REGION**

(Co’s Dublin, Kildare, Wicklow)
Contact: Ina Murphy, Community Resource Officer, Epilepsy Ireland, 249 Crumlin Road, Dublin 12. Tel: 01 4557500. Email: irmurphy@epilepsy.ie. Office Hours: Mon, Tue & Wed, 10am - 6pm; Thur 1.30pm - 6pm.

**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 January 20th
Wednesday February 24th
10.30am

**Killarney:** Support group for parents of children with epilepsy
Killarney office
Wednesday February 3rd
10.30am

**MID-WEST REGION**

(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: 9am - 4.30pm; Wed & Thur 8am – 1pm.

**Upcoming Events**

**Limerick:** STEPS Self-Management Programme
Kilmurry Lodge, Hotel Limerick
Satudays January 9th, 16th, 23rd, & 30th & February 6th

**Clare:** Teachers afternoon
Clare Education Centre, Government Buildings, Kilrush Road, Ennis.
Monday January 11th
4.00pm – 5.00pm

**Limerick:** Group Workshops
Education Centre, Marshal House, Dooradoyle Road, Limerick
Wednesday January 20th
Wednesday March 2nd
10.15am – 12.30pm

Group limited to 15 places so early booking is essential

**Kilmurry:** STEPS Self-Management Programme for Parents
Kilmurry Lodge Hotel, Limerick
Monday February 8th
International Epilepsy Day

Time 2.30pm – 4.30pm

Ennis: Outreach Service
Citizens Information Centre – Ennis
Wednesday March 9th
Brain Awareness Week
9.30am - 4.30pm

Outreach is by appointment only please contact Anna to make an appointment

**WESTERN REGION**

(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 – 4.00pm; Friday 9.00am - 1.00pm

**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**

**Letterkenny:** STEPS Self-Management Programme for Adults with epilepsy
Station House Hotel, Letterkenny Tuesdays: January 12th, 19th, & 23rd and February 2nd, 9th & 16th
10.00am – 1.00pm
Places are limited, to book a place please contact Agnes

**Donegal:** Epilepsy Awareness Presentation for Schools
St Patricks Girls National School, Carradonagh, Co Donegal
Monday January 18th
3.00pm - 4.00pm
This event is open to all schools in the Inishowen area; places are limited and must be booked in advance, please contact Agnes

**Sligo:** Epilepsy for Everyone.
St Michaels Family Life Centre, Church Hill, Sligo
Monday February 8th
International Epilepsy Day
11.00am to 12.30pm
Guest Speakers: Epilepsy Nurses: Geraldine O’Rourke, Cara Conway. This event is open to all people with epilepsy, their families, carers, and health professionals working with people with epilepsy

**Sligo:** Outreach Service
Epilepsy Ireland Office, Castle House, Castle Street, Sligo
Monday February 8th
Wednesday March 23rd
2pm to 4pm.

Outreach is by appointment only; please call Agnes to confirm your attendance

**Letterkenny:** Health & Wellness Morning.
Venue: to be confirmed.
March 2016
11.00am - 12.30pm.
Time for Wellness, a joint event with the MS Society, in Letterkenny

**MIDLANDS**

(Co’s Offaly, Laois, Westmeath & Longford)
Contact: Margaret Bassett, Community Resource Officer, Epilepsy Ireland, c/o Care Association, Market Square, Tullamore, Co. Offaly. Tel: 057 9346790. Email: mbassett@epilepsy.ie. Office Hours: Mon, Tue & Wed 10am - 2.30pm, Thur 9am - 5pm.

**Upcoming Events**

**Tullamore:** Launch of International Epilepsy Day by Senator John Whelan
Tullamore Court Hotel
Monday February 8th
12 noon
Call Midlands regional office to book a place

**Tullamore:** Epilepsy and Safety Seminar
Clonamore House, Arden Rd
Tullamore
Wednesday March 9th
7.00pm
Admission free but early booking essential

**Tullamore:** STEPS Self-Management Programme for Parents
Venue: to be confirmed
Tuesday 26th April - One evening per week for 4 weeks
Booking is essential as places are limited

**Check out Regional News on www.epilepsy.ie for all local events**
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).

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

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 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

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 ______________________
Charity Cycle supporting Epilepsy Ireland

SADDLE UP FOR EPILEPSY

Saturday, 27th February 2016
@ Breaffy Sports Arena, Castlebar, Co. Mayo
62km & 128km

OUR PARTNERS

OUR SPONSORS

www.saddleupforepilepsy.com