



EPILEPSY NEWS

Issue 98 Spring 2023

The official Epilepsy Ireland members' newsletter



In this issue:

- #EpilepsyDay report
- EI investment in research surpasses €1.5 million!
- Jack's Story
- Information on medication supply issues
- ... much much more!

NOTE FROM THE EDITOR



Welcome to our first member's Newsletter of 2023!

It's been a busy start to the year here at Epilepsy Ireland and as we head into the Easter Break, we'll update you on some of the work that has been ongoing since the turn of the year.

You'll read about our flagship days of International Epilepsy Day and Purple Day®, a new investment in epilepsy research by Epilepsy Ireland, as well as the latest updates regarding our ongoing campaigns around access to the deferred sittings of Leaving Cert exams and Sodium Valproate.

Since the beginning of the year, there has also been a continued focus on medication shortages – some of which have impacted on people with epilepsy, but equally, some of the reporting around this issue has overstated the impact this issue is having on epilepsy medications, which has caused a lot of worry. We provide further information on where to find correct information on medication shortages and how we can help.

We'll also feature a fantastic personal story from Jack which was shared with us as part

of International Epilepsy Day, and we'll look back on our Infantile Spasms Awareness Week Campaign towards the end of 2022, as well as featuring ****SOME**** of the incredible fundraising efforts which have taken place in support of work since our last edition.

Looking ahead, we'll let you know how you can get involved in this year's National Epilepsy Week. All this and more – including an extended Creative Corner to feature some of the incredible pieces from Ireland which were submitted to the International Bureau for Epilepsy as part of an online Art exhibition for International Epilepsy Day.

As we continue our journey towards a society where no person's life is limited by epilepsy, we would like to remind our members that we are here for you. Please do not hesitate to get in touch with your local Epilepsy Ireland Community Resource Officer should we be of assistance to you or call our Head Office on 014557500.

Thank you all for your continued support and we hope you have a fantastic break over the Easter.

Paddy McGeoghegan

Advocacy & Communications Manager

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Front Page Image:
It's been a busy start to 2023 for epilepsy warrior Aine, who not only took part in a Virgin Media News feature on #EpilepsyDay to raise awareness, but as the front page image shows, was busy on Purple Day® raising awareness too!

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 Epilepsy Ireland

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WELCOME SOPHIE & PAM!

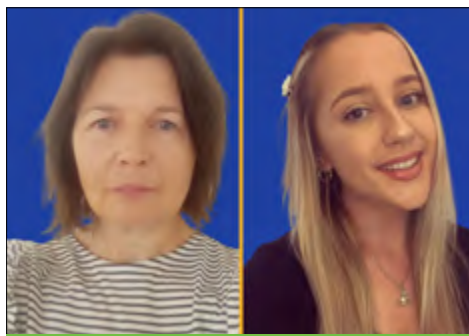
We have two new faces to introduce to our members! First up is Pam O'Brien, our new Community Resource Officer for Kerry. Pam joined our team at the beginning of the year, taking over from our former Community Resource Officer, Kathryn Foley. We'd like to thank Kathryn for her years of service and wish her every success in her new role.

Pam joins us from Cheshire Homes and she is a registered Intellectual Disability Nurse with 25 years' experience in a range of community-based services across the Cork and Kerry areas.

If you are from the Kerry region, you can contact Pam by emailing pobrien@epilepsy.ie or by calling 0858766627.

The second face we have to introduce to you may be a bit more familiar! Sophie Williams recently joined our team as our new Receptionist/Administration Officer. You may be familiar with Sophie as in a previous edition of our newsletter, she shared her story of living with epilepsy. Sophie has a Masters in Health Promotion and has been an Epilepsy Ireland media volunteer for a number of years.

Welcome Pam & Sophie to the team!



Our new Community Resource Officer Pam O'Brien and our new Receptionist/Administration Officer, Sophie Williams.

Notice on Changes to Buccolam® packaging



Graphic showing slight change to the BUCCOLAM® packages which people will see going forward.

In recent months, we have received queries from people with epilepsy, their family members; and people who may regularly administer BUCCOLAM® regarding changes to the packaging – particularly in reference to the removal of the self-adhesive strap (seal) that was on the tube up until recently.

This has led to concerns that the medication may not be usable as the seal was not there. We have been informed that this is not the case and the manufacturers have removed the seal from the packaging.

Neuraxpharm Ireland – who are the license holder for this medication in Ireland – have advised that the original seal was never intended as a marker to tell whether the tube had been tampered with; but was actually there to properly hold the tube cap in place.

BUCCOLAM® is now fitted with a new, more ridged cap, that is an improved fit for the tube. The new cap has been shown to stay in place without the need for the seal, whilst still allowing the cap to be removed quickly, when access to the oral syringe is needed.

informed healthcare professionals of the recent changes. The recent changes are also reflected in the new patient information leaflet and guide.

In a meeting with Neuraxpharm, we raised our concerns and the concerns of the individuals and organisations that we have heard from about this recent change. We will update our readers when we have further information regarding this.

You can read more on this recent change by visiting our website or contact your local Community Resource Officer.

▶▶ <https://bit.ly/BMEI23>

Rare Disease Day

February 28th marked Rare Disease Day and Epilepsy Ireland joined with organisations across the globe to raise awareness of rare conditions, the people who live with them, and the organisations that support them. Epilepsy as a condition is not rare. However, while epilepsy is not rare, there are rare forms of the condition and there are conditions where epilepsy is the dominant characteristic of that rare disease/condition. These include conditions such as Dravet Syndrome, Infantile Spasms, Lennox Gastaut Syndrome or Tuberous Sclerosis Complex.

Many of these conditions can be particularly challenging for those living with them due to the uncontrolled nature of the seizures associated with them, and due to other impacts of a person's rare condition. To mark the day, Epilepsy Ireland added a new section of our website focussing on some of the rare types of epilepsy that exist and providing further information about them. To read this new resource, visit our website.

▶▶ <https://bit.ly/REDEIRDD>

| New Irish study could lead to seizure prediction technology



Dr. Cian McCafferty, study lead and Lecturer in the Department of Anatomy and Neuroscience University College Cork.

At the beginning of the year, a new Irish study identified a brain activity pattern in epilepsy which could lead to technology to predict seizures in future.

The study was a transatlantic collaboration – involving researchers at both University College Cork and Yale University.

The study focused on absence seizures. During a seizure, it is well established that the normal brain activity is disrupted by the misfiring of neurons. This abnormal activity is known as spike wave discharges.

Absence seizures are usually accompanied by impaired consciousness and while it is known that the seizures are caused by abnormal brain activity, there is a knowledge gap as to why this can happen in a person's brain.

As part of their research, researchers replicated human absence seizure presentation in a rodent model and continually monitored brain activity in these models. Researchers found that during spike wave discharges, neuron activity in two parts of the brain were decreased – namely the cortex and thalamus.

Neurons are information messengers in our brain. They use electrical impulses and chemical signals to transmit information between different areas of the brain, and between the brain and the rest of the nervous system. Therefore, when they are disrupted as part of seizure activity, this leads to the loss of consciousness.

In total, the research went on to identify four distinct patterns of specific neuron activity which led to seizures. These are significant findings as previously, it had been believed that that all neurons in the brain had similar activity patterns during a seizure. Researchers involved believe that this could therefore lead to the development of seizure prediction technology. To read about this research in full, visit our website.

▶▶ <https://bit.ly/UCCStudy>

| Beaumont Neuroscience Study Day & Cork Ketogenic Diet Event

We had a busy Saturday at the beginning of March, with EI attending two specific events to highlight how we can support people with epilepsy and their families. First up, our Community Resource Officer Sharon O'Connell attended a patient event held by Vitaflo for patients who are on a Ketogenic Diet. The day was extremely successful with families getting the opportunity to have access to expert advice on the ketogenic diet and the opportunity to link with other families and create support networks in their community.

Meanwhile, in Dublin, our Community Resource Officer, Mary Baker spoke at the Beaumont Neuroscience Study Day, providing further information to the audience there about how we support people with epilepsy. We look forward to continuing to work with our colleagues in the medical community throughout 2023.

JACK'S STORY



In the lead-up to International Epilepsy Day, a number of people living with epilepsy shared their story to help raise awareness of epilepsy and the real experiences of living with epilepsy. One such person was Jack O'Connor from Cork and we have decided to feature his story as part of this edition of our Newsletter. . .

My epilepsy journey began in 2017 when after a night on the town I had my first tonic-clonic seizure. I had been looking at a potential option for college next year, when my friend came into the room to find me seizing on the ground. At that time I had no idea how my life would change from this one incident.

A year on, and I was entering my first year of college, despite not fully knowing the extent of my seizures. Alongside that, I had moved to a new city, began living independently and trying to figure out my future.

Almost immediately I found myself crumbling under the pressure of new surroundings, people, and responsibilities.

From here my seizures became worse as I would push my body to limits, I had not imagined before.

At this time in my life, I had been an avid runner, averaging about 10 kilometres a day just to clear my head and keep active and out of nowhere I was unable to run 100 meters without feeling anxious, confused, and disorientated. Having an outlet like running in my life was one of my main routines and to this day I am heartbroken every time I try to run, and my body gives up almost immediately. It's been one of the crueler impacts of epilepsy for me – as I know not everyone living with the condition is affected in such a way.

Throughout college I made it my goal to try to educate as many of my peers about epilepsy. I found that most young people in Ireland had a preconceived notion of epilepsy being a one-fits-all kind of diagnosis but even with that experience,

almost everyone who I have been open with over the years have been eager to find out more about the condition and the many way it affects people.

If I was to redo that portion of my life, I would have definitely looked upon my condition with a more positive view and tried to educate more people on how to safely care for a person having a seizure. The anxiety I felt when trying to tell my peers was excruciating yet over the years it has become easier and easier.

“

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”

Post-graduation I have become better at measuring, yet enjoying my time safely figuring out how to mind myself at festivals, playing sports and working. I am incredibly lucky to have a supportive family with my mother and father educating themselves through Epilepsy Ireland and finding a support system through my closest friends – with my close friends Rory and Ewan looking out for signs of a seizure and dealing with me in a controlled manner.

I would highly recommend any young person beginning their journey through college or living independently to be open

and upfront with their diagnosis. I have found that people are eager to learn about different forms of epilepsy, I found that whenever I have had a seizure, from Cork to Milan, there has always been somebody who will help a person in need, regardless of their understanding of the condition. People wanting to help is not a problem – but its so important that they know how to do correctly.

I have discarded the idea of dealing with this alone. I am done with hiding my condition and embraced that there is good in people, no matter where you turn for support, people want to help a person in need, it is just a matter of helping them learn how, which is why the message of making Time, Safe, Stay general knowledge is one everyone needs to hear!

We'd like to thank Jack for sharing and we have no doubt that his message will have a positive impact on many of those reading our Newsletter today. As noted, Jack was one of a number of people to share their journeys with epilepsy with us as part of the lead-up to #EpilepsyDay. All these stories chart the individual nature of epilepsy and are well worth reading. If you missed any of them in the lead-up to the day, we'd recommend that you take some time to visit our website and take a read.

 <https://bit.ly/IED23EI>

If you are interested in sharing your story in a future edition of 'Epilepsy News', please contact our Advocacy & Communications Manager, Paddy McGeoghegan, by emailing pmcgeoghegan@epilepsy.ie.

INTERNATIONAL EPILEPSY DAY

On February 13th, we celebrated International Epilepsy Day and we launched a new campaign to highlight the need for the public to make seizure first aid part of their general knowledge.

The campaign aimed to highlight how trivial things form a wide part of a person's general knowledge, while important information such as seizure first aid, does not. The campaign was a change of tack to that of previous years in that the campaign was not fronted by people with epilepsy, but members of the public themselves.

The key feature videos of the campaign saw a series of simple general knowledge questions being put to the public such as "H2O is the chemical formula for what?" and "A pug is a breed of which animal?" While the public easily answered these questions, they were much less forthcoming with the correct answer when asked "What three words do you need to remember if you witness a person having a seizure?"

The campaign highlighted how seizure first aid and our key words of Time, Safe, Stay unfortunately are still not part of the public's general knowledge – with the key message being that Time, Safe, Stay needs to become part of everyone's general knowledge.

While we hope our members are familiar with Time, Safe, Stay by now, we have outlined the key information behind these three words below:

TIME

The first thing you should do is **TIME** the seizure. This is because if a seizure goes over five minutes, an ambulance should be called.

SAFE

Keep the person **SAFE** during the seizure. If a person is having a convulsive seizure,



cushion their head with something soft if possible and remove any harmful objects, e.g. furniture from their vicinity. **NEVER** put anything in a person's mouth or restrain them during a seizure. Be aware that there are also types of seizures where the person does not experience convulsions. Instead, they may "zone out" or stare blankly, become confused or agitated, display behaviours like chewing, smacking their lips, fiddling with their clothes, or wandering aimlessly. In this type of seizure, the person's awareness of their surroundings is affected, and it is important to gently guide the person away from any danger.

STAY

During the seizure and after it passes, **STAY** with the person. Often after a seizure, a person with epilepsy will be confused and,

in many cases, exhausted. Make sure to stay with them until recovery is complete, explain what has happened and gently reassure them. The person may have experienced an injury if they have fallen, and if this is the case, ensure normal first aid steps are taken.

While this year's #EpilepsyDay campaign was a different approach to what we have taken in previous years, we were pleased with the response the campaign received and hope that it has gone some way to making seizure first aid part of the public's general knowledge into the future. If you missed the campaign when it was shared, you can look back on it and the feature videos by visiting our website:

▶▶ <https://bit.ly/IED23E1>

While there were many highlights from the day, we have outlined a few specific highlights from the campaign below:

- Throughout the week of #EpilepsyDay, adverts ran across Today FM highlighting the Time, Safe, Stay message.
- Similarly, adverts ran across streaming platform Spotify highlighting the Time, Safe, Stay message.
- A print ad was featured in the Irish Times featuring Time, Safe, Stay
- Digital advertisements also ran on the Irish Independent and Irish Times highlighting the Time, Safe, Stay message.
- Bernie Hart, her daughter Aine and Dr. Danny Costello featured on the Virgin Media news to discuss their personal journey with epilepsy and to promote the Time, Safe, Stay message.
- Melissa Ryan and her family from Tipperary took part in a fantastic personal feature with the Irish Farmers Journal

▶▶ <https://bit.ly/IFJMR23>

- The Time, Safe, Stay message was also promoted in the Irish Examiner, Irish Independent, online on Joe.ie, Her.ie,

Herfamily.ie, the Irish Country Magazine and in RSVP.ie to name but a few

- Once again, our campaign was supported by our incredible media volunteers who took to the airwaves and local papers to discuss their journeys with epilepsy. There were appearances by our volunteers on wide-reaching regional stations such as Highland Radio, Midlands 103, Galway Bay FM, Mid-West Radio, Ocean FM, Tipp FM, Northern Sound and Clare FM to name but a few!
- As noted in Jack's personal story on pages 6&7, several volunteers shared their stories of life with epilepsy across our channels in the lead up to the day and we'd strongly encourage everyone to take the time to go and have a read of these fantastic testimonies.
- Finally, there was strong political engagement with our campaign with TDs and Senators using their platforms to amplify our message of Time, Safe, Stay to their constituents. Senator Fiona O'Loughlin also promoted the key message of Time, Safe, Stay in a Seanad business contribution!

Thank you again to everyone who supported our campaign in any way on #EpilepsyDay - it is greatly appreciated. If they haven't already, please encourage all your family, friends and colleagues to make Time, Safe, Stay part of their general knowledge today!

With #EpilepsyDay now in the history books, we're already looking ahead to 2024. We'd welcome any feedback you may have on this year's campaign and any suggestions you might have for 2024. Please feel free to email your thoughts to our Advocacy & Communications Manager, Paddy McGeoghegan by emailing pmcgeoghegan@epilepsy.ie. Likewise, we know media volunteering has been mentioned throughout this piece – if you are interested in joining our media volunteering list, drop Paddy a line as well!

MEDICATION SUPPLY ISSUES

We know that there has been a lot of coverage since the start of the year on this issue, with some epilepsy medications being impacted by shortages. However, we wanted to include this piece in this edition of our newsletter to provide some further information and context around supply issues as we do feel that while there has been genuine shortages recently, there has also been heightened anxiety around this.

Medication supply issues have always happened and will continue to happen for a variety of reasons such as the shortage of an active ingredient used to make the medication or staffing issues at a manufacturing site. However, most issues are short-lived and contingency plans are put in place to avoid causing harm to patients. Most shortages pass without any impact on patient care or safety.

If there are shortages of certain epilepsy medications, these will be reported to the Health Products Regulatory Authority (the HPRA). The Health Products Regulatory Authority (HPRA) is responsible for co-ordinating the management of shortages of medicines on the Irish market. They work with a variety of stakeholders including manufacturers, wholesale distributors, pharmaceutical companies, healthcare professionals, the Health Service Executive, patients, and representative groups to respond to potential shortages and reduce the impact of shortages on patients.

All current shortages will be listed on the HPRA website. If you have a concern regarding the availability of a certain medication, you can search the name within the shortages section of the HPRA website and quickly establish whether there is an issue or not.

It is important to note there can also be local shortages of medication. For example, a medication may be unavailable at the pharmacy you usually use BUT it may be available at another outlet in the same area. Most pharmacists will be able to advise on whether a national shortage is being experienced with a certain medication.

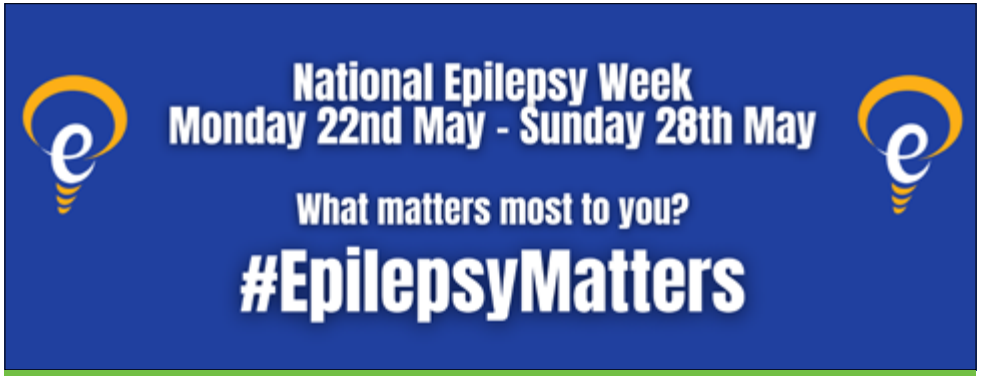
We are highlighting this particular point as we have seen situations where a local shortage has been reported as a national shortage on social media. While this intended to help other people with epilepsy, it has also had the unintended result of causing great anxiety and stress – which is often unwarranted.

If we can establish an actual or impending epilepsy medication shortage, we will publicise it on our website and do all we can to ensure that people with epilepsy and their families are kept informed. However, please note that we are not always directly informed of when a shortage might be happening so if you're concerned about a medication supply issue, please get in touch with us and we will make enquiries to check on reports of possible shortages. Please email our Advocacy & Communications Manager, Paddy McGeoghegan on pmcgeoghegan@epilepsy.ie if you have a query around medication supply.

▶▶ <https://bit.ly/MedSupplyEI>



NATIONAL EPILEPSY WEEK - #EPILEPSYMATTERS



While International Epilepsy Day is in the history books, we have another major awareness raising event coming up in the not-too-distant future!

While International Epilepsy Day is our headline, public-facing awareness day of the year, National Epilepsy Week has grown in prominence in recent years and has been another vital platform to raise awareness of epilepsy. The week is more central to the awareness raising efforts for our colleagues in the UK, and it seen as the central focus of their awareness raising initiatives for the year. However, Epilepsy Ireland have always taken part in the week to help raise awareness in Ireland as well.

Primarily, we use the week to share stories on our social media channels from those living with epilepsy, to help support others living with epilepsy at various stages of their journey with the condition.

The theme chosen for this year's National Epilepsy Week is #EpilepsyMatters and we are appealing for our members, volunteers

and supporters to get involved in the awareness raising efforts for the week.

The theme #EpilepsyMatters, could allow you to focus on the lack of awareness of the condition and draw on personal experiences to highlight this; speak or write about the impact of epilepsy on your/your family's life; or to highlight what matters most to you on your journey with epilepsy and why you think epilepsy should matter to the general public.

National Epilepsy Week is set to take place from May 22nd to May 28th so there's plenty of time to get your thoughts together and work with us in sharing your story. If you'd like to take part in our campaign for National Epilepsy Week 2023, please get in touch with our Advocacy & Communications Manager Paddy McGeoghegan by emailing pmcgeoghegan@epilepsy.ie.

We look forward to hearing from you and sharing your stories across National Epilepsy Week!

PURPLE DAY® 2023

Purple Day® 2023 took place on March 26th and it was fantastic to see our social media channels become a sea of purple with so many people taking part in the day to raise awareness and funds for Epilepsy Ireland.

Since we first took part in the day in 2017, it has grown to become one of our flagship fundraising events and once again, our members, volunteers & supporters rowed in behind our activities for the day to support our work.

There were incredible efforts throughout the week by so many – too many to feature here individually but please know that your efforts in support of Epilepsy Ireland have not gone unnoticed by our team and have been vital in helping us to continue our work towards a society where no person's life is limited by epilepsy.

While final tallies are still being totalled and funds are still being received from regional fundraising efforts, the collective efforts of our supporters have raised over €12k in support of our work.

ELAINE'S GIVEAWAY

Not content with all the awareness she had raised around Infantile Spasms (*see page 20*) Elaine Brosnan launched a wonderful fundraiser in support of Epilepsy Ireland during the week leading up to Purple Day®. Elaine is passionate about home interiors – and her Instagram page 'homenotbeforetime' – charts her journey of designing her own home. With her large social media following, Elaine used her page to launch a fundraiser giveaway in support of Epilepsy Ireland – in which the top prize was a Marc Jacobs handbag. While we're not experts on handbags here at Epilepsy Ireland, we're reliably informed that this was an



The main man Ben – the inspiration behind Elaine's incredible giveaway.

incredible prize – and the response showed that! Throughout the week, several other Irish companies rowed in behind Elaine's fundraiser, offering additional prizes – adding to the fundraising efforts. In total, over €6.5k was raised in support of Epilepsy Ireland's work!

CARMEN'S PLANKS

In the days leading up to Purple Day®, we launched a special challenge to help raise awareness and funds for our work. The challenge asked participants to be Plankers for Purple Day®! Across the week of Purple Day®, participants had to commit to doing 7 planks from Monday to Saturday, with 8 on Purple Day® itself – meaning by the end of the week, they completed 50 planks, in recognition of the 50 million people living with epilepsy across the globe! They had to hold each plank for 45 seconds, in recognition of the 45,000 people living with epilepsy in Ireland today.

There are too many fantastic plankers out there to mention them all individually, but one such incredible planker was Carmen Hernandez aged 14 from Donegal who took



An action shot of Carmen getting her planks in!

part in (and smashed!) the challenge in recognition of her little sister Lulu, aged 5 who is living with epilepsy. At the time of print, Carmen's fundraiser had raised just under €1,200 for Epilepsy Ireland – a fantastic amount! Well done Carmen!

VALLEYMOUNT NATIONAL SCHOOL & NEWS 2DAY

Not content with raising over €350 for Epilepsy Ireland across the week of Purple Day®, Valleymount National School in Co. Wicklow were visited by RTÉ News2day to highlight how they were celebrating the big day. Senior infant and Epilepsy Warrior Finn spoke about his own epilepsy, supported by his brother's Harry & Zachary – while Eoin spoke about how he supports his mum who lives with epilepsy. If you haven't seen the piece yet, we'd encourage you to go and visit our Youtube channel to watch it back – the future is bright when it comes to Epilepsy Awareness!

▶▶ <https://bit.ly/EIVMSNS>

ABOUT PURPLE DAY®

Purple Day® is a Registered Trademark of The Anita Kaufmann Foundation. For more on Purple Day®, visit Purpledayeveryday.org. Purple Day® is an international grassroots campaign founded by Canadian woman, Cassidy Megan. The day sees people across the world encouraged to wear purple in the name of epilepsy awareness and well-known buildings across the globe also light up purple in recognition of the estimated 50 million people living with epilepsy across the globe. Purple Day® is a Registered Trademark of The Anita Kaufmann Foundation. For more on Purple Day®, visit Purpledayeveryday.org.



Epilepsy Warrior Finn and his brother Zachary & Harry who took part in the piece with RTÉ News2day!



Eoin Leonard who spoke about his Mum's epilepsy as part of the News2day feature.

CREATIVE CORNER

In the lead-up to #EpilepsyDay, our colleagues in the International Bureau for Epilepsy launched an online art exhibition focused on the theme of Stigma. The exhibition was open to anyone to enter and as you can see, there were some incredible entries from these shores. A huge well done to everyone featured!



FEELING BLUE by Lorraine Lally

"With epilepsy you feel blue at times and there are days where it's easier to stay at home. If you feel blue at home there is a need to reach out and get support. It's alright to feel depressed with a neurological condition and you can move on from it."



FOREVER FIFTEEN by Hesma Lomax

"This artwork shows the inner turmoil of a seizure and is inspired by the colour of Archie's Eyes. Remembering Archie (Forever 15) 29.8.2000 – 2.8.2016"



TANGLED by Kate Ní Ghacháin

"I like to describe my epilepsy as there being a dropped stitch somewhere in my brain. It often feels like my thoughts are tangled. In terms of stigma, people rarely recognise that, even when under control, epilepsy plays a daily role in people's lives especially when medication side effects are taken into account."



BRAIN FOG AT THE BUS STOP by Laurence Jones

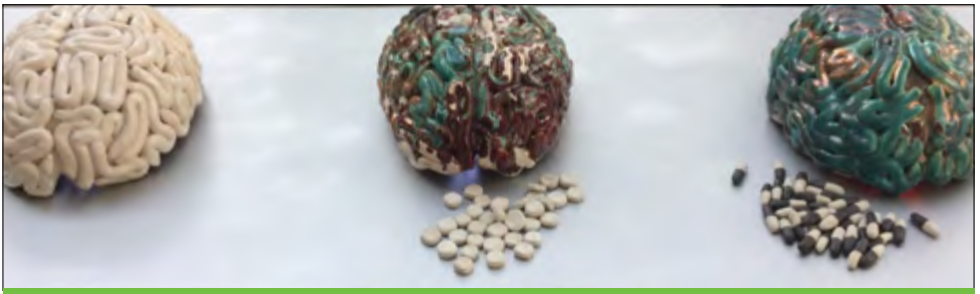
"The difficulties of travel. Worrying about whether I will be worried. Will I get the right bus, train or plane? Will I remember where I'm going or get off at the right place? I always seem to have too much to carry – will I leave something behind. And I drop things – tickets, travel cards, ATM cards, wallets, phone. Or I think I will. Patting pockets to see where things are. Repeatedly."



FOGGY DAY IN THE WOODS by Rupert Bowen

"I am fortunate that my seizures are under control. One side effect is that I do not feel as sharp as I used to. Sometimes I suffer from "brain fog" which people can see as me being

in a dream or not paying attention. But it's a small price to pay for being seizure free! This painting is inspired by a foggy walk in the woods near where I live."



PROGRESSION by Niamh Beirne

"This ceramic artwork is on the progression of epilepsy in the brain. The first brain is clear of any faults by then it gets more colourful as epilepsy progresses. There are multiple tablets in front of the brains to represent how many people may need to take during their lifetime and

if they need a change in their medication as their epilepsy continues. I want to make people aware of epilepsy through other means of media like ceramics as it is still not fully understood. People like to question artworks when they are curious, so it is a great chance to educate people on epilepsy."



SHE'S NOT RIGHT IN THE HEAD by Lucy Jones

"The stigma of epilepsy often leads people to see you as crazy or a bit slow. They rarely look at you and see a unique human being dealing with an invisible illness. As icons like Van Gogh show, despite a damaged brain we are capable of producing great beauty and creating wonderful things."

If you would like to submit a poem, piece of art etc. for the next edition of our Creative Corner, please email our Advocacy & Communications Manager Paddy McGeoghegan on pmcgeoghegan@epilepsy.ie.



Deferred Exam Criteria

As our members will be aware, this is an issue that Epilepsy Ireland have long campaigned on, due to the impact that having a seizure could have on a person's ability to complete their state exams to the best of their abilities. Last year, there was a major step forward on this matter with the introduction of deferred sittings of the Leaving Cert exams. This was a welcome development and the criteria announced made specific reference to the impact seizures can have on students with epilepsy. However, there was a major caveat with what was announced – with distinction made in the criteria between medical emergencies (such as a seizure) which happened before and during an exam. If a student experienced a seizure before their exam, they would be eligible to apply for access to the deferred sitting of exams but if a student had a seizure during their exam, they would not. This was due to a requirement to protect the integrity of the exams according to the State Exams Commission. As our members will be aware from previous editions of our Newsletter, this is not something we agreed with and it led to the criteria being applied differently in practice – leading to students being treated differently in different parts of the country.

Since the criteria were announced last year and with the subsequent issues that arose, we have been campaigning to have this distinction changed in order to address this challenge which has faced students with epilepsy for many years. We have been supported in this campaign by our colleagues in the Irish Epilepsy League, who have added their clinical expertise to our calls. Alongside the Irish Epilepsy League, we met with both the State Exams Commission and the Minister for Education, Deputy Norma Foley in separate meetings to stress the need for all the issues we have identified to be addressed as part of any new criteria for the deferred examinations for 2023. A review of the current criteria is currently being undertaken by the SEC, with a view to announcing updated criteria before the sitting of this year's Leaving Cert. We felt both meetings were positive and that there was little doubt as to why this situation needs to be addressed. However, we currently eagerly await an update from the SEC.

At the time of print, it had recently been confirmed with us that the SEC intends on meeting with us again in advance of publishing any amended criteria, and the matter was raised once again with the Minister as part of Priority Education

Questions in the Dáil by Deputy Gary Gannon. Please follow our website and social media channels to follow the latest news on this ongoing campaign and we hope that 2023 will finally mark the end of this issue.

Sodium Valproate (Epilim) Campaign

We are pleased to inform our members that there has been marked progress in two key issues regarding our ongoing joint campaign surrounding the Anti-Seizure Medication Sodium Valproate.

The first relates to the recruitment of additional epilepsy specialist nurses for the implementation of the Valproate pregnancy prevention programme (PPP). In 2018, it was recommended that 6 additional Epilepsy Nurse Specialists be recruited to provide further capacity to epilepsy services to implement the PPP. However, only two nursing posts were filled at the time and the recruitment of the remaining four posts has been a key aspect of our campaign for the past four years. One further post was filled in 2022 and at the end of last year, we were informed by the Department of Health that funding has been secured for the recruitment of the three outstanding posts through the Women's Health Taskforce. While this is very welcome and a key development in this campaign, it is now critical that recruitment begins without delay to improve patient safety and the management of epilepsy in women of childbearing potential more generally. We will be seeking regular updates from the Department and the HSE on this process.

In a further positive development, the Sodium Valproate Stakeholder Group has now been established. This forum is something we have been calling for since

2018, alongside our colleagues in OACS Ireland.

Despite positive efforts in recent years to increase the knowledge of the risks of Sodium Valproate use during pregnancy, data collected by Epilepsy Ireland and via studies conducted by the Royal College of Surgeons in Ireland showed that there was still a concerning lack of awareness of the risks and risk reduction measures amongst both patients and healthcare professionals.

Because of this, Epilepsy Ireland and OACS Ireland had continually stated that a forum needed to be established; consisting of representatives from the different pillars of the medical community, the state, and patient representatives; to assess the effectiveness of the measures that have been taken to date and establish how we can work together to strengthen them. While the headline focus of the group is on Sodium Valproate and the measures which exist currently exist around the prescribing and dispensing of the medication, there will also be a wider scope to assess practices around all anti-seizure medications.

Since its formation, the group has met twice and we look forward to working with all members of the Stakeholder Group to achieve positive progress on this most important matter. We would like to thank all our members and supporters who have helped to support these calls in recent years and raised them with your local representatives.

In addition to the above, Epilepsy Ireland also attended a European Stakeholder Group meeting in February to discuss the experiences of the Pregnancy Prevention Programme in Member States.

Continued on next page

ADVOCACY UPDATES

We highlighted the key data which has been collected in Ireland and how there needs to be a renewed focus on strengthening awareness of existing measures at a European level, rather than seeking to add additional measures. Our work as part of this group will continue throughout the year.

Finally, in relation the establishment of the historical inquiry regarding the licensing and prescribing of Sodium Valproate which was promised in 2020, terms of reference were agreed with the Department of Health in late November 2022. It had been expected that these terms would be sent to Cabinet prior to the Christmas recess but this unfortunately did not happen. Since terms were agreed, there have been two high-profile court cases which involved multi-million euro settlements for children who were impacted by Sodium Valproate, meaning the risks around Sodium Valproate have been widely reported in the media. In a recent meeting with the Department of Health, we have been informed that the some of the logistical groundwork for the inquiry is taking much longer than expected but that this should be rectified soon. The inquiry is very important as not every family affected will be able to pursue action via the courts and the inquiry will act as a forum for them to share their experience, understand what went wrong and hopefully, lead to recommendations that will help to support them.



Free Travel

We have been continuing to use every avenue available to us to progress this ongoing campaign and the matter continues to be raised via Parliamentary Questions in the Dáil. Our proposals to improve access to the Free Travel scheme for people with epilepsy have also been discussed a number of times since the beginning of the year in the Oireachtas Committee for Social Protection, who in turn, have been seeking updates from the Minister about the status of her Department's position on our proposals.

In addition, since the beginning of the year, our colleagues in the Irish Epilepsy League (the Irish Chapter of the International League Against epilepsy who's membership is made up of clinicians, researchers and scientists working in epilepsy care in Ireland) wrote to the Minister for Social Protection in support of our proposals – outlining their clinical expertise and awareness of the impact that being unable to drive due to epilepsy can have on their patients.

All of the above has added further pressure on this matter but the current status is that we await a report from the Department of Social Protection on our proposals. This report has been expected for some time. However, in recent Dáil responses, the Minister has confirmed that she expects this by the end of Q1 2023. The Minister has also confirmed that she will strongly consider the report and any recommendations that it may contain. We will continue to pursue this matter and provide further updates in the next edition of our Newsletter.

Further updates and information on all the articles within this section can be found by visiting the 'Advocacy' section of our website.

NEW RESEARCH INVESTMENT - EI SURPASSES €1.5MILL TOTAL INVESTMENT IN RESEARCH

We are delighted to update our members that earlier this year, we again added to our investment in Irish epilepsy research, meaning we have now passed the €1.5 million mark in terms of total investment in Irish epilepsy research.

The latest project focuses on the health education and information needs of women with epilepsy and is being led by Dr. Aisling Walsh, Department of Public Health and Epidemiology at the RCSI.

The study will last two years, and Epilepsy Ireland has committed to investing €15,000 in the project, alongside principal funding from the Health Research Board.

Approximately 25% of all people with epilepsy in Ireland are women of childbearing age.

Although most women with epilepsy can expect normal pregnancy outcomes, reproductive choices are complex. To date, no study has examined the health information needs of women with epilepsy and their families from preconception through to postpartum in Ireland.

This study will aim to address that gap. It will also identify and co-develop prioritised evidence-based resources to support women and health professionals during this period.

The researchers will firstly identify existing national and international evidence-informed resources. Secondly, they will explore the health information, education and resource needs of women with epilepsy in Ireland, from the perspective of women, families and health professionals, through in-depth interviews.

Thirdly, they will undertake a consensus building study to prioritise and plan health information and education resources.

Finally, they will co-design and co-produce health educational resources to support women with epilepsy and health professionals. Professionals will use these resources to complement their services from primary care to specialist epilepsy care and across maternity settings.

Throughout the project, women living with epilepsy will be included as experts by experience. Through the co-production of resources, women will have better access to evidenced-based health educational resources to improve knowledge from preconception to postpartum.

We hope our members will agree that this is a very important piece of research, and one which has the potential to make a lasting impact on the care of women with epilepsy who are planning pregnancies in the future. We look forward to working with the team and providing further updates as the study progresses.

Investing in research like this and the seven other EI-funded projects which are currently active would not be possible without the continued fundraising efforts of our members, supporters and volunteers and we would like to thank them for their continued support. We would also particularly like to thank all subscribers to our 'Time for a Break' monthly draw for their continued support.

For more on this and other funded projects, visit the 'Research' section of www.epilepsy.ie.

INFANTILE SPASMS AWARENESS WEEK



Elaine, her husband Anil, and son Ben – and Fiona & her son Theo; both of whom shared incredible personal stories during #ISAW2022!

Towards the end of last year, we took part in Infantile Spasms Awareness Week. Infantile Spasms are a rare but extremely serious type of seizure which occur in approximately 1 of every 2,000 children. If undiagnosed and untreated, Infantile spasms can cause catastrophic, permanent damage to a child's developing brain.

The seizures include repetitive but often subtle movements – including jerking of the mid-section, dropping of the head, raising of the arms or wide-eyed blinks. Infantile spasms can often be overlooked or misdiagnosed for other conditions, including colic, reflux, or a startle reflex.

We used the week to appeal to new or expecting parents to learn more about these serious types of seizures and to raise awareness of the key word of **STOP**:

- See the signs
- Take a video
- Obtain Diagnosis
- Prioritise Treatment

In addition to this, we hosted a special webinar for a varied audience (including parents, expectant parents and healthcare professional) regarding Infantile Spasms. The

webinar featured the expertise of Dr. Mary O'Regan, Consultant Paediatric Neurologist at Children's Health Ireland, Crumlin. The event provided clinical insight and expertise to all those in attendance, arming them with key information about Infantile Spasms.

A key feature of the week for our awareness raising activities was featuring real-life stories of families who have experienced Infantile Spasms through their child. We had two incredible contributions – the first from Elaine Brosnan, regarding her son Ben and his experience of Infantile Spasms – and the second was Fiona Conlon's story of her son Theo's experience of Infantile Spasms.

These personal stories helped our wider audience better understand how Infantile Spasms can present and affect a child's development, but also helped parents understand why it is just so important to be aware of Infantile Spasms.

We would like to thank both Elaine and Fiona for these incredible personal stories, which we have no doubt helped so many better understand Infantile Spasms. If you didn't see them at the time, we would highly recommend that our members visit our website to read their stories in full. We would also ask that you please make any new or expectant parents in your life aware of our resource on Infantile Spasms so they are aware of them and the key word of STOP.

Thank you to all our members, volunteers and supporters who helped raised awareness of Infantile Spasms across the week of #ISAW2022!

Elaine's Story

▶▶ <https://bit.ly/ISAWI22MOR>

Fiona's Story

▶▶ <https://bit.ly/ISAW22EI>

SERVICES

Online Monthly Meet Up!

Since the beginning of the year, we have been running an online Monthly Meet up for young adults with epilepsy aged 18-24.

Young adulthood can be a challenging time for those living with the condition – people can be facing exams; experience increased independence; starting out in their careers; or building new relationships. The natural stresses and anxiety that this can bring, can have a knock-on effect on a person's epilepsy.

This event allows young adults to meet with others of a similar age who are living with epilepsy and an opportunity to discuss how they are getting on with their condition. It is a platform to allow them to discuss any challenges or experiences they may have on various aspects of young adulthood – and to hear about and learn from the experiences of others.

We are delighted with the response so far and if you or someone you know would be interested in joining the next meet-up, visit the 'Events' section of our website!

Get ChARTy!

It can be hard for children/young people

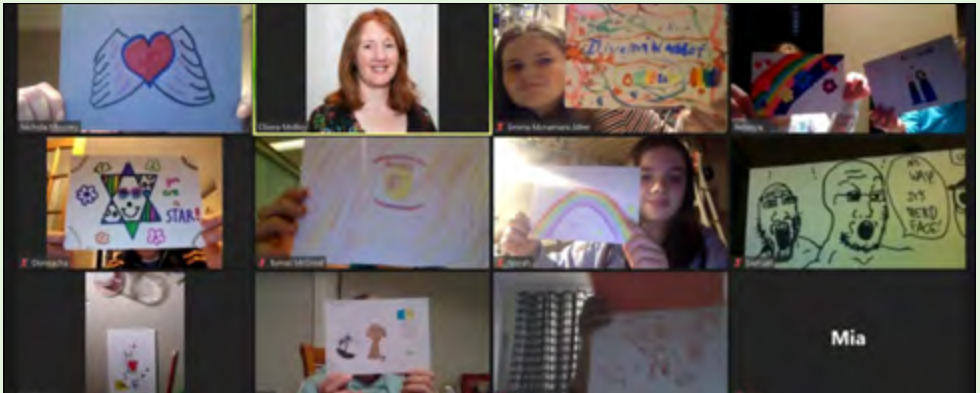
with epilepsy to sometimes meet with others living with the condition which is why we have been hosting our regular Get ChARTy virtual sessions.

These sessions allow 10-13 year old's living with epilepsy to meet with others to have a chat and do some art at the same time – all from the comfort of their home.

The event is facilitated by Nichola Mooney – who is an executive council member of the Irish Association of Creative Arts Therapists. Throughout her career, Nichola has used embodiment, projection, role (EPR) and play to help support children living with long-term health conditions and in other difficult situations.

While those in attendance will be getting to know each other while getting creative, Nichola will be using these techniques to help them better understand themselves and hopefully, help them understand that their epilepsy is not a barrier to doing all the things they want to do in life.

If you have a child/young person with epilepsy who would benefit from attending, visit the 'Events' section of our website to learn more!



Attendees of our Get ChARTy session showing off their creations online!

FUNDRAISING

Annual Raffle

A huge thank you to all our members who bought and sold tickets for our Annual Raffle towards the end of last year. Our Annual Raffle took place on the 25th of November, and we would like to thank everyone who took the time to enter our draw.

We would also like to thank Turkish Airlines and Dunnes Stores for their generous support of the draw and congratulate all our lucky winners once again, who are listed below:

- A. Gillespie; Galway – 2 Return Flights to Turkey and €1,000 cash
- T. Laiseca; Dublin - €500 cash
- D. Curran; Donegal - €250 cash
- S. Deegan; Dublin - €250 cash
- S. Fergus; Cavan - €250 cash
- A. Humphrey; Dublin - €250 cash
- G. Burrows; Kildare - €200 Dunnes Stores Voucher

A fantastic €12,920 was raised in support of work via the raffle.



Well done Adam!

A huge thank you to Adam Farrell from Kilkenny, who took part in the 50 Million Steps campaign earlier this year in support of Epilepsy Ireland. The challenge is launched by our colleagues in the International Bureau for Epilepsy every year in the lead up to #EpilepsyDay and asks people across the globe to collectively walk over 50 Million Steps in recognition of the 50 Million people living with epilepsy across the globe! Adam was diagnosed with epilepsy last year and wanted to take part in the campaign and raise funds for Epilepsy Ireland. Amazingly, he contributed over 346,682 steps himself to the overall count and raised €725 for our work in the process. Well done Adam – you should be very proud!

Thank you Coláitise Dún an Rí!

A huge thank you to the staff and students of Coláiste Dún an Rí Cavan who held a bake sale and raffled off a PWC All-stars jersey to raise funds for Epilepsy Ireland. Their efforts raised a fantastic €537 in support of our work towards a society where no person's life is limited by epilepsy.

Pic: The students are pictured presenting a cheque for the funds raised to their local Community Resource Officer, Mary Baker.





NIGHT FOR LOUISE

Epilepsy Ireland were delighted to attend a 'Night for Louise' early in the New Year to celebrate the life of Louise Young, and the amazing efforts that continue in support of Epilepsy Ireland in her name. The night gave us an opportunity to update Louise's local community on our plans for the funds raised in her name, and to remember the incredible Louise and the work she did in support of Epilepsy Ireland during her life. There was a further outpouring of support for Epilepsy Ireland in Louise's name via the night, with over €10k being added for the continuation of the 'Louise Young Research & Seizure Alarm Fund' which was launched at our conference last year. Thank you to everyone involved and to the Young Family for their continued support for Epilepsy Ireland in Louise's name.

Louise Young - Ar dheis Dé go raibh a hanam.

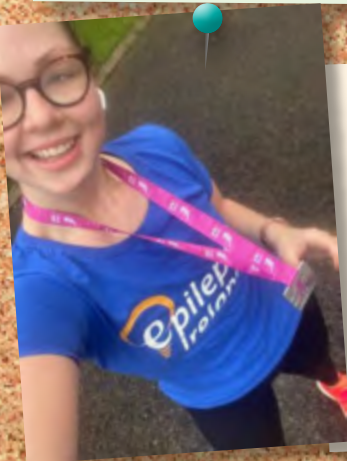
Pic: Madeleine Quirke with Katie Young, Cllr Maura Bell Mayor, Borough District of Wexford, Tina Young, Paddy McGeoghegan from Epilepsy Ireland, Jenny Young and Stewart Young at a Night to Remember for Louise



Did you know?

The days may be getting longer and warmer, but given it's Ireland, there can still be a nip in the air! Did you know we now have Epilepsy Ireland hoodies on sale in our shop to help keep you warm and cosy? Well, you do now! The hoodies can be purchased on our shop at a cost of €35 and come in a royal blue or navy option! Get yours today!

▶▶ <https://bit.ly/EiHoodie>



It's nearly Marathon Season!

Marathons are a fantastic way to support our work and we have been privileged to have hundreds of people represent Epilepsy Ireland in marathons right across the globe. Whether you come in first or last, you are a champion in our eyes if you decide to take on the ultimate endurance test in our name! With a number of marathons coming up and people getting signed up, we wanted to remind our members to please consider taking part in a race in support of EI! To see upcoming marathons, visit our website to learn more and further details!

▶▶ <https://bit.ly/EIMara>

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Cover for the Mid-West region is currently being provided by our Community Resource Officer team and the lead point of contact for the service is Agnieszka:
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If you need information or support on your journey with epilepsy, we are here for you. Get in touch with your local Community Resource Officer.



The Scheme to Support National Organisations is funded by the Government of Ireland through the Department of Rural and Community Development

