



# EPILEPSY NEWS

Issue 99 Summer 2023

The official Epilepsy Ireland members' newsletter

**All roads lead to Dublin for the 35th  
International Epilepsy Congress!**

## **In this issue:**

- Major progress on longstanding Epilepsy Ireland advocacy campaign!
- Have you downloaded 'EpiLearn'?
- Mary's story
- Details of our plans for the International Epilepsy Congress!
- ... much much more!

## NOTE FROM THE EDITOR



### ***Welcome to the latest edition of Epilepsy News!***

As I write this, there is fantastic sunshine coming through my window so let's hope that's a sign of things to come for the summer ahead!

With the hope of a warm summer ahead in Ireland – and for those heading overseas – in this edition of our newsletter, you'll find some tips for staying safe in the sun.

It's going to be a busy summer ahead for Epilepsy Ireland as there is a major event at the end of the summer – with the International Epilepsy Congress taking place in the Convention Centre in Dublin in September. This is a huge global event, that brings together leading epilepsy clinicians from across the world. You'll be pleased to know that Epilepsy Ireland is playing a significant role in the Congress, particularly in arranging public-facing events over two nights as part of the congress for people with epilepsy and their families. These events will replace our National Conference this year, and this edition of our newsletter will give you an update on what we have planned.

In recent weeks, we have also had a major resolution to one of our most longstanding advocacy campaigns – concerning the

need for reasonable accommodations for students sitting the Leaving Cert exams. There's also more good news on the advocacy front – with the recent reimbursement of Cenobamate (Ontozry®). This edition will bring you up to date on all of this.

We also have a personal feature from Mark McGuire, who is taking on Kilimanjaro in support of Epilepsy Ireland in August, in his son Ciaran's name - and we look at the launch of our new app 'EpiLearn', which is Epilepsy Ireland's first foray into the world of e-learning.

Alongside the above, we have updates on some of the incredible fundraising efforts which have taken place in support of Epilepsy Ireland since the last edition of our Newsletter; information about a new event for teens with epilepsy that we are planning to start in September; while our Creative Corner returns once again with two fantastic thought-provoking poems about the lived experience of epilepsy.

All this and much more!

As always, we remain here for support and information that you or your family may need regarding your journey with epilepsy. Contact your local Community Resource Officer if you need support. You can find their details on the back page of this edition of our Newsletter.

Have a great summer and hope to see you at the Congress in September!

***Paddy McGeoghegan***

*Advocacy & Communications Manager*

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**Front Page Image:**  
We're heading to the Convention Centre in Dublin in September for the 35th International Epilepsy Congress.

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# QUESTION TIME!

For our members who may have missed it, we have relaunched an awareness raising initiative on our Instagram page, aimed at people living with epilepsy.

Every month, we will ask a question, which people can answer anonymously with their own experiences or thoughts. The idea behind this initiative is that people who may not be totally comfortable with being open about their epilepsy can contribute to the awareness raising efforts of our organisation by responding to our questions.

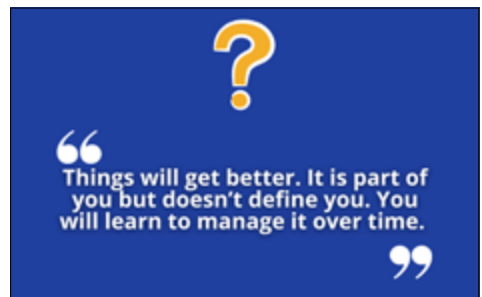
After the question box has been closed, we collate the answers and share them directly on our page anonymously to help people on their journeys with epilepsy and to help educate the wider public on the realities of living with the condition.

Make sure you're following us on Instagram and be sure to answer our next question time! We'd welcome any suggestions you may have for questions – and you can forward these to our Advocacy & Communications Manager, Paddy McGeoghegan by emailing [pmcgeoghegan@epilepsy.ie](mailto:pmcgeoghegan@epilepsy.ie).

Check out some of our most recent Question Times by visiting the links below.

▶▶ <https://bit.ly/QT2E1>

▶▶ <https://bit.ly/QT1E1>



A response from one of our followers to the question "What would you say to someone who is newly diagnosed with epilepsy?"

## Thank you Cara!



Cara getting ready to tell her story in front of the camera.

For National Epilepsy Week 2023 and tying into the theme of #EpilepsyMatters, we arranged for our media volunteer Cara Downey Martin from Mayo to speak about her recent breakthrough seizure – when unfortunately, her seizure wasn't recognised by those around her.

In the video, Cara spoke about having her seizure – as did her boyfriend Ciaran – who luckily recognised what was happening and knew how to respond. The video highlighted why it matters that the wider public know that there is more than one type of seizure – and how to respond correctly.

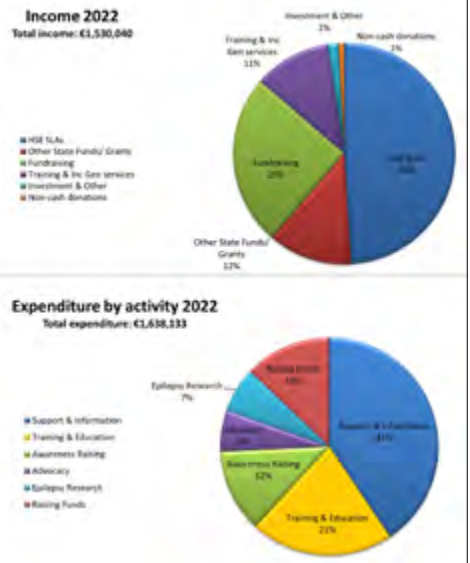
Thank you and well done to Cara - and Ciaran - for sharing their story. We have no doubt what they said resonated with both the public and people with epilepsy alike. If you didn't see the video, you can watch it back on our Youtube.

▶▶ <https://bit.ly/CDMNEW23>

## Use of Funds 2022

Epilepsy Ireland have published our 'Use of Funds' statement for 2022. The statement is based on our audited accounts for 2022.

Total income was €1,530,040 while total expenditure was €1,638,133 – meaning a deficit of €108,093 was recorded.



Of every euro donated to Epilepsy Ireland, 87c was spent on direct charitable objectives – while 13c was spent on raising funds.

While total fundraising income was down 7% compared to 2021, when adjusted for a significant one-off legacy donation of €100,000 in 2021, fundraising income showed a 22% increase in 2022 as the impact of the Covid-19 pandemic began to lessen. However, fundraising income remains substantially lower than pre-Covid – for example, €594,762 was raised in 2019.

The impact of the pandemic and the current cost of living crisis will continue to impact on our organisation for years to come so we would appeal to our members to please consider supporting us in any way you can – be it hosting an event, donating, or taking part in a fundraising challenge.

We would like to thank everyone who contributed to work of Epilepsy Ireland in 2022 and we hope we can continue to have your support as we look to the future. To read the full Use of Funds statement, visit the link below.

▶▶ <https://bit.ly/UOFEI>

## | Study suggests people with epilepsy can experience social avoidance

A study recently featured in leading epilepsy medical journal, *Epilepsia*, has investigated the impact the condition can have on a person's friendships.

The study was conducted by researchers in Germany and their findings are ones which will perhaps not come as a surprise to many people living with epilepsy in Ireland. The researchers concluded that people with epilepsy can still experience social avoidance, and this can increase when a person's seizures are more severe.

As part of their research, 64 people with epilepsy (PWE); 64 relatives of people with epilepsy; and 98 controls (members of the public with no connection to epilepsy) were surveyed using a Likert scaling method. This is a method which measures either positive or negative responses to a statement.

The main finding of this study was that the controls (individuals who have no prior exposure to epilepsy) were less interested in a friendship with a PWE with mild epilepsy (-3%) and even more avoided PWEs with severe epilepsy (-12%), whereas in PWEs with tonic-clonic seizures, a mild form of epilepsy was actually conducive to friendship (+7%).

The study therefore highlights that social avoidance of people with epilepsy exists and that people who have had no prior contact with epilepsy are more reluctant toward friendship with PWE. There was no discrimination regarding the control disease of diabetes, indicating that social avoidance relates specifically to people with epilepsy.

We know that the findings will not come as a surprise to many people reading this article.

The research highlights why awareness-raising efforts (such as Cara's mentioned on page 4) are so important in order to break down perceived stigma of the condition across the globe.

To read more about this study, and to see resources we have available to help aid you discussing epilepsy, visit our website below.

▶▶ <https://bit.ly/SAEI23>

## | Could a blood test help diagnose epilepsy in the future?

A new study from Sweden has suggested that a blood test could help to identify epilepsy. The study was recently published in the medical journal, *Heliyon*.

The study investigated a small group of people – 56 in total. However, it was found that there was an increased level of an immune system protein called IL-6 in the blood of people with epilepsy.

The researchers investigating the 56 patients knew whether they were taking blood samples before or after seizures. When they compared the bloods of the study participants against "healthy" counterparts, the increased level of the protein IL-6 was discovered. In fact, it was found that the levels of protein further increased in people with Temporal Lobe epilepsy after they had a seizure.

While the findings suggesting a possible new biomarker for epilepsy are certainly interesting, the researchers have acknowledged that further research on this will be required – with plans already afoot to further investigate this in adults and children with epilepsy.

You can read more about this research and access the full paper by visiting our website!

▶▶ <https://bit.ly/BTEI23>

# 35th INTERNATIONAL EPILEPSY CONGRESS COMES TO DUBLIN!



*There is a huge event coming to Dublin in September – and we're delighted to inform our members that you will have a chance to be part of it!*

The 35th International Epilepsy Congress (IEC) will take place in the Convention Centre from the 2nd - 6th September.

Organised every two years by the International League Against Epilepsy (ILAE) and International Bureau for Epilepsy (IBE), the Congress is the biggest international epilepsy meeting, with over 3,000 professionals in epilepsy care expected to attend this year.

As the local epilepsy patient organisation, Epilepsy Ireland has been working closely with the IBE and the ILAE in planning the Congress and our CEO, Peter Murphy is a member of the Scientific Organising Committee.

The scientific programme will have a wide

range of sessions and teaching programmes for the medical and scientific community. While the main Congress remains a medical-only event, a number of proposals from Epilepsy Ireland and the IBE have been accepted this year to increase public and patient engagement and to make this major event more relevant and accessible to people with epilepsy and their families.

For the first time, the Congress will include a special public programme to be held over two evenings and organised by Epilepsy Ireland. The evenings will feature expert international speakers who will present 'plain English' versions of their presentations from the main congress.

A wide range of topics have been chosen and with many of the world's leading epilepsy experts taking part, these public sessions are not to be missed.

While the full agenda has not yet been finalised, you will see a provisional agenda included on page 7. **Please note that this is a provisional agenda at the time of print and details are subject to change.** Further updates will be on [www.epilepsy.ie](http://www.epilepsy.ie) and our social media channels throughout the summer.

We invite all our members to register for one or both evenings as capacity is limited. Registration details will open on [www.epilepsy.ie](http://www.epilepsy.ie) on **June 19th**. There is a booking fee of €5 per ticket, but no other costs apply, and light refreshments will be provided.

This is a once-in-a-generation event (the Congress was last held in Ireland in 1997!) and we are very fortunate to have so many of the world's leading epilepsy minds right here in Dublin for a week. Thank you to all the speakers for making themselves

available to EI and our members & service users; and of course to the International League Against Epilepsy for their support in facilitating these public sessions.

Please note that these events will be replacing the traditional Epilepsy Ireland National conference this year. The conference will return in 2024. In the

meantime, we look forward to welcoming you to the magnificent Convention Centre venue on September 4th and 5th and to making the 35th IEC the best one yet!

To register to attend, please visit [www.epilepsy.ie](http://www.epilepsy.ie) from June 19th! If you need further information, please contact us at 01 4557500 or [info@epilepsy.ie](mailto:info@epilepsy.ie).

## International Epilepsy Congress 2023

The Convention Centre, Dublin, Spencer Dock, Dublin 1

### PUBLIC PROGRAMME (PROVISIONAL)

#### Monday 4th September, 5pm – 8pm

##### ***The genetics of epilepsy in 2023***

Prof Sam Berkovic, Laureate Professor in the Department of Medicine, University of Melbourne & Director of the Epilepsy Research Centre at Austin Health.

##### ***Managing the challenge of anxiety in epilepsy***

Dr Sophie Bennett, Clinical Psychologist, UCL Great Ormond Street Institute of Child Health, London & Dr Gaston Baslet, Assistant Professor of Psychiatry, Harvard Medical School.

##### ***Ketogenic diet and beyond: what is on the horizon?***

Prof Manisha Patel, Department of Pharmaceutical Sciences, University of Colorado & President of the American Epilepsy Society.

##### ***Climate Change & Epilepsy***

Prof Sanjay Sisodiya, Professor of Neurology at the UCL Queen Square Institute of Neurology, London.

##### ***Precision therapies for epilepsy; what's available and how well do they work?***

Dr Floor Jansen, Paediatric Neurologist, University Medical Center Utrecht, Netherlands.

##### ***The relationship between sleep & epilepsy***

Dr Birgit Frauscher, Associate Professor of Neurology, Montreal Neurological Institute & Hospital, McGill University, Canada.

#### Tuesday 5th September, 5pm – 8pm

##### ***Seizure detection systems & devices – the current state of play***

Prof Sándor Beniczky, Head of Clinical Neurophysiology, Danish Epilepsy Centre & Aarhus University.

##### ***Complex and Rare Epilepsies: The past, the present, and the future***

Prof Kette Valente, Paediatric Neurologist & Associate Professor University of São Paulo, Brazil.

##### ***When should surgery be considered?***

Prof Guy McKhann, Professor of Neurological Surgery, Columbia University Irving Medical Center, New York.

##### ***Neuropsychological Interventions in newly diagnosed epilepsy***

Prof Gus Baker, Consultant Clinical Neuropsychologist, The Walton Centre and University of Liverpool & Secretary General of IBE.

##### ***The role of exercise in managing epilepsy***

Dr Halley Alexander, Assistant Professor of Neurology, Wake Forest School of Medicine Winston-Salem, USA.

##### ***Plant based therapies for epilepsy***

Speaker TBC

# MARK'S KILIMANJARO CLIMB FOR CIARÁN & EPILEPSY IRELAND!



***In August, Kildare man Mark McGuire is set to take to take on a major challenge, all to raise funds for Epilepsy Ireland in the name of his son Ciarán. Mark will be scaling Kilimanjaro – we told you it was a major challenge!! With Mark's challenge for Ciarán now fast approaching, we wanted to share their story in full, and why Mark is taking on Kilimanjaro for Ciarán and in support of Epilepsy Ireland! Who better to tell you than Mark himself. . .***

I booked Kilimanjaro for my 40th and wasn't initially going to do a charity drive around it. But a little over 12 months ago we got the fright of our lives and thought Ciarán, then aged 6, was having a stroke in our kitchen one Saturday morning.

I'll let you use your imagination to come up with the reactions we had to that rather than upsetting you with the reality of how we felt.

This was followed by the worry and concern while we sat in the hospital for a week to find out what was happening - hearing things like 'stroke, brain bleed, brain tumor,' and so on. It was discovered that Ciarán has BREC, a form of Epilepsy that effects the Rolandic region of the brain.

Within our wider family, there's already been a significant and sad story with Epilepsy, but it's not my story to share but it had a significant effect on us all. For that reason, nothing grates my gears more than someone trivialising the condition as 'just epilepsy' and it was hard for all our family to hear that Ciarán has a rare form of epilepsy – as we already knew about some of the realities involved.

The area of the brain Ciarán's epilepsy affects is the area that controls facial muscles and speech - hence why we thought he was having a having a stroke when he was having his first seizure.

Even knowing this, I can safely say I'll never get used to seeing him have a seizure. As a parent, each one is as traumatizing as the last and while you have to accept it, you never want to see your child in that situation. Having said that, our response to Ciarán has gotten better and calmer as we learn more and more about this new part of all our lives.

Ciarán's been in and out of hospital over the past year after being diagnosed. And while we're quickly learning that epilepsy is a journey that has many ups and downs and bumps in the road, we did have an additional unexpected bump. Unfortunately, he had a severe allergic reaction to the first Anti-Seizure Medication he was put on

which made the beginning of our journey all the more difficult.

Thankfully, that's now behind us and our little warrior is responding well to his current meds. Although he's not seizure free, we've moved past a period in which he was having daily seizures.

And with that, I suppose that brings me nicely to the climb I'm doing in August. Ciarán and this whole episode has brought into my life a cause that now means quite a lot to me.

“

*As a parent,  
each one is as traumatizing as the last  
and while you have to accept it,  
you never want to see your child in  
that situation.*

”

Epilepsy is not just seizures at flashing lights as most people can view it - there's risks to some with SUDEP (Sudden Unexpected Death in Epilepsy), associated stigma, sometimes limits a person in terms of sports and activities, and so on and so forth – many reading this will know these impacts much better than me. But I know it's not all doom and gloom - having awareness of Epilepsy and knowing how to respond to it and manage it is key really - and that's where great services like Epilepsy Ireland are playing their part for my family and other families like mine.

So, the reason I am now doing this for fundraising drive, is firstly to dedicate what will likely be my greatest personal achievement in my life to Ciarán, who is to me, the most amazing little guy to ever walk the earth - and also a superhero of strength, resilience and adaptability to this condition, while the supposedly mature and strong parents struggle to keep up with him.

Secondly, I want to try and drum up some funding for a great service, Epilepsy Ireland, so that they can continue to build awareness and support structures for those like us affected by Epilepsy as well as for the wider community.

So, if you can – please donate as much or as little as you like to help me raise funds for Epilepsy Ireland as I try to take on the World's Tallest Free-Standing Mountain at nearly 20,000 feet! I'd also appreciate any good vibes or good luck wishes you can send my way as well!

*Thank you Mark for taking on this incredible challenge in support of Epilepsy Ireland in Ciarán's name. We can't wait to see you at the top of Kilimanjaro! If you would like to donate to Mark's efforts, you can do so on his idonate page below:*

▶▶ <https://bit.ly/MCGCKIL>

*Mark also regularly shares updates of his training before the climb on his business page, Mark Maguire Photography. You can follow him on Instagram at the link below:*

▶▶ [bit.ly/3WArSg1](https://bit.ly/3WArSg1)

## STUDENTS WHO HAVE A SEIZURE DURING LEAVING CERT EXAMS CAN NOW ACCESS DEFERRED SITTING



We received very good news at the end of April, which has effectively brought a conclusion to one of our most longstanding advocacy campaigns, with the State Examinations Commission (SEC) finally providing a pathway for students with epilepsy who experience a seizure DURING their leaving cert exam to access a deferred sitting of the exam later in the summer.

Now historically, a long-standing issue facing students with epilepsy had been that if a seizure happened before or during their Leaving Cert exams – that meant they were unable to sit or complete their exam(s) – there was no option for them resit within the same exam cycle. They would instead have to wait until the following academic year to try again.

In 2022, deferred exams for medical emergencies were announced for the first time in the history of the state. However, there was a major caveat as distinction was made between medical emergencies before and during exams. The 2022 criteria stated that students could not apply for access to deferred exams if a medical event, such

as a seizure, happened during their exam. According to the SEC, this was to protect the integrity of the exams.

The announcement made in April, built on the progress made on this matter in 2022 with an amended criteria issued to all schools, with the key change we had campaigned for included. The circular issued to schools included the following:

“The scheme for 2023 is being provided on the same grounds as in 2022 with one change in order to provide for a candidate who experiences an extreme medical emergency during an examination.”

Within the new criteria, specific reference is made to epilepsy and a seizure during an exam as an example of what constitutes a medical emergency which might prevent a student from completing their paper.

The new criteria in place for the 2023 exams means that students with epilepsy who are unable to sit an exam because of a seizure either prior to or during their exam will now be able to apply for access to a deferred sitting.

This was not the only welcome development within the amended criteria, as additional time for the application process was also built into the criteria – again something we had raised since last year.

Overall, this news was an extremely welcome development for students with epilepsy sitting the Leaving Cert this year, and will alleviate what for decades, was an

recent years. Additionally, we would like to thank the Irish Epilepsy League and Dr. Peter Widdess Walsh for their support in helping us achieve this outcome.

Most importantly, we want to thank you – our members, service users, and volunteers – for regularly using your voice to help amplify our calls to finally achieve this positive change for future generations of students with epilepsy.

“

*The scheme for 2023 is being provided on the same grounds as in 2022 with one change in order to provide for a candidate who experiences an extreme medical emergency during an examination.”*

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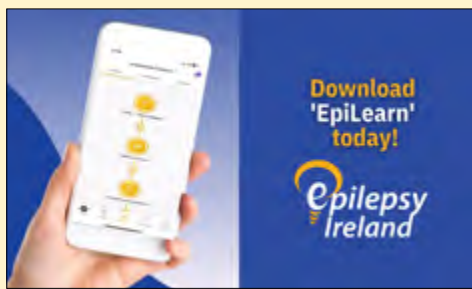
unnecessary additional worry at one of the most stressful periods of the young person's life. We will monitor how the new system works in practice in June, and we hope that the new rules will finally close the door on the longstanding issue of appropriate 'reasonable accommodations' for students with epilepsy.

We would like to thank the State Examinations Commission and the Minister for Education for their understanding and for addressing this matter. We also want to thank the dozens of TDs and Senators who regularly raised this issue in the Dáil in

Together, we can achieve a society where no person's life is limited by epilepsy.

*Full details of the new criteria, as well as the history of this issue can be found by visiting the Advocacy section of [www.epilepsy.ie](http://www.epilepsy.ie). While we hope this hasn't happened for the Leaving Cert students of 2023, if your loved one with epilepsy experienced a seizure during the Leaving Cert exam and had to apply for access to the deferred sitting, we'd be interested in hearing your experience of the process in order for us to monitor same. You can let us know by emailing our Advocacy & Communications Manager, Paddy McGeoghegan on [pmcgeoghegan@epilepsy.ie](mailto:pmcgeoghegan@epilepsy.ie).*

# EPILEPSY IRELAND LAUNCH NEW EPILEPSY EDUCATION APP - EPILEARN



Our members will know that we have a wealth of information and resources about epilepsy on our website; and how people with epilepsy, their families and local communities can access the vital supports provided by our team of Community Resource Officers. However, we know that people want access to information on the condition in different ways.

That is why we were delighted to complement our existing service by adding a new digital, interactive layer to our information resources for those seeking to learn more about epilepsy – by launching 'EpiLearn' during National Epilepsy Week.

The new app provides bitesize information on epilepsy, structured into pathways of learning that features videos, quizzes, and practical exercises. The app was launched with one pathway, designed to give users an introduction to epilepsy and features four distinct levels focussed on:

- Level 1 What is Epilepsy?
- Level 2 Non-Convulsive Seizures
- Level 3 Convulsive Seizures
- Level 4 Supporting information on Epilepsy.

The app is Epilepsy Ireland's first foray into the world of e-learning, and we plan to

add further pathways and resources to the app for a range of different audiences and stakeholders.

The new app has been designed and developed in collaboration with healthcare e-learning specialists, Aurion Learning, developed using their latest learning platform offering, ByteKast.

Commenting on the launch of EpiLearn, Epilepsy Ireland's Training and Quality Manager, Edel Curran said:

"The availability of this engaging new platform will be an accessible resource that will take the user on a journey to increase their understanding of epilepsy at a time that is convenient for them. The aim of this is to provide information in an interactive way that will engage the user through different activities, to help people to gain valuable insight into the condition of epilepsy."

We hope that the app will be a great addition to information services on epilepsy we already provide – and will help us progress further on our journey towards a society where no person's life is limited by epilepsy.

EpiLearn is **FREE** to download and use via both the Google Play Store (Android) and iTunes Store (Apple) while a desktop version is also available. Visit our website to download EpiLearn today and encourage others to do likewise!

▶▶ <https://bit.ly/3qgXJpO>

*While the app has now been launched, we are still in the infancy of its existence. Therefore, we would welcome any feedback or suggestions you may have. Please email our Training & Quality Manager, Edel Curran, on [training@epilepsy.ie](mailto:training@epilepsy.ie) with any feedback you may have.*

# HSE CONFIRMS REIMBURSEMENT OF CENOZRY®

We are pleased to confirm with our members that the anti-seizure medication, Cenobamate (Ontozry®) has been approved for reimbursement by the HSE. Approval for reimbursement means the cost of the medication will now be covered by the state under the Long-Term Illness, Drug Repayment and Medical Card Schemes.

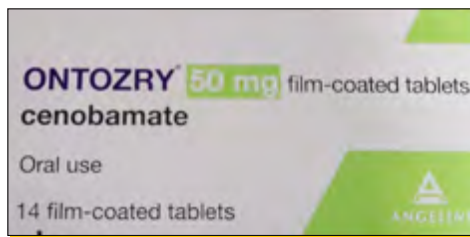
This is a very welcome development and marks the end of a process which saw Epilepsy Ireland advocate for approval of reimbursement through an extensive submission to the National Centre for Pharmacoeconomics (NCPE).

Our submission to the NCPE focussed on the experience of those living with refractory focal-onset seizures, to give decision makers a clear insight as to why this medication needed to be reimbursed.

As many reading this will know, focal-onset seizures can often be misunderstood and can have an impact on all aspects of a person's life such as emotional wellbeing, social interactions, or a person's ability to work or pursue further education.

In addition, epilepsy is an individual condition and while there are currently many anti-seizure medications available in Ireland, it is crucially important that people with epilepsy have access to new treatments. This is because there is a percentage of the epilepsy community for whom which currently available treatments do not have an impact in treating their condition.

The submission we made also contained various powerful personal experiences that we received directly from people with



epilepsy on the lived experience of living with these types of seizures and the impact they can have.

We have no doubt that all the personal testimonies we received were paramount in bringing about this positive decision and we would like to thank everyone who contributed to this submission, many of whom may have been our members reading today – given we have featured articles about Cenobamate in previous editions of 'Epilepsy News'.

We are delighted that this new treatment is now available to people with epilepsy, and we hope for those prescribed, that they see positive results from same. *(Please note that any decision around treatments is a conversation you must have with your medical team.)*

In a general sense, Epilepsy Ireland will continue to monitor evidence around emerging treatments and advocate that people with epilepsy across Ireland have access to proven and effective treatments as soon as possible.

Once again, we would like to thank everyone who contributed to our submission which was crucial in bringing about this positive development.

# TIPS FOR STAYING SAFE IN THE SUN



*As we write this, the sun is splitting the stones in Ireland and in the hope that this wonderful weather is here to stay, we thought we'd share a few useful tips with our members on staying safe in the sun with epilepsy.*

Extremes of heat can trigger seizures for some people with epilepsy so bear these tips in mind while enjoying the sunshine over the summer!

## 1) Be cool

An obvious one but take a break in the shade for periods to help reduce the impact of the heat on your body.

## 2) Hydrate

Stay hydrated but don't overdo it either. Under and over-hydration can lead to seizures so adjust your daily intake of fluids accordingly to suit your needs.

## 3) Stick to routines

This again might appear obvious but when out and about in the sunshine or travelling to the nearest beach, heading to or arranging a BBQ, it can be easy to lose track of time so a reminder to make sure you stick to your medication routine as normal.

## 4) Stay protected in the sun

Many of you reading this will have had the experience of being sun burned at some point in your life – nobody will recommend it! We all know how difficult it can be to get to sleep when you've been caught by the sun but for a person with epilepsy, it's important to remember about how important good sleep and rest can be to maintaining seizure freedom.

So – make sure you have that sun cream on and keep topping up to try and avoid this!

## 5) Alcohol

Many people will point to alcohol being a seizure trigger. Some people with epilepsy drink and some do not but bear in mind about the impact alcohol could have on your condition combined with the heat. Manage your intake and remember that alcohol can dehydrate as well.

## 6) Enjoy!

**The most important tip of all!** We don't often have good weather like this in Ireland so enjoy it while it's here! These tips are no way meant to deter your enjoyment of what is a rare occasion in Ireland (the sun!) but are important to bear in mind during a period when we can all fall out of routine as we aim to make the most of the good weather.

If you need any information or support about epilepsy over the summer period, be sure to link in with your local Community Resource Officer – you can find their details on the back page. We also have a resource around holidays and travel on our website. If you're jetting off over the summer, be sure to check it out.

▶▶ <https://bit.ly/23HTEI>

# STUDY SUGGESTS POSSIBLE INCREASED RISK TO CHILDREN OF FATHERS TREATED WITH SODIUM VALPROATE (EPILIM)

Findings from a new study, which was undertaken at the request of the European Medicines Agency (EMA), has highlighted potential increased risks of neurodevelopmental disorders in children whose fathers were treated with Sodium Valproate (Epilim) at the time of conception.

The study was conducted using data from several registry databases in Norway, Sweden and Denmark and compared children whose fathers were treated with valproate in the three months preceding conception with children whose fathers were treated with lamotrigine or levetiracetam (other medicines to treat epilepsy and/or bipolar disorder).

The results may indicate an increase in the risk of neurodevelopmental disorders, such as autism spectrum disorders, in children whose fathers were treated with valproate. The study reported a risk of 5.6% to 6.3% for children born to fathers treated with valproate, compared with 2.5% to 3.6% for children born to fathers treated with lamotrigine (Lamictal) or levetiracetam (Keppra).

The study was undertaken by pharmaceutical companies that market valproate-containing medicines as an outcome of the EMA's safety review of valproate that concluded in 2018.

As a result of the findings, the study is being carefully examined and the EMA has requested additional data and analyses from the pharmaceutical companies to ensure the study findings, including the strengths and limitations of the data, can be fully understood. The EMA have stated that the outcome of this evaluation will be communicated to patients and healthcare

professionals once available.

The risks of Sodium Valproate use in women who are pregnant have been well established in recent decades. In 30-40% of cases where the child has been exposed to valproate in utero, the child will have serious developmental disorders. In 10% of cases, the child will have congenital malformations.

However, until now, there has been a lack of data on the impact of the medication on the child if the father was treated with Sodium Valproate at the time of conception. One previous study from 2020 had found no statistically significant increased risk of adverse outcomes.

While these are concerning findings and may be worrying to men with epilepsy planning to start a family, it is important to re-state that further analysis of the data will be undertaken throughout 2023. Until the outcome of this evaluation is known, the results should not be taken as conclusive.

In the meantime, if you are a man with epilepsy taking Sodium Valproate (Epilim) and are planning to start a family, **DO NOT** stop taking your medication without first having a discussion with your medical team. Discontinuing or reducing your anti-seizure medications is likely to lead to the recurrence of seizures or an increase in seizure frequency.

Epilepsy Ireland will continue to closely monitor developments regarding this and we will provide updates on our website, social media channels and in future editions of our newsletters once further information is available.

▶▶ <https://bit.ly/HPRAPat23>

## CREATIVE CORNER

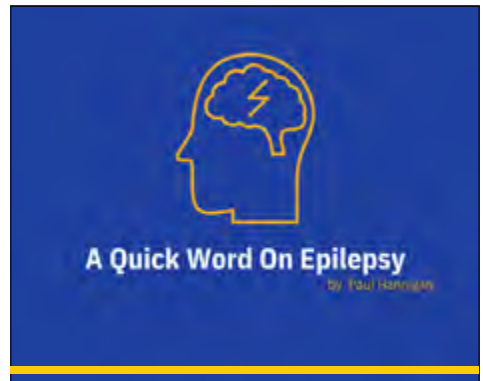
The creative corner is back and in this edition, we have two incredible poems on the lived experience of epilepsy. If you would like to make a submission to the Creative Corner for a future edition Epilepsy News, please email our Advocacy & Communications Manager, Paddy McGeoghegan on pmcgeoghegan@epilepsy.ie.



### YOU BY CLAIRE

*I've never known a life without you,  
I've had you from the time I was a baby and said coo.  
As a child you were always in the way,  
But my neurologist, my parents and grandparents did their  
best to keep you at bay.  
I've fought many battles with you over the years,  
Especially at school, college and with other things I do.  
Sometimes you strike at the most inopportune of times,  
And getting lucky for me, was unlucky because of you the  
first time.  
When you strike, it feels like you're cutting my brain with  
a knife,  
You try to knock me down and put me in strife.  
You may win the battles, but I will win the war,  
I'm an adult now, a fighter and I'll fight you even if sore.  
You're striking a lot lately with seizures and side-effects,*

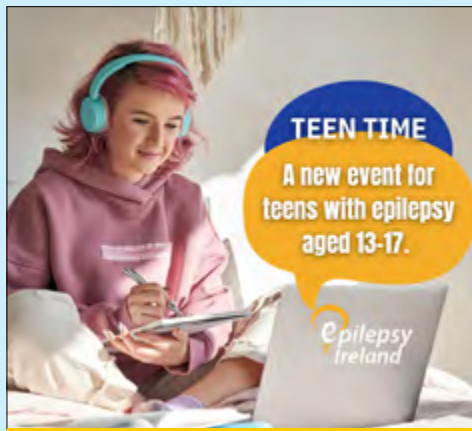
*But I do come back stronger and give everyone a shock.  
I've had you on public transport and holidays,  
But I won't let you take over my life.  
You affect everyone around me too,  
It's heart-breaking for everyone who loves me to see what  
you do to me.  
But they support every day still,  
And just treat seizures like a spilt cup of tea.  
They're here beside me in my fight with you,  
And always help me see the light.  
I've my job, my independence, my life,  
And someday I plan on being a wife!  
I'll put you back in your box,  
And keep on fighting like a feisty fox!  
You don't have me, I have YOU!*



### A QUICK WORD ON EPILEPSY BY PAUL HANNIGAN

*Epilepsy is my neurological condition  
Paranoia anxt and fear are unwelcome additions  
Inability to remember, that comes with it too  
Losing treasured memories is horrific to go through  
Education helps me along with much endurance  
Prescription meds are may I say an unwelcome insurance  
Seizures take the spotlight as they chip away at you  
Yet living with epilepsy is just one thing that I do.*

## TEEN TIME



We are delighted to inform our members that beginning on the 20th September, we will be beginning a new monthly offering targeted at teens living with epilepsy.

The addition of 'Teen Time' follows on from new initiatives which we have introduced for young people and children with epilepsy over the past year or so – including 'Get ChARTy' for children with epilepsy aged 10-13; and the MMU for young adults with epilepsy aged 18-24.

'Teen Time' has been specifically designed to fill the gap between these two offerings, and to be an outlet for teenagers with epilepsy to meet with other living with the condition.

We know that the teenage years can be some of the most difficult on a person's journey with epilepsy. Hormonal changes can lead to an increase in seizures or even a change in seizure presentation. Furthermore, teenagers become more conscious of their surroundings, their peers, want increased independence etc – and this is often when some of the realities of living with a lifelong health condition become clearer.

We know from our day-to-day engagement with people with epilepsy and their families

– and indeed, from our media volunteers – that many point to the teenage years of their respective journeys with epilepsy as being the most difficult.

'Teen Time' will be a safe space for teens living with epilepsy to discuss their condition and meet with others living with the condition to share their stories and experiences. This offering is planned to continue throughout term-time, and it will be targeted at 13-17 years old. Throughout this offering, where appropriate, we also plan to have guest speakers attend sessions on key topics of interest to teenagers – such as the importance of speaking about epilepsy; managing stress and anxiety; and workshops on study skills. We will also take feedback from the teens in attendance on specific topics that they might want insight on.

Meetings will also be attended by our Community Resource Officers Agnieszka Polak and Joanne Lynch, who will be jointly leading on this event. It is important to note – while parental permission for this event will be required, this event will be for **teens only** and we will be strictly enforcing rules around parents/guardians attending or sitting in on these events. Having parents or guardians present in any way at these sessions will not enhance the environment we are trying to build.

The first session of 'Teen Talk' will take place on September 20th on Zoom from 7:00 -8:00pm. If you have a teenager who would be interested in attending or have any further questions, please contact Agnieszka by calling 0858063959 or emailing [apolak@epilepsy.ie](mailto:apolak@epilepsy.ie); or Joanne by calling 0858766584 or emailing [jlynch@epilepsy.ie](mailto:jlynch@epilepsy.ie).

*Further information on this event and all our upcoming events can be found in the 'Events' section of our website.*

## MARY'S STORY



*For National Epilepsy Week 2023, Mary Maher from Dublin penned a piece reflecting on her own personal journey with epilepsy. In it, Mary reflects on the changes and attitudes to epilepsy that she has seen throughout her life. We wanted to share Mary's story in this edition of Epilepsy News as we have no doubt that it will resonate with people with epilepsy of all generations . . .*

I was born with epilepsy – and I'm 66 years old now.

Back when I was diagnosed, for my parents there was nowhere or no one to turn to about your concerns or how to support your child with epilepsy. Every once and a while, my parents would meet with my neurologist and reported how things were going with my condition. I can also remember intermittent EEG appointments every now and then.

But we were very much on our own. It was my mother who learnt how to manage my seizures and used her gut instinct to guide her. My seizures were controlled by the time I was 8 or 9 years old.

For me, the golden rule was to not get overtired, get good sleep and to take my medications as directed.

It was tough as a teenager. I hated not being able to stay out late with friends. They would be heading off to a disco, but I would have to go home. I felt as if I was looking in at them living their life from the outside, and my life lacked spontaneity. Everything had to be planned in advance and I felt like I was constantly missing out on all the fun. I was famous for saying 'I can't, I need to get x hours of sleep'.

It was tough but I got through it but as we all know, once you're diagnosed, there's always a possibility that your seizures could return – and mine returned when I was 27 – this time, a different type of seizure compared to what I was having in childhood.

Medications had to be changed and it took years for me to gain seizure control once more. I couldn't get work at the time. Remember, this was in the mid-80s and I was told how I would be a liability to have on the premises or worse, how I would be an embarrassment to the firm should I have a seizure.

“

*While no doubt there is much more to do, I think we have come such a long way and everyone who has done anything to raise awareness of epilepsy should be immensely proud of themselves.*

”

With my seizures still presenting, after many tests, it was found that I would be a candidate for surgery – and over 20 years ago, I had a successful surgery on my right temporal lobe. I still take my medications every day, a small price to pay for being seizure free. Despite the ups and downs that epilepsy has brought, and the dark days which I have had, I have still had a full

and happy life – and I was able to return to employment. I'm now actually retired and enjoying this new chapter of my life.

I wanted to share my story during National Epilepsy Week, as a reflection on my journey but also to highlight how far we have come. There is a dedicated community of people out there, there is much more understanding and awareness about the condition. As someone who has lived with epilepsy my entire life, it's really heartening to see the supports that are offered by Epilepsy Ireland and to see people talking more openly about their condition.

While no doubt there is much more to do, I think we have come such a long way and everyone who has done anything to raise awareness of epilepsy should be immensely proud of themselves.

To the wider public, I would say take two minutes to learn more about epilepsy – it only takes a few minutes.

#EpilepsyMatters

*Thank you Mary for sharing your story – we really appreciate it! Alongside sharing her story with us for National Epilepsy Week, Mary also spoke to her Active Retirement Group about her journey with the condition to help raise awareness. Mary was on brand as you can see from the pic included alongside this article and even had printed off a new version of our Time, Safe, Stay logo to share with everyone there. Well done Mary!*

*If you would like to share your story for a future edition of Epilepsy News, or become a media volunteer, please contact our Advocacy & Communications Manager, Paddy McGeoghegan on [pmcgeoghegan@epilepsy.ie](mailto:pmcgeoghegan@epilepsy.ie).*

## FREE TRAVEL CAMPAIGN UPDATES



While we finally had good news regarding one of our other most longstanding Advocacy campaigns concerning deferred sittings of Leaving Cert exams, there has also been a lot of activity around our other key campaign concerning improved access to the Free Travel scheme for people with epilepsy.

Our members will be aware that following our budget proposals in 2021 and 2022, and a subsequent meeting with the Minister for Social Protection, the Department has been investigating our proposals and toward the end of last year, began to state that they would issue a final report to the Minister on this in the first quarter of 2023.

Unfortunately, quarter 1 of 2023 has been and gone with no sign of a final report being issued yet. Therefore, we have been continuing to use every avenue available to us to draw attention to this matter and add further pressure.

At the end of April, we wrote to the Minister seeking an update regarding her Department's ongoing assessment of our proposals.

As part of our correspondence, we noted how the report needs to be completed urgently – and we highlighted how, given the amount of time that has gone into its

preparation, we sincerely hoped that when produced, it will contain a step forward on this longstanding issue which faces people with epilepsy.

Following this, we also wrote to all members of the Oireachtas Committee on Social Protection, highlighting our correspondence and seeking the Committee's support for our proposals. We also reached out again to all opposition and Government party's spokespeople, highlighting our campaign and seeking their support.

During National Epilepsy Week, the campaign was then raised by Deputy Donnchadh Ó Laoghaire with the Minister for Social Protection, Deputy Heather Humphreys, under Priority Questions.

Deputy Ó Laoghaire raised many of the key points of our campaign and highlighted the impact driving restrictions can have for people with epilepsy.

While the Minister did not give defined timelines on when the long-awaited report will be presented to her, and would not be drawn on what it would contain, she did make reference to expecting it in the coming weeks. Additionally, the Minister also noted in her reply to Deputy Ó Laoghaire a need to consult with Minister for Transport, Deputy Eamon Ryan, on foot

of her receiving this report.

On this particular point, we believe that the proposals we have put forward are the most logical approach to address this issue, especially given that other categories of people with disabilities can already access the Free Travel scheme without needing a qualifying payment from the Department of Social Protection. Furthermore, the Free Travel scheme already exists, has a clear purpose, and can be amended to expand eligibility to people with epilepsy who have been restricted from driving. With the necessary eligibility amendments, we believe it would make more sense to work within the existing scheme rather than create a new one to address this issue.

However, as we noted in our meeting with the Minister last year, an effective solution that addresses the challenges facing people with epilepsy is paramount, regardless of what mechanism is put in place to achieve it.

We are urging the Department to finalise its report for the Minister so that we can move towards a positive outcome on this long-standing issue affecting many people living with epilepsy.

Finally, in the latest recent development regarding this campaign, Epilepsy Ireland have made a further submission to the Oireachtas Committee on Social Protection at the end of May as part of their pre-budget consultation process. Once again we have highlighted our key points around this issue and urged that the Committee support our campaign and include our submission within their own budget submission to the Minister and the Department.

As always, we will continue to keep members informed of this campaign in future editions of our Newsletter and we will post the latest developments on our website and social media channels. If you would like to support this campaign, you can do so by visiting the 'Advocacy' section of [www.epilepsy.ie](http://www.epilepsy.ie), where you can find a template letter to send to your local TD or Senator.

In addition, if you are willing to share your own personal story of the impact of this issue is having on you personally or your family, we would like to hear from you. Being able to share direct experiences as part of our continued campaigning on this matter is vital as it highlights the realities that driving restrictions due to epilepsy can have. If you would like to learn more about this or contribute, please contact our Advocacy & Communications Manager, Paddy McGeoghegan by emailing [pmcgeoghegan@epilepsy.ie](mailto:pmcgeoghegan@epilepsy.ie).

We would like to thank our members for their continued support on this most important matter.

▶▶ **Deputy Ó Laoghaire debate with Minister Humphreys** - <https://bit.ly/DOLFT23>

▶▶ **EI Correspondence to Minister Humphreys** - <https://bit.ly/EIHH23>



# FUNDRAISING

## Hold an event in support of EI!

Over the years, we have had our incredible members, volunteers and supporters host fantastic events in an effort to raise funds for Epilepsy Ireland and our journey towards a society where no person's life is limited by epilepsy. These have included coffee mornings; non-uniform days at school or even purple themed days at work! With the good weather and the long evenings now here, if you want to host an event in support of Epilepsy Ireland, please get in touch with our team on [fundraising@epilepsy.ie](mailto:fundraising@epilepsy.ie) and we will work with you to make your event the best it possibly can be! Perhaps you can take inspiration from the incredible efforts which are featured on this page!



## Thank you to #TeamEI!

A huge thank you to anyone who has run a marathon in support of Epilepsy Ireland since the last edition of our Newsletter. At the time of print, we have just had a number of incredible women smash the VHI Women's Mini-Marathon! We hope that our runners are having a well-deserved rest! We've also had supporters recently take on Cork City Marathon, Run Mayo, the Great Ireland Run and countless others training and getting ready to take on other marathons later this year!

Once such group who have smashed their challenge recently, was the Lavery family from Belfast – who took on the Belfast City Marathon in memory of their Uncle Ciaran and in support of Epilepsy Ireland. They raised a fantastic £1,474 for Epilepsy Ireland in his memory – thank you all!

Pic: Leontia and Margaret with a picture of Ciaran.

## Donegal Horizons Coffee Morning!

A huge thank you to everyone at Donegal Horizons for their support of Epilepsy Ireland, through a fantastic Coffee Morning and raffle in May.

We seen pictures of the spread that was offered up on the day – and the prizes that were on offer through the support of the local community (including a signed jersey by Ireland Captain, Seamus Coleman) – and by seeing those, it's clear why you raised over €4,000 in support of our work!

A huge thank you to everyone involved in this incredible fundraiser – we really appreciate it!





## Will it be third time lucky for Anita?

Anita O'Leary from Tipperary will be taking on a serious challenge in support of Epilepsy Ireland on the 25th of June!!

Irish weather permitting, Anita will be taking to the skies and then subsequently jumping out of a plane to raise funds for our work towards a society where no person's life is limited by epilepsy.

Unfortunately for Anita, her jump has been cancelled now on two occasions so hopefully it will be third time lucky for her!

Anita informs us that she is scared of heights so let's just say this mammoth challenge isn't going to be the easiest on her, yet she wants to take it on to raise funds for EI in the name of her daughter Aine, who is 12 years old.

Aine was diagnosed with epilepsy last year and Anita has used our services for support & information around the condition as the family & Aine continue their journey with epilepsy.

Thank you, Anita, for your support and we really appreciate your incredible efforts in support of our work, in Aine's name.

If you would like to support Anita's fundraising efforts, you can donate directly on our website. Click the 'Donate' button below but be sure to select 'Anita's Skydive' from the drop-down menu!

▶▶ <https://bit.ly/EIDon23>

Pic: Anita has her T-shirt and is ready to jump!



## Jake's Walk

Kilkenny epilepsy warrior Jake led an incredible fundraising and awareness event in support of Epilepsy Ireland on the 6th of May!

11-year-old Jake was joined by his Mum & Dad, Zoe & John, and his siblings Abbie, Ava, Charlie & Zoey; as well as his friends and local community to walk from Lacken Walkway; through Castle Park and through Kilkenny town – covering a total distance of over 5k.

Since Jake's diagnosis of epilepsy, his family have lent on our service for information and support about the condition, and they wanted to organise this event to support our service and raise awareness of the condition within their local community.

They certainly did that as there was sea of blue and yellow Epilepsy Ireland t-shirts walking the 5k alongside Jake in support of Epilepsy Ireland. Final tallies are being counted but €340 was donated online alone which is a fantastic amount!

Pic: A collage of some pics taken on the walk.

## COMMUNITY RESOURCE OFFICER DETAILS

### Donegal, Sligo & Leitrim

Agnes Mooney  
amooney@epilepsy.ie  
0858689433

### Galway, Mayo & Roscommon

Our Community Resource Officer for the West, Catherine Caffrey is on extended leave until April 2024. Please contact our Head Office on 014557500 and you will be redirected to another member of our Community Resource Officer team.

### Louth, Meath, Monaghan & Cavan

Mary Baker  
mbaker@epilepsy.ie  
0858766583

### Offaly, Longford & Westmeath

Cliona Molloy  
cmolloy@epilepsy.ie  
0858766585

### Limerick, Clare & Tipperary

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:  
Agnieszka Polak  
apolak@epilepsy.ie  
0858063959

### Kilkenny, Wexford, Carlow, Waterford & Tipperary South

Joanne Lynch  
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0858766587

### South Dublin & Wicklow

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0858766587

### North Dublin & Kildare

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0858063959

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0858766626

Niamh Jones  
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njones@epilepsy.ie  
0858766628

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

