



# Epilepsy News

Shining a light on epilepsy

Epilepsy Ireland Issue 79 Winter 2017



Epilepsy Ireland recognises its outstanding volunteers

## IN THIS ISSUE:

- Sodium valproate latest news
- Seizure the Day Premiere
- SUDEP awareness and communication
- Transitioning to adult services



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## NOTE FROM THE EDITOR

Conor Culkin



Well there goes another hectic year for Epilepsy Ireland! Christmas is a time for reflection and in this winter issue of Epilepsy News we look back on a busy three months since the autumn issue. Our front cover features two incredible women whose campaigning and fundraising has left an indelible mark on 2017 and many previous years. Both Brenda Quigg and Karen Keely are covered on page 4 having received volunteer of the year awards at our National Conference in Sligo. It's been a hugely significant few months for the sodium valproate campaign which is analysed on the following page.

Epilepsy Ireland is always open to partnering with other charities as we showed with our I See Beyond campaign and in this issue we feature a film premiere which involved a collaboration with Helium Arts throughout 2017. The day and the entire project was extremely rewarding for all involved in the film which is featured on page 6.

Teenage years can be extremely testing for a young person with epilepsy and Epilepsy Transition Nurse Yvonne Owen begins a new series on page 7 with some helpful tips and advice. On page 8 we focus on SUDEP awareness and communication with results from our recent survey and a new personal story from up and coming actress Eva-Jayne Gaffney features on the following page.

Epilepsy Ireland also never forgets our fantastic fundraisers who are as always featured on page 10 and we also preview all the ways you can help raise money in 2018. Our 'Out and About' section on page 12 features images from our National Conference and Quiz which were both great opportunities to meet our supporters in the epilepsy community.

As 2017 comes to end we would like to take this opportunity to say a huge thank you to all our members and volunteers across the country who continue to make our work possible, your dedication is not forgotten.

*Have a peaceful Christmas and Happy New Year from all at Epilepsy Ireland.*

## TFS GRADUATION



*Students and staff at the recent Training For Success graduation in IT Sligo. Back row L-R: Chris O'Brien, Alex Griffen, Thomas Byrne, Sean Scanlon, Jack Markham. Front row staff L-R: Maire Tansy Course Facilitator, Honor Broderick Course Manager, Dr Jennifer Van Aswegen.*



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CHY Number: 6170



Design and layout by  
PlipSpace.com

Printed by Doggett Print & Design

## Epilepsy Ireland Research Funding Call



Epilepsy Ireland is delighted to launch our sixth Research Funding Scheme call and we are currently inviting applications for epilepsy-focused research projects of up to three-year duration to a maximum of €50,000 p.a.

Epilepsy Ireland is committed to supporting Irish epilepsy research and since 2009, over €900,000 has been invested in a wide range of high quality projects, many in conjunction with the Health Research Board under the HRB/MRCG Joint Funding Scheme.

For this round of funding, we are inviting applications that cover one or more of the following important research areas: AEDs & Pregnancy/ Foetal Anti-Convulsant Syndrome; Epilepsy & Intellectual Disability; Evaluating epilepsy services in Ireland (including Epilepsy Ireland services); Medicinal Cannabis & Epilepsy; Psychosocial aspects of epilepsy; Rare epilepsies and SUDEP/ Epilepsy mortality. The review process for applications will take place in early 2018 to ensure that only the highest quality proposals are funded. Successful projects will begin in September 2018.

[GO https://goo.gl/MBs7TD](https://goo.gl/MBs7TD)

## Largest ever collection of families' epilepsy

Researchers from Swansea University Medical School have teamed up with five other centres from around the world, including The Royal College of Surgeons in Ireland, to collect the largest recorded collection of families with forms of epilepsy where genetics may be a factor in the condition.

The goal was to decide if specific clinical epilepsy features aggregate within families and whether this may constitute distinct family syndromes that could inform on subsequent genetic research.

According to News-Medical.Net: "Clinical analysis of the 303 families revealed that

families had a range of epilepsies that were the same by diagnosis but also had mixed forms of epilepsy. In addition, some familial epilepsies, that were regarded as rare, are more common than had been appreciated. Also by having well-characterized families this will help in the search for epilepsy genes – a search which is underway at the Columbia University Institute of Genomic Medicine."

[GO https://goo.gl/LYo86d](https://goo.gl/LYo86d)

## Patient Survey of outpatient neurology services

The Neurological Alliance of Ireland (NAI), the umbrella representing over 30 patient organisations, in partnership with the National Clinical Programme in Neurology, has launched the first ever patient experience survey of outpatient neurology services in Ireland.

This survey represents an important opportunity for people with neurological conditions and their families to share their experiences of neurology services in order to identify areas of the service that can be improved over time. Epilepsy Ireland members and service users are invited to take part. The closing date for completing the survey is December 15th 2017.

[GO https://goo.gl/udPm9W](https://goo.gl/udPm9W)

## Budget 2018: Main points for disability and health



There were a number of significant measures in Budget 2018 which were announced by Minister For Finance, Paschal Donohoe

### Income and Social Welfare Payments

- Increase in Disability Payments of €5/week
- Increased funding for the Free Travel Scheme (specific details to be released)
- Christmas bonus for all social welfare recipients to be paid out at 85%

### Education

- 10 NEPS psychologists will be recruited in 2018

- 100 extra teachers for implementing the new special education teaching model

### Health

- Prescription charge for those on the medical card reduced to €2 per item, and the maximum charge to be €20 per month
- Monthly threshold for drug payment scheme reduced from €144 to €134
- 1,800 front-line health service personnel to be recruited across the acute, mental health, disability, primary and community care sectors

Epilepsy Ireland also welcomes a VAT refund scheme for charities that will be introduced after last October's Budget. This will allow charities to reclaim a portion of their VAT costs based on the level of non-public funding they receive.

[GO https://goo.gl/K8A7bS](https://goo.gl/K8A7bS)

## Medical Cannabis Bill moves to Committee stage

The Dáil has voted to allow the Cannabis for Medicinal Use Regulation Bill to proceed to Committee Stage, the next stage of the legislative process. Following another impassioned debate in the Dail chamber in early November, the Government chose not to oppose the passage of Deputy Gino Kenny's Bill, while recognising that it contains a number of significant flaws and 'unintended consequences' such as potentially legalising cannabis for recreational use. The Oireachtas Health Committee had previously advised against continuing with the Bill, and it is now widely accepted that significant amendments, and potentially redrafting will be needed at Committee stage.

Meanwhile, the Minister's expert reference group is finalising clinical guidelines for prescribing cannabis for medicinal purposes, which are expected in the near future. The expert group was established earlier this year following the HPRA's report on medical cannabis with the aim of establishing an access programme for medical cannabis. Epilepsy Ireland has provided feedback to the Group on their draft guidelines earlier in the summer. The Minister is also planning to introduce secondary legislation in December to give a legal basis for the proposed access programme.

[GO https://goo.gl/o5U62r](https://goo.gl/o5U62r)

# EPILEPSY IRELAND RECOGNISES TWO OUTSTANDING

## VOLUNTEERS AT NATIONAL CONFERENCE



**Brenda receiving her award.**



**Karen pictured with Epilepsy Ireland CEO, Peter Murphy.**

and continued to be prescribed valproate throughout her three pregnancies and all three of her sons – Harry, Lee and Lorcan have been affected by FACS.

The consequences of sodium valproate have dominated her life. Her sons have all had repeated medical, surgical and clinical interventions and two require lifelong care. Despite all the difficulties and challenges that this has brought, and the battles she's endured, Karen has for the past decade devoted herself to raising awareness among other Irish women with epilepsy of the risks of valproate. Additionally, she fights for recognition and justice for the families affected.

She has set up the Irish branch of OACS, Organisation for Anti-Convulsant Syndrome. She brought about the formation of the FACS Forum, a group of organisations including Epilepsy Ireland who have come together to help deliver on Karen's campaigning. She is a true epilepsy advocate who never gives up, not just for her own boys, but for all the mothers and children who are similarly affected or are at risk. Her passion and determination has brought this issue to an international focus.

**You can see more images from the National Conference on page 12 and you can also watch a selection of the presentations on the Epilepsy Ireland website via the URL below.**

<https://goo.gl/Th7bHJ>

**At the 2017 National Conference in the Clayton Hotel, Sligo last September, Epilepsy Ireland recognised two special volunteers.**

### Brenda Quigg

The first recipient was Brenda Quigg (pictured above), from Balla Co. Mayo. Epilepsy first crossed Brenda's path about eight years ago but she didn't recognise the early symptoms and it was only after her first tonic clonic seizure that she was diagnosed.

The diagnosis had a huge impact on her life and she was confronted by the realisation that awareness of epilepsy and health services for people with epilepsy in the community are not always ideal. However, Brenda's positive outlook soon shone through and she decided to take action.

One morning in late 2014 she woke up with an idea – to organise a cycle for epilepsy. Within just a few months after much hard work, over 250 cyclists took to the start line in Castlebar on a cold February morning to mark International Epilepsy Day. The event raised a fantastic €15,000 and there wasn't a person in Mayo who didn't know about it. In 2016, the event was back again with over 400 people taking part from all over the country and an incredible €35,000 was raised which helped Epilepsy Ireland expand our service in the West, particularly with self-management

programmes like STEPS. In 2017 the event increased to over 500 cyclists and in excess of €33,000 was raised.

### Karen Keely

Karen Keely (pictured above), was diagnosed with epilepsy as a child and put on the drug sodium valproate (Epilim) to treat her seizures. Today we know that it should not be taken by women of childbearing age because of the risks to the foetus in the womb. This is now known as Foetal Valproate or Foetal Anti Convulsant Syndrome (FACS). However, Karen was never fully advised of the risks



**A full house attended the National Conference.**

# ENCOURAGING PROGRESS FOR SODIUM VALPROATE CAMPAIGN



**Karen Keely pictured before her speech to the European Medicines Agency in London.**

Last September Karen Keely of the FACS Forum and OACS Ireland addressed the European Medicines Agency (EMA) public hearing on sodium valproate in London. The hearing was investigating whether 2014 European-wide measures to restrict the use of valproate (often known by the brand name Epilim) in girls and women of childbearing potential have been effective and whether additional measures to reduce risks associated with the drug are needed. The drug is associated with significantly increased risks of physical and developmental disabilities in children exposed to it in the womb.

Karen's speech received national and international media attention and led to a report on RTE's Prime Time which also featured Epilepsy Ireland CEO, Peter Murphy and parent Susan Dolan.

At the EMA hearing, Karen emotionally revealed her story: "Behind all statistics are real human stories and mine is that I am the mother of three adult children – Harry, Lee and Lorcan – who have all been affected by exposure to valproate. We are living evidence of the risks and the devastating impact of this drug. Two of my three boys require lifelong care and will never be able to have a normal life. They will never be able to get married. Never be able to have children. They have been robbed of all the joys of life. The effects of sodium valproate have been unbearable."

## Key demands

The FACS Forum is an umbrella group of charities including Epilepsy Ireland who have come together to campaign on this issue. Karen highlighted to EMA the FACS Forum's key demands on what now needs to happen in Ireland and across Europe to reduce valproate related risks:

- All existing and new risk-reduction measures must be outcome-driven and measurable. Ticking a box is never enough.
- The use of Valproate information resources should be mandatory and evidenced. A signed Checklist should be recorded for all women of childbearing potential on the drug, including those under GP care.
- There needs to be nationally maintained registers for women prescribed with valproate and children already affected
- National implementation groups, including patients and patient organisations, must be established to oversee

implementation of existing and new measures.

- There needs to be properly resourced public awareness campaigns to ensure that all women taking the drug are aware of risks.
- Brand names as well as generic names should be used on all patient-focused information.
- Warnings must be displayed on external packaging and medication should not be dispensed without the original internal and external packaging.
- There should be a greater role for pharmacists in identifying women at risk and reporting back to the prescriber.
- The Forum is not currently calling for any actions to be taken to restrict access to valproate, which is still a very effective drug and for some women, the only drug that will control their seizures.

In October, Karen and Peter attended a follow up meeting at EMA with where future safety measures were discussed in more detail with key stakeholders from around Europe. EMA will shortly announce new measures, which we hope will reflect all the points above.

## Political demands

Following recent media coverage, many more affected families have come forward. Some were present in the Dail this month when Louise O'Reilly TD urged the Government to undertake an investigation into the current and historical use of sodium valproate during a recent Leaders Questions sitting.

"The women concerned have had to fight for every single element of treatment for their children. They have had to fight and scrap hard and want to hear that the Tánaiste, the Government and the Dáil are on their side... There is a black mark on the history of the State in that regard, as the Tánaiste has acknowledged. We have an opportunity to do this the right way and I urge the Government to take it", she said.

In response Frances Fitzgerald, the Tánaiste said: "A review is under way and it is expected that a decision will be made by the end of the year by the European Medicines Agency on whether there should be further warnings about the drug being given to women who are pregnant or girls. This is a European as well as an Irish issue. I have no doubt that the Minister for Health will take the results of the review fully into account when making a decision on the management of this issue, as will the HPRA."

## Next steps

The FACS Forum has requested to meet with the Minister for Health on a number of occasions over the past year to discuss not only risk reduction but also catering for the health needs of children already affected. However, a meeting has not yet materialised. At the time of writing, a meeting has been organised with senior Department of Health officials, as well as with a number of TDs and Senators. After the EMA announce their new safety measures, Epilepsy Ireland and the Forum will also meet with the Health Product Regularly Authority (HPRA) to discuss the next steps in Ireland.

**For the latest news, including updates on the EMA's imminent safety guidelines, follow Epilepsy Ireland's website ([www.epilepsy.ie](http://www.epilepsy.ie)) and our social media channels. If you are a woman taking valproate or the parent of a girl on the drug and have any concerns, please contact your healthcare team or call us at 01- 4557500 or your local EI office.**

# SEIZURE THE DAY PREMIERS AT THE IRISH FILM INSTITUTE



**L-R Fíachra Byrne, Participant Leader; Wendy Crampton, Deputy CEO Epilepsy Ireland; Emma Eager, Project Manager, Helium Arts; Participants Sean McGarry, Shannon Keane, Art Oakes; Maria Carty-Mole, Participant Leader; Participants Ciarán Gubbins and Bobby Dolan; Siobhán Clancy, lead artist; Participant Leah Crowley. Photo credit: Thom McDermott.**

'Seizure the Day', a short fictional film created by young people with epilepsy and inspired by their experiences, recently had its premiere at the Irish Film Institute (IFI) in Dublin. As mentioned in the previous issue of Epilepsy News 'Seizure the Day' was written, filmed and acted by the young people during a national filmmaking project in 2017, led by Epilepsy Ireland and Helium Arts, the national children's arts and health organisation.

Over 60 people attended the screening, including participants and their families, Community Resource Officers and volunteer participant leaders from Epilepsy Ireland who supported the wellbeing of the young people during the project, artists and filmmakers from Helium Arts who mentored the young people, funders, healthcare professionals and supporters. There was a terrific atmosphere and it was wonderful to hear from participants at the reception afterwards about what it meant to them to see their work on the big screen.

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***"Absolutely fabulous! So many familiar names and faces. Really awe-inspiring!"***

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

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The screening included a behind the scenes documentary, following the young people's journey from regional workshops in Galway, Sligo, Dublin and Cork where themes and ideas were developed through to the film camp at the Irish Museum of Modern Art. During the Q&A, we heard from participants Lucy Prevo and Shannon Keane about what it was like to make the film. Audience members remarked on how the film brought to the surface the emotions and feelings of teenagers with epilepsy when trying to communicate their experiences to others. Following the screening, further insights were shared during participant and parent workshops.



***An engaged audience in the IFI.***

On the day Lucy Prevo spoke about what it meant to be involved in the film during the Q&A: "I hope that you enjoyed the film as much as we did making it! It was the most wonderful and educational experience. Epilepsy is usually viewed as an obstacle when it comes to creative outlets such as filmmaking and all that it entails. However, we, as a team, proved that wrong. So much effort was put into this film and the experience that this workshop gave us was incredible. Being able to work behind and in front of the camera was amazing.

The film project was principally funded by Qualcomm and we were delighted to welcome John and Faye Finnerty on the day. Many thanks to the Arts Council, the Hospital Saturday Fund and the Cork Foundation who provided additional funding; the Irish Museum of Modern Art for the use of their beautiful venue and facilities during film camp and to all the venues and cafes across the country who supported the regional workshops.

**Get inspired! Watch the film and documentary on the Epilepsy Ireland YouTube page.**



***Participants Lucy Prevo (left) and Shannon Keane take part in the Q&A at the IFI. Photo credit: Thom McDermott.***

**Epilepsy Ireland Transition Nurse Yvonne Owen starts a new series of articles giving advice to young people with epilepsy as they move into adulthood.**



Moving from paediatric to adult services can be a daunting prospect for some people. It may mean having to repeat your story all over again to complete strangers and getting to know lots of new names, faces and places. But you may also feel that you are ready for a move. You may feel like you have outgrown the paediatric services and

your needs are better suited to an adult setting. 'Transition' is what we in healthcare call the process of moving from paediatric to adult services. So how can you get ready for your transition? In future issues of Epilepsy News I will explore different aspects of transition and provide young people and their families with helpful tips on how to prepare for adult services.

Firstly we will discuss self-advocacy. This means the ability to speak up for yourself about things that matter to you. As a child your parents have been your advocate - asking questions and making decisions on your behalf. As you get older the responsibility shifts from your parents to you and you may start to make your own decisions about your health. Your parents can still support you but it is important that you begin to take ownership and get more involved in independently managing your epilepsy.

## **How can you build self-advocacy and independence skills?**

**Start early** – it's never too early. No matter what your age you can get involved. As you become a teenager / young adult you should gradually take on more responsibility so that by the time you reach 18 you are nearer to being your own advocate.

**Practice** - for some people this may come naturally but for others it may take time to be comfortable with the changes of responsibility. Lots of practice will help you gain the confidence and skills you need to become more independent in managing your condition.

**Learn about your epilepsy** – knowing the facts and understanding about your epilepsy can help you make informed decisions about your own health. You can ask your doctor or nurse to explain it to you. Alternatively, you can contact your local Epilepsy Ireland office or go on-line to find out more. Wherever you go make sure it's a reputable source of information. There is lots of information out there that is inaccurate and can lead to even more confusion.



**Know your medications** - Find out the names of doses and side effects of your medication. Practice getting your own tablets organised. Get a pill dispenser from your chemist and organise your medication into morning and evening time doses. This can help you to not forget doses. Find out how to get a prescription or more supplies if you need them.

**Ask and answer questions** - Instead of taking a back seat and listening to others talking about you start getting involved. Have a list of questions ready before you come to clinic. Often people forget to ask the questions or run out of time. Talk to your parents beforehand as they may have some of the answers already. Practice answering questions - if you don't know the answer that's okay, your parents may be able to help you out. You are not expected to know everything.

**Spend some time alone** - Spending time alone with the doctor or nurse at the clinic gives you a chance to speak up for yourself and practice being more independent. It may only be for a few minutes to begin with but over time you can increase the time you spend alone in clinic. Some clinics will encourage you to do this but if not don't be afraid to ask.

**Know your rights** - Once you are 16 you can attend a doctor/nurse on your own. You might like to talk to your team on your own about concerns or worries that are private and confidential. If your team feel it is something that your family should hear about they will discuss this with you and try to help you with talking to them about your concerns or worries.

**Making appointments** – try to practice ringing the secretary to arrange or reschedule your own appointments. Keep a diary or calendar to remind you of when you need to come to clinic.

**Know where to get help** - find out where to get more information or help to support you. Know the names of your epilepsy team and who to contact if you have an issue with your epilepsy. Epilepsy Ireland can advise you on what supports are available to you so you can get on with your life.

**If you want to find out more about transition you can speak to me directly. The Epilepsy Ireland Transition Advice line is available Monday afternoons 2-5pm on (01) 4554133.**

# AWARENESS AND COMMUNICATION OF

## SUDDEN UNEXPECTED DEATH IN EPILEPSY

Epilepsy Ireland was pleased to support SUDEP Action Day (October 23rd), an annual event aimed at raising awareness of Sudden Unexpected Death in Epilepsy (SUDEP). As part of the day Epilepsy Ireland launched a survey to find out more about awareness of SUDEP among people with epilepsy and about communications between them and their healthcare team about SUDEP.

SUDEP is defined as "sudden unexpected, witnessed or unwitnessed, non-traumatic and non-drowning death in an individual with epilepsy, with or without evidence of a seizure and excluding documented status epilepticus where post-mortem examination does not reveal a cause for death". Based on international data, we estimate that there are at least 40 cases of SUDEP in Ireland each year.

Our survey ran online from October 23rd to November 9th and 323 people with epilepsy took part.

57% of people said that they had an understanding of SUDEP prior to taking the survey while 43% said they did not. Of those that did not, the vast majority (86%) said that they would have liked to have been made aware of SUDEP. The preferred communicator about SUDEP for this group was the neurologist (50%) and a third of people would have liked the discussion to have happened with their Epilepsy Specialist Nurse (ESN). A minority of people wanted to hear about it from their GP or from Epilepsy Ireland.

### Awareness at diagnosis

Of people who were not aware of SUDEP, over half (53%) said they would have liked to have been told about it at diagnosis. Of those who did not want to be made aware of SUDEP (14%), the most common reasons given were anxiety and perceived lack of control.

In the group of people who were aware of SUDEP before the survey, 58% said that they were never told about it by a medical professional but had read about it or found out online. 24% had found out from a neurologist, 21% from an ESN, 9% from Epilepsy Ireland and 6% from a GP. People were told about it at different stages, although it was less common to be told at diagnosis compared to within the first year or after that. Of those who were told by a

professional, there were equal numbers who were satisfied and unsatisfied with the information and how it was conveyed. Only 15% of respondents received information to take away with them. It was also notable how many people had first come across SUDEP due to a family member's death.

### Behaviour changes

55% of respondents stated that being made aware of SUDEP had influenced their behaviour and perceptions of managing epilepsy. While some people commented that their behaviour had changed in a positive way e.g. taking medications on time, using anti-smother pillows, getting sleep etc, other people referred to the stress and mental health effects that knowledge of SUDEP had brought on.

We also asked people who were aware of SUDEP to look back and say who they would have preferred to have been the first person to raise SUDEP with them. 55% of people wanted this to be their neurologist, 29% said the ESN, while others included Epilepsy Ireland, the GP and family members. 54% said that they would have liked to know at the point of diagnosis, while only 14% said that they would have preferred not to know about it for at least a year after diagnosis (see bar chart).

Of all respondents, just 1% felt that it was not important for medical professionals to discuss SUDEP with people who have epilepsy. 13% felt that it was an important point to discuss but only with people at high risk, while 81% felt that it was an important point to discuss with people whether they were at high or low risk (see bar chart).

### Conclusions

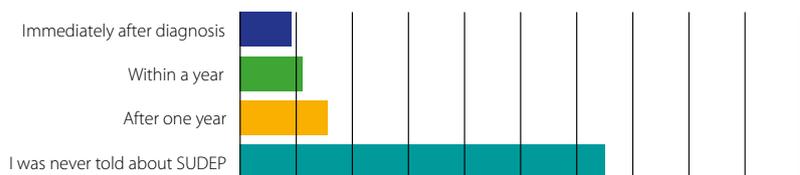
These details are headline figures only and over the coming months we hope to analyse the data in more detail to see if there are any significant differences in people's attitudes and preferences depending on their gender, age, seizure type or seizure frequency. However, there is much to learn even from the basic data.

Over 40% of people, even those in contact with Epilepsy Ireland and hospital teams are not aware of SUDEP, yet there is an overwhelming preference for being told about it by medical teams, particularly neurologists, either at the point of diagnosis or soon afterwards. There is also very strong support for communication on SUDEP with all people with epilepsy, whether at high or low risk. These findings challenge many traditionally held beliefs that people do not want to know about SUDEP or that it can have a negative impact to discuss it. While some respondents do feel this way, it seems that attitudes towards SUDEP may have changed over time.

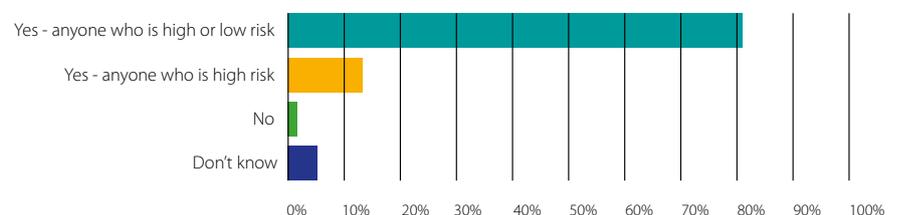
Currently, many people are finding out about SUDEP in unstructured ways through their own research and we need to ask if this is desirable, or if more efforts need to be made to proactively discuss SUDEP in one-to-one community and hospital settings where concerns can be addressed promptly by an expert.

We hope that this survey can help kickstart a new conversation in Ireland about how to communicate SUDEP and improve SUDEP knowledge among people with epilepsy.

### When following diagnosis were you first told about SUDEP?



### In general, do you think it's important for a medical professional to discuss SUDEP with people who have epilepsy?





***Eva-Jayne Gaffney is an actress whose star is rising after appearances in the multi-award winning *Sing Street* as well as *Red Rock* and *Can't Cope Won't Cope*. Almost one year ago she had a tonic-clonic seizure and has been learning to live with epilepsy ever since.***

I had a tonic-clonic seizure on the morning of December 27th, 2016, I had never experienced any seizures before this so it came as a shock to myself and the people close to me. In the months leading up to this first seizure, I had been feeling very strange. I was convinced that I was having slight panic attacks due to the anxiety of Christmas coming up, I did not realise that this was the beginning of something much bigger. I was getting an overwhelming feeling of discomfort in my whole body, unsure what was real. I got strong feelings of déjà-vu and smells that weren't actually there. I later learned that the "strange feelings" I was having were actually simple focal seizures.

It's been great to speak to other people with epilepsy about this as it has made me feel less alone. I didn't think anyone would understand, but they do. It is essential to speak about things that make you feel scared, worried or upset. I still have simple focal seizures quite regularly, the way I cope with them is to breathe deeply and try to fight any thoughts of fear. I repeat in my head "this will pass". It seems to work for me.

## Temporal Lobe Epilepsy

Although my seizures started at the end of December last year, I was not diagnosed with Temporal Lobe Epilepsy until May of this year when I had three tonic-clonic seizures within a couple of hours. Like a lot of people, my EEG and MRI did not show up any classic signs of epilepsy so it took a long time to diagnose the condition. Following my diagnosis I was not myself at all, the seizures had affected my memory and moods quite intensely and I was advised to take two months away from work. Having to take time off was difficult and frustrating as I really enjoy my job. It is challenging to spend days upon days at home, I began to feel left out as I couldn't do the things I would usually do. I wasn't able to go out with friends regularly, firstly because I was still in a lot of pain and secondly because I could not afford to. I am happy to be back working full time now but I do have to take extra good care of myself. I cannot do the strenuous hours I would have done before my seizures started. If I overdo it, I am guaranteed to begin having simple focal seizures within 24 hours.

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***"Having to take time off was difficult and frustrating as I really enjoy my job."***

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## Friends and family

Living with epilepsy is challenging, it is a challenge for those who have the condition but it's also a challenge for their friends and family. I have a wonderful support system around me, my family and friends are very understanding and do not get angry if I cancel plans or don't feel up for the day that lies ahead. However, when I was first diagnosed, some people



***Eva-Jayne in 'Sing Street'***

weren't so understanding. I have fallen out of touch with friends who weren't prepared to help out when the seizures began to strike. Everyone is different, but for myself I have to make my social circle as easy going as possible. Due to my diagnosis of Temporal Lobe Epilepsy, my emotions are heightened and I am overwhelmed by difficult or upsetting situations. The more of those situations I can avoid, the better!

I have been on Lamictal for 6 months now and it seems to be doing the job. I recently had my 6 month check up this week, my doctor has also been a fantastic help throughout this journey. I am confident that he has my best interest at heart. If you are ever having problems with a doctor, I would suggest a change. It's vital to feel comfortable in the hands of the person who is looking after a medical condition you have.

## Epilepsy Ireland's help

This Christmas will mark one year since epilepsy became part of my life, I have learnt a lot about myself and this condition in the last year. The support that Epilepsy Ireland gives is incredible. I attended an Innerwise seminar last month and I thoroughly enjoyed it. It is reassuring to know that my symptoms don't only belong to me. This past year has been testing but I have found a sense of pride in myself that I did not have before, I hope others have found this too.

**In the next issue of *Epilepsy News* we feature a heartfelt personal story from Mark Earley who lost his wife after she tragically suffered a fatal seizure.**

## Swimming for Epilepsy Ireland



Massive thanks to Catherine Kennedy who swam two miles in open water in the Serpentine Lake in London and raised €1,153.19.

## Barcelona to Valencia Cycle



A massive thanks to the Dublin Chamber for the funds received of €5,525.90, for the Barcelona to Valencia Cycle. The Dublin chamber raises funds for two charities including Epilepsy Ireland and we would like to thank them for their support.

## Christmas Cards



Please support our Christmas card appeal and support the work of Epilepsy Ireland. Pack of 12 cards can be purchased from our website or call us on 01 4557500.

## All Cash Mega Raffle



Thanks to everyone who bought and sold our raffle tickets in our All Cash Mega Draw. We have raised over €20,000 and congrats to the winners and runners up. Picture above with the winning ticket is Epilepsy Ireland, CEO Peter Murphy who made the draw on November 10th.

**1st Prize** of €2000 - M. McGrath, Tipperary,  
**2nd Prize** of €1000 - P. McEvoy, Kerry,  
**3rd Prize** of €500 - S. Culloty, Kerry.

## Hell and Back Challenge



A heartfelt thanks to Cyril Hennessy who took part in the Hell and Back challenge and raised over €500. Cyril took part in memory of his brother Kyle who passed away last Christmas and who had epilepsy. Taheera Lunat also took part in the Hell and Back Challenge and raised over €360.

## In memory



So far an outstanding €26,923.04 has been raised by Mark Deasy and their family and friends. Mark's wife Lianne (both pictured above) died from SUDEP last April. Thanks also to Gonzaga College, where Marks teaches, which held a cooking demonstration with Chef Kevin Thornton to help raise further funds and the many supporters who have organised and took part in events in memory of Lianne.

## Brainteaser Quiz



A big thanks to everyone who attended our annual quiz night in Diceys on November 2nd and to Mary Rowe and Permanent TSB who took 5 tables. Well done to everyone who raised €2085 on the night (pictures on page 12).

## Dublin City Marathon



Thanks to John McClafferty who took part in the Dublin City Marathon and raised €355 for Epilepsy Ireland. Patrick Leahy (pictured left) also took part in the event and raised over €1,400 for Epilepsy Ireland.

# FUNDRAISING IN 2018

Here are some of the ways you can support the work of Epilepsy Ireland in 2018.



## Wedding Favours

Your Civil Ceremony or Wedding day is one of the most important days of your life. Why not make your special day both personal and memorable by considering an alternative to the customary wedding favours and make a donation in lieu to Epilepsy Ireland. Not only will your donation help improve our services but your guests will be impressed by the thoughtful gesture on your special day.

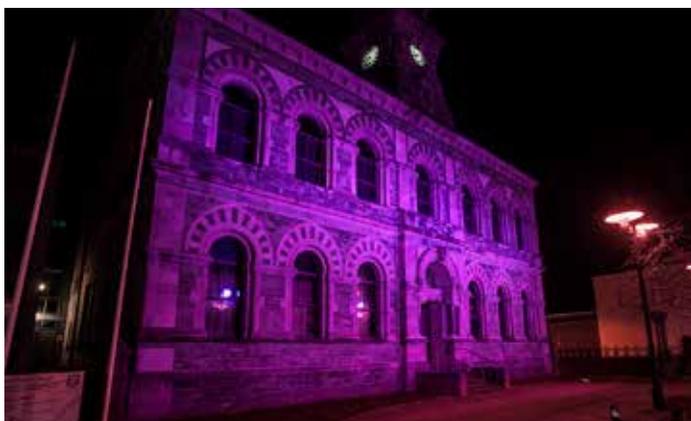
You can choose from our two different designs. To find out more, contact our fundraising team on 01 4557500.



## Leave a Gift in your Will to Epilepsy Ireland

Leaving a gift in your will to Epilepsy Ireland will help us to plan well into the future. How much you choose to leave is entirely up to you, but every legacy, no matter the amount, will make a significant difference to Epilepsy Ireland. If or when the time is right for you to include a gift in your will, please consider us.

For further information or to speak in total confidence, without obligation, about the possibilities of leaving a legacy to Epilepsy Ireland, please contact Michael on 01 4557500.



## Purple Day

This year, Epilepsy Ireland embraced 'Purple Day' which took place on 26th March and saw over 35 of Ireland's most famous landmarks lighting up purple to raise awareness about epilepsy.

For 2018, we are looking to develop 'Purple' themed fundraising events and would welcome any support from our readers and members by hosting a Coffee Morning, getting your classmates to wear purple to school or organising a purple event at your workplace. To find out more or to receive your 'Purple Pack', contact John on 01 4557500.



## Rose Week

Our Annual Rose Appeal is taking place from Monday 12th February to Friday 23rd February. During this time, volunteers will be selling our Roses and Pins throughout Ireland. We are also looking for Rose Week Ambassadors to assist us in coordinating our appeal in their local area or to host a Rose Coffee Morning.

## COMPETITION TIME - Sunway Holiday Voucher

Rose Week is taking place from the 12th February. To be in with a chance to win a Sunway Holiday voucher, register to volunteer for an hour or two during Rose Week. We urgently need Volunteers throughout Ireland to get involved and sell our Roses/Pins. Register at [volunteer@epilepsy.ie](mailto:volunteer@epilepsy.ie).



## Ireland's Ancient East Peaks Challenge

May 2017 saw the introduction of Epilepsy Ireland's newest challenge event – 'Ireland's Ancient East Peaks Challenge' which had participants climb the 4 highest mountains along Ireland's Ancient East with only 36 hours to complete. The first of the peaks to be attempted was Lugnaquilla which is the highest

mountain in Wicklow and followed closely behind by The Ridge of Capard. It was then on to a medieval style feast where 'Pig on a Spit' was served. Participants got to stay overnight in farmhouse accommodation and it was up bright an early on the Sunday morning to tackle Luggalla which has breathtaking scenery. Now it's time to make your story in the ancient east by registering to take part in this challenge. To find out more and to receive a fundraising pack, contact Michael on 01 4557500.

## 2017 National Conference



*Yvonne Cahalane speaking during a Q&A session.*

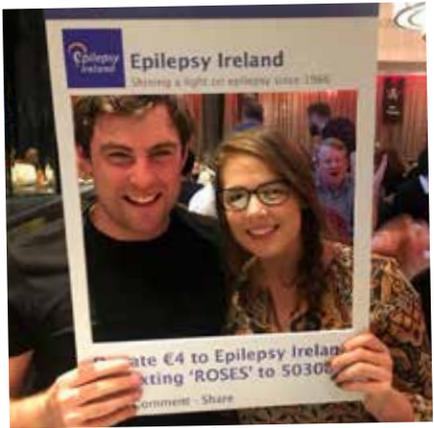


*Dr. Andrea Higgins, Senior Neuropsychologist, Bloomfield Hospital and Health Services, Dublin, spoke about the 'Top 10 things you should know about memory & epilepsy.'*



*Dr. Kevin Murphy, Consultant Neurologist, Sligo Regional Hospital, discussed the Top 10 things adults should know about their epilepsy.*

## Brainteaser Quiz



*Sean Murphy and Sinead Margalit enjoying the quiz in Diceys Bar, Dublin.*



*Darragh Molloy reminding you to support Rose Week.*



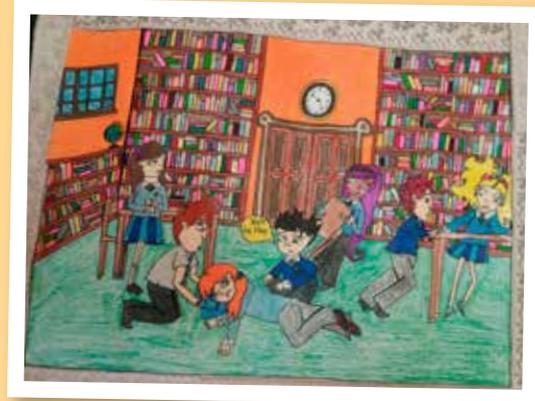
*Nikki Saarsteiner also supporting Epilepsy Ireland.*

## Cork student with epilepsy shows her creative talent



**20 Year old St John's College Student, Clioghna O'Leary from Cork has drawn a special poster to help raise epilepsy awareness (pictured above).**

"Each picture is how I view epilepsy. One photo shows a pupil with epilepsy with an SNA as I have learning difficulties myself.



Another picture shows a kid having a seizure and all the children know what they are doing as they're seizure aware. There is also a picture with all the famous people that have epilepsy. Art is a big part of my life and it's something I want to do long term", says Clioghna.

# EPILEPSY IRELAND DELIGHTED TO BE ANNOUNCED

## AS PERMANENT TSB'S CHARITY OF THE YEAR



**Epilepsy Ireland Fundraising and Communications Manager Michael Carty pictured with Mags Cotter of Permanent TSB's Fundraising Committee.**

Epilepsy Ireland is pleased to confirm that it's been voted Permanent TSB's Charity of the Year for 2017/2018 after a staff vote. The charity topped the poll which also included Ronald McDonald House, Down Syndrome Centre, Action Aid, Oesophageal Cancer Research Fund, Our Lady's Hospice and St. Vincent de Paul Ireland.

Speaking about the announcement Epilepsy Ireland CEO, Peter Murphy said: "I'd like to thank everyone who voted for us as we were up against some wellknown charities who all do fantastic work. Our recent partnerships with Dublin Chamber and Kepak have shown how effective corporate sponsorship can be in resourcing current and future activities. A huge thanks must go to Mary Rowe of Permanent TSB who was extremely influential in Epilepsy Ireland receiving a nomination. We're looking forward to working with Permanent TSB over the next twelve months and I know they have many ideas as to how they can help Epilepsy Ireland."

Explaining the reasons why Epilepsy Ireland was selected, Mags Cotter of Permanent

TSB's Fundraising Committee said: "Each year the staff at Permanent TSB nominates a number of Irish based charities with the aim of assisting the charity, via staff fundraising events and volunteering.

"Epilepsy Ireland assisted one of our staff members and her family over the past years and she nominated them for consideration. Permanent TSB is proud to support Epilepsy Ireland and will host fundraising events throughout the year such as our annual table quiz in February, Hell & Back event and also our special Charity Rugby match.

"Our aim is to also assist with raising awareness of the charity, in what it does and to help improve the understanding of epilepsy. Permanent TSB's Charity Committee sets a target each year to raise funds to help the charity in their day to day activity. We like to keep the target a closely guarded secret but through our own work we hope Epilepsy Ireland will be happy with the donation we can provide at the end of our fundraising year."

## NEW RESOURCES FROM EPILEPSY IRELAND



### Safety & Seizures

This new 36 page booklet (pictured above) focuses on all aspect of managing risk and safety relating to epilepsy care. This includes sections relating to

seizure prevention, managing triggers and reducing risk, as well as First Aid for seizures, a checklist for home safety and information and advice relating to safety when out and about – including night clubs, cinemas and concerts, summer camps, holidays and travel. The final section provides a list of alarm suppliers and other seizure supports.

### Epilepsy Explained – Frequently Asked Questions

This new 20 page booklet brings together all the basic facts and figures about epilepsy and provides introductory but comprehensive explanations relating to the brain, epilepsy, and seizures. We address the new seizure categories and how to manage seizures, and discuss the basics relating to managing treatment and medication. The final sections provide information for those living with epilepsy relating to work, family and lifestyle concerns, and provides support and information for carers, parents and guardians.

### Driving & Epilepsy

Driving & Epilepsy provides the most up to date information for people with epilepsy relating to the driving regulations in Ireland for epilepsy and seizures. This short six page guide provides the basic details in a clear concise manner for all concerned.

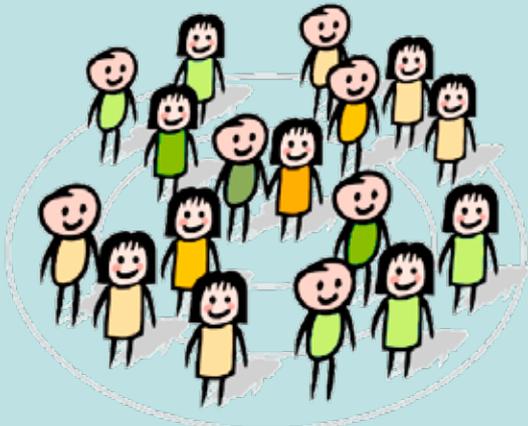
### How2Tell

This booklet was produced by Trinity College Dublin and supported by Epilepsy Ireland to provide people with epilepsy the support they need to be able to talk about their epilepsy and how and when to do this. It addresses questions such as how to make it ordinary, how to deal with people's reactions, how, when, and why to tell about epilepsy. It features shared experiences from people with epilepsy and was developed as part of a research project undertaken by Prof. Naomi Elliott of Trinity College Dublin.

**If you would like to receive a booklet please call 01 455 7500.**

Epilepsy Ireland has recently adopted new policies to ensure the highest level of service.

## Safeguarding Policy Statement



Developing positive relationships with our Service Users is a core value in Epilepsy Ireland. Our staff understand that the very foundation on which such relationships are built is based on respect for, and dignity of, each individual. We have a philosophy of ensuring that our services are person centred and meet the needs of each individual. We support service users to advocate for their rights in society.

Abuse is a violation of that relationship and an individual's human and civil rights. The staff and volunteers in Epilepsy Ireland are committed to practices which promote the welfare of all our service users, uphold their rights and safeguard them from harm.

We are committed to promoting an atmosphere of inclusion, openness and transparency and greatly welcome feedback from the people who use our services, their families, carers, our staff and volunteers so that we can continue to try to improve our services.

We will strive to safeguard those who use our services by adhering to the Epilepsy Ireland Policy – Safeguarding Vulnerable Persons – and the HSE Safeguarding Policy – Safeguarding Vulnerable Persons at Risk of Abuse – National Policy and Procedures.

You may contact us if you have any concerns that you or another adult you know is being or has been abused. If you would like a copy of our Safeguarding Vulnerable Adults Policy & Procedures please contact any member of staff.

The Designated Officer for Epilepsy Ireland is Wendy Crampton (Deputy CEO) at (01) 455 7500.

If you wish to make an external complaint about abuse you may also contact HSE services directly via the HSE complaints process – contact 1850 24 1850

## Confidentiality



Epilepsy Ireland offers you the opportunity to share your personal information with us and we hope that we can build a relationship of trust to support you and your family member with their epilepsy.

We appreciate that by keeping what you tell us confidential, we are valuing your rights and integrity. As much as is possible, we keep information about you confidential within the organisation.

However, sometimes this is not always possible. There are times that we will share your information outside of the organisation. This will be:

- If you tell us that you are a danger to yourself (feeling suicidal) or to other people (planning to harm another person) we will contact someone to help you.
- If a criminal act has occurred or is about to occur we will contact the Gardai.
- If you tell us about a child or vulnerable adult who is experiencing or is at risk of experiencing abuse, or where abuse occurred in the past, we will follow HSE Children First and HSE Safeguarding Vulnerable Adults procedures and contact the HSE and/or the Gardai as required.
- If we are contacted by subpoena (a court order) and asked for information by legal obligation we must provide this.
- If you require an immediate medical intervention and we have medical information relating to you, we will provide the ambulance service with this information.

***Otherwise, we will share your information with other services only with your consent, for example if we are discussing your situation on your behalf with a medical professional or another relevant service.***

# REGIONAL EVENTS

## CORK

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

### Upcoming Events

#### Support Group for Parents of Children with Epilepsy

Bishopstown GAA Club  
Wednesday 29th November 2017  
7.30pm

## 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

Wednesday 13th December - 10.30am venue-TBC  
Wednesday 24th January - 10.30am Killarney office  
Wednesday 21st February - 10.30am Killarney office

#### Tralee: Support meeting for parents of children with epilepsy

Manor West Hotel Tralee  
Tuesday 5th December  
Wednesday 7th February  
10.00am

#### Kerry: University Hospital Outreach Service

Appointments available on Mondays before clinic visit - for further information please do not hesitate to contact Kathryn.

## EAST

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

### Upcoming Events

#### Toolkit Information and Support Session for People with Epilepsy or Parents of Children with Epilepsy

The Carmelite Community Centre, 56 Aungier Street, Dublin 2  
27th November 2017  
6pm - 9pm

The Carmelite Community Centre, 56 Aungier Street, Dublin 2  
Jan / February 2018 (Dates TBC)  
Time: 6pm - 9pm

#### Epilepsy Ireland in Partnership with Helium Arts present Creative Arts Workshops for Teens with Epilepsy

Saturdays 20th January and 3rd February 2018 (must attend both sessions as it is a continuous piece of work)  
Dublin City Location (TBC)  
Time: 10.30am - 1pm

#### Epilepsy Awareness Nurse Talk and Buccal Midazolam Demonstration

Rose Week - 12th - 23rd February 2018  
Where: (TBC)  
When: (TBC)

#### STEPS (Support and Training in Epilepsy Self-Management) for People with Epilepsy

February / March 2018: (Dates TBC)  
The Carmelite Community Centre, 56 Aungier Street, Dublin 2.  
To book a place please contact Edel or Carina on 01 455 7500 or ecurran@epilepsy.ie or cfitzgerald@epilepsy.ie

## NORTH EAST

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

### Upcoming Events

**Information stand**  
Cavan General Hospital  
February 12th  
Time TBC

#### Open BM training Drogheda

D Hotel  
February 14th  
Time TBC

## MID-WEST

(Co's Limerick, Clare & North Tipperary)

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

### Upcoming Events

**Paediatric Epilepsy Nurse Specialist - Maria Keegan - Parent and Creche information morning**

Strand Hotel Limerick  
December 2nd  
10.00-14.00

**Buccal Midazolam Training**  
Limerick Education Centre (Fully Booked)  
December 6th

**Buccal Midazolam Training**  
St. Anne's Centre - Roscrea (in house - fully Booked)  
December 14th

**Buccal Midazolam Training**  
Limerick Education Centre  
January 15th  
Time: TBC

## WESTERN REGION

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

### Upcoming Events

**Family Puppet Day**  
Thursday, 23rd February 2018 - Mayo Education Centre

**Innerwise Self Development & Meditation Programme**  
Wednesday, 5th April 2018 - Mayo Education Centre

## NORTH WEST

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

### Upcoming Events

**Sligo Outreach Service**  
Sligo Office  
28th November - 2.30pm to 4.30pm  
Tuesday 12th December - 10.00am to 12.00pm  
February 12th - 10.30am to 12.30pm  
Please call to make an appointment and to confirm your attendance:

**Sligo International Epilepsy Day**  
Epilepsy Information Stand  
Quayside Shopping Centre, Sligo Town  
Monday 12th February 2018  
12.00pm to 3.00pm

#### Sligo: Epilepsy Awareness & the Administration of Buccal Midazolam

For Teachers, SNAs and Health Professionals only  
Clayton Hotel, Sligo  
27th February  
9.30am to 4pm.  
Places must be booked and confirmed in advance.

#### Donegal: Neurology Out patients Clinic

Out Patients, Scally House, Letterkenny  
15th November  
Agnes will be available to meet with you at The Neurology Clinic. Please call 074 91 68725 to confirm time

## MIDLANDS

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

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

### Upcoming Events

**Christmas Coffee Morning**  
Charleville Centre, Tullamore,  
December 13th  
11am - 1pm

#### Open Buccal Midazolam Training

Venue TBC in Tullamore  
February 7th  
9.30am-4pm

#### Information Stand

in Longford Town  
(venue TBC)  
February 12th

## 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.

**Galway Support Group Meeting**  
Venue: Imperial Hotel, Eyre Square, Galway.  
Friday 1st December  
10 am-12pm

**Mayo Support Group Meeting**  
Mayo Education Centre, Westport Road, Castlebar.  
Wednesday, 6th December  
10am-12pm

**Mayo Outreach Service**  
Wednesday, 6th December  
Venue to be confirmed.



# *Epilepsy Ireland*

## *Rose Appeal*

February 12th - 23rd

**“Wear a rose and help us grow”**

**Thank you...**

**for your support**

[www.epilepsy.ie](http://www.epilepsy.ie)

CHY Number: 6170