



# EPILEPSY NEWS

Issue 101 Winter 2023

The official Epilepsy Ireland members' newsletter



## In this issue:

- Budget commitment to Free Travel
- Coverage of the International Epilepsy Congress
- Pregnancy Prevention Programme to be introduced for Topiramate
- ... much much more!

## NOTE FROM THE EDITOR



Whether you can believe it or not, we're in the home straight towards the end of 2023 and to begin this final edition of 'Epilepsy News' for the year, we'd like to thank all our members for your incredible support throughout 2023! We have a bumper edition of our newsletter to bring you right up to date with the latest epilepsy and Epilepsy Ireland news.

Perhaps the biggest of these updates is progress on one of our most longstanding advocacy campaigns – with a major commitment made in the October budget concerning access to the Free Travel scheme. This edition will bring you up to date on what happened and what we're looking ahead to.

We'll also look back on SUDEP Action Day 2023, a very important day for the entire epilepsy community. We'll let you know what we highlighted on the day and why – while we also feature a personal story from Jenny Kelly, who writes about the loss of her husband Noel due to SUDEP. It is an incredibly personal but poignant piece, with a very important message to people with epilepsy and their families.

We'll also provide information on a new Pregnancy Prevention Programme introduced for the anti-seizure medication Topirimate (Topamax) following a decision

by European regulators; look ahead to Infantile Spasms Awareness Week at the beginning of December; and we'll look back on the incredible event that was the 35th International Epilepsy Congress!

Looking to 2024, we'll be giving our members a not-so-secret sneak peek of some of our plans for International Epilepsy Day 2024 - given that parts of the campaign have already been widely publicly featured – and of course, we'll let you know how you can get involved in the big day!

And finally, we'll look at **\*\*some\*\*** of the incredible efforts that our members, supporters and volunteers have undertaken in support of our journey towards a society where no person's life is limited by epilepsy – including somebody our members will be very familiar with from previous editions, standing atop the massive Kilimanjaro!

As we approach the end of the year, a reminder that our team are here for information and support on your and/or your loved one's journey with epilepsy.

Once again, thank you for all your support throughout 2023 and we hope you will continue to be there with us in 2024.

Enjoy the Christmas celebrations!

**Paddy McGeoghegan**

*Advocacy & Communications Manager*

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## Front Page Image:

Delegates at a special State Reception to mark #IEC2023 - see page 16!

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# WELCOME MARGARET & ROISIN!

We have two new faces to introduce to our members!

The first is our new Community Resource Officer for the Mid-West, Margaret Dixon. Margaret brings a wealth of experience to our team – joining us from Enable Ireland, where she regionally managed part of their Family Support Service for children with disabilities. She is also a registered nurse in General and Intellectual Disability and has worked previously in intensive care in the UK and Saudi Arabia. If you're from the Mid-West and would like to reach out to Margaret, you can do so by emailing [mdixon@epilepsy.ie](mailto:mdixon@epilepsy.ie) or by calling 085 876 6629.

Our second new face is Roisin Dolan – who is our new Fundraising & Development Executive. Roisin is a UCD graduate in Law and Social Justice – with the Social Justice aspect of her education sparking her interest in working in the non-profit sector. She also has community-based fundraising experience with her local GAA club, which we are sure will assist Roisin with helping our supporters with their fantastic events. If you'd like to reach out to Roisin, you can contact her by emailing [rdolan@epilepsy.ie](mailto:rdolan@epilepsy.ie) or by calling 085 871 4580.

We'd like to officially welcome both Margaret and Roisin to the team!



## Epilepsy risk in DNA changes identified



Professor Gianpiero Cavalleri

A major international study, involving Irish researchers, has identified 26 distinct areas in our DNA that appear to be involved in developing epilepsy.

Epilepsy is known to have a genetic component and to sometimes run in families. As part of their project, researchers compared the DNA from diverse groups of almost 30,000 people with epilepsy to the DNA of 52,500 people without epilepsy. The differences highlighted areas of our DNA that might be involved in the development of epilepsy.

Professor Gianpiero Cavalleri, Professor of Human Genetics at RCSI School of Pharmacy and Biomolecular Science and Deputy Director of the SFI FutureNeuro Research Centre said was involved in this discovery and commented on the findings of the research and what it could potentially mean in the future:

“Gaining a better understanding of the genetic underpinnings of epilepsy is key to developing new therapeutic options and consequently a better quality of life for the over 50 million people globally living with epilepsy.

The discoveries we report on here could only be achieved through international collaboration, on a global scale. We are proud of how the global community of scientists working to better understand the genetics of the epilepsies have pooled resources and collaborated effectively, for the benefit of people impacted by the condition.

Undertaking such a comprehensive study is a remarkable achievement that RCSI and Futureneuro are proud to have played a leading role in. The challenge now is to translate the findings of this research to improve the lives of people with epilepsy.”

We would like to congratulate all involved in this research, particularly our colleagues in the RCSI and FutureNeuro. To learn more about this research, visit our website.

▶▶ <https://bit.ly/GenStudy23>

## Reminder – complete our survey!

A gentle reminder to our members to please complete our survey about your experience of engaging with Epilepsy Ireland.

Every response will help us plan for the future, further understand the needs of people with epilepsy and their families and identify how our services could potentially be improved or adapted.

The amount of time it will take to complete the survey will depend on how much you want to say – but we would greatly



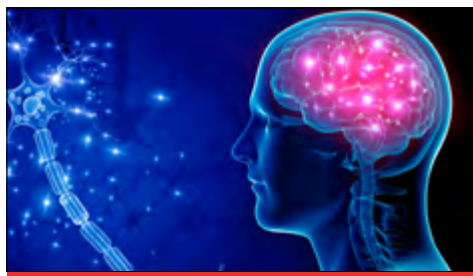
appreciate you taking whatever time required to complete the survey.

You can complete the survey by scanning the QR code alongside this article or by visiting the website below.

▶▶ <https://bit.ly/EIExpSur>

*The survey will close on December 1st and thank you in advance for completing!*

## | New Tech could help treat drug-resistant epilepsy



The Tyndall National Institute, which is based in University College Cork, recently announced details of a new technology which they believe could help to reduce seizures in drug resistant epilepsy.

Many people with epilepsy and their families will be familiar with treatments that target the Vagus Nerve - and how this can potentially help to reduce a person's seizures. Vagus nerve stimulation applies electrical current pulses on a nerve originating deep in the brain, which can potentially help to reduce the number, length, and severity of a person's seizures. The best current example of this is Vagus Nerve Stimulation therapy.

The technology developed at Tyndall builds on this via the use of photonics (the science and application of light) - to create a metal-free neurostimulator. This means that the technology replaces electrically conducting wires with non-conductive optical fibres and appropriate optoelectronics to stimulate the

vagus nerve. This is significant as it means the device would be suitable for use in MRI systems, as the wires are not metal.

With this, the level of stimulation can be tailored to each individual's requirements, potentially leading to better outcomes for patients fitted with the new technology.

We look forward to following the continuing development of this technology – with in-human clinical trials planned for next year. To learn more about this research, visit our website.

▶▶ <https://bit.ly/TyndEI>

## | Paternal Valproate Exposure Update

As many of our members will be aware, a European review is currently ongoing assessing the potential risk of neurodevelopmental disorders in children conceived by fathers who are taking Sodium Valproate.

In an update to the ongoing review, the Health Product Regulatory Authority recently issued a Direct Healthcare Professional Communication (DHPC) regarding this ongoing review. These communications are designed to ensure that clinicians have the most up to date information about a medication. However, it is important to note that the issuing of a DHPC does not mean the review is concluded or that the findings of the initial study can be seen as definite.

If you are a man with epilepsy taking Sodium Valproate (Epilim), **DO NOT** stop taking your medication without first having a discussion with your medical team.

You can read more about this communication – as well as this ongoing review – by visiting our website.

▶▶ <https://bit.ly/ValPat23>

# PREGNANCY PREVENTION PROGRAMME TO BE INTRODUCED FOR TOPIRAMATE



We can confirm that the recommendation of a Pregnancy Prevention Programme (PPP) for the Anti-Seizure Medication Topiramate has now been formally approved by the European Medicines Agency (EMA).

The recommendation of the PPP came from the European Medicines Agency's Pharmacovigilance Risk Assessment Committee (PRAC) - following their assessment of research which found that the risk of neurodevelopmental impacts associated with the medication if prescribed during pregnancy was more significant than previously thought.

With the formal adoption of the PPP by the EMA, the Health Products Regulatory Authority have now written to all Irish Healthcare professionals to begin the implementation of the programme in Ireland.

The key point of a PPP is to put in place measures to ensure that the risk of exposure of babies to Topiramate in the womb are reduced – and that women on the medication are fully informed of the risks. This means that:

1. Topiramate must not be used in pregnancy for women with epilepsy unless there is no suitable alternative treatment.

2. Topiramate must not be used in patients with epilepsy unless the conditions of the PPP are met.

The key aspects of the new Pregnancy Prevention Programme are outlined in full on our website.

▶▶ <https://bit.ly/PPPTop>

As part of the implementation of the new PPP associated with Topiramate, new patient materials and information resources are being developed to go alongside the medication - to further reinforce the new information and warnings. There will also be a guide developed for Healthcare Professionals. We are in close contact with our colleagues in the HPRC regarding this and will share these new materials on our website when they are available. These are expected in the coming weeks.

We are fully aware of how the introduction of the PPP with Topiramate will be worrying for many women with epilepsy on the medication - particularly those who are planning to start a family.

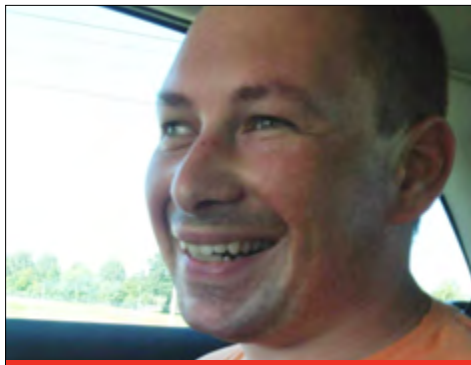
**PLEASE DO NOT** cease taking your medication without first speaking to your medical team. If you have any concerns, seek advice from your epilepsy specialist team. Tell your doctor immediately if you become pregnant or think you may be pregnant.

It is important to note that there is a risk with all medications when taken during pregnancy, and pre-conceptual planning with your medical team is highly recommended in order to take tailored decisions that are best suited for you and your child.

You can read more about this by visiting the 'Pregnancy' section of our website.

▶▶ <https://bit.ly/PCPEI>

# SUDEP ACTION DAY 2023



The late Kieran O'Connor, who sadly passed away due to SUDEP in 2014. Read Orla's story about Kieran by visiting our website.

October 18th marked SUDEP Action Day, one of the most important days in the global epilepsy calendar.

As part of our activities for the day, we raised awareness of Sudden Unexpected Death in Epilepsy – a rare but devastating aspect of the condition. While what exactly causes SUDEP remains unknown, research has identified several factors which can reduce a person's risk of SUDEP – such as adhering to medication regimes and knowing your epilepsy in terms of triggers and patterns. The better a person's seizure control, the less a risk of SUDEP. It is vitally important for everyone within the epilepsy community to be aware of the risks and potential actions to reduce them.

We also shared two powerful personal testimonies from families who have been bereaved due to SUDEP – with the key message being that everyone with epilepsy and their families should be aware of SUDEP. The first of these was Orla O'Connor, about the loss of her brother Kieran, while the second was from Jenny Kelly, about the loss of her husband Noel – which is featured in full overleaf.

- An EI survey on patient awareness and attitudes to SUDEP, as well as the communication that can happen between patients and their medical teams around SUDEP, was also issued. The survey had a total of 326 respondents, with 182 people with epilepsy responding, and 144 parents/guardians. Key findings include:
- 82% of respondents believe that SUDEP should be discussed with people with epilepsy by medical professionals regardless of whether they are deemed at high risk or not.
- 50% believed that SUDEP should be discussed immediately on diagnosis; while 34% believed that it should be discussed within 1 year of diagnosis.
- 63% believed that the neurologist should be the first person to have discussion with a person with epilepsy/family member about SUDEP.
- 55% of respondents were never told directly about SUDEP but found out about it after reading or finding something online.
- 47% believed that being aware of SUDEP influenced their behaviour towards managing their/their loved one's epilepsy.

It is clear there is a strong appetite within the epilepsy community to be informed about SUDEP at the earliest opportunity and we will continue to push for stronger and more immediate communication about SUDEP.

Please visit our website and learn more about SUDEP – it is vital information to know.

*Learn more about SUDEP:*

▶▶ <https://bit.ly/SUDEI23>

*Read more about EI's activities for #SUDEPActionDay2023:*

▶▶ <https://bit.ly/SADEI23>

## SUDEP ACTION DAY 2023 - "THE FIRST TIME I HEARD ABOUT SUDEP WAS AFTER THE AUTOPSY – TOO LITTLE, TOO LATE."



*For SUDEP Action Day 2023, Jenny Kelly shared her story about the loss of her husband Noel due to SUDEP in 2009. Please take a moment to read this powerful and poignant testimony. . .*

The night I met Noel I knew by the head of him he was a Kelly from the Hill! He was the 2nd youngest of his family – a family of 14 – and our families were long intertwined before I met him.

We met when I was 18 and he was 20. Six months later, we were engaged and by the time I turned 21, I was married.

Noel was plumber by trade and we two wonderful children – our daughter Mikayla and our son Matt. Matt was just two months old when Noel had his first seizure. It was totally out of the blue when I found Noel seizing in bed one night. He was 27 years of age when he was diagnosed with epilepsy.

Noel struggled to accept his diagnosis – but over time, and with a little pressure from me, he settled into his medication routine and learned more about his triggers.

Our second son Dara arrived, and our family was complete. We had so much happiness and laughter in our house, despite the fear of seizures that comes with living with epilepsy.

I was always aware of the risks that seizures could pose to Noel's life – as in, if he had a seizure while driving, he could crash; if he was in the bath and had a seizure, he could drown. He was also a goalkeeper, so he could potentially have a seizure during a match.

We took measures to eliminate these risks – I would drive; would sit and talk with him as he bathed; and when he was playing a match, I would follow him to either end of the pitch behind the goals so if he needed me, I'd be there quick.

Noel returned to college in September 2009 to study mechanical engineering – which he loved.

On the 27th of March 2009, he told me that he didn't feel well. I told him that after he dropped the kids off to school, to go back to bed and I'd come home from work at lunch.

When I got home, there was no sign of him. I remember going looking for him and opening our bedroom door and asking, "are you getting up or what?"



When I approached him, reached out and turned him over, I knew immediately he was dead.

The first time I heard about SUDEP was after the autopsy – too little, too late. I don't understand why we weren't told. When I had my children, I knew about SIDS, and I did everything I could to prevent it and followed the guidelines. I never knew about SUDEP, and I never knew Noel could just die in his sleep, in his bed – and I told him to go back to bed! That's haunted me since.

Why wasn't I told? Why wasn't he given a chance to potentially prevent it?

He died at 35, I was 33, our kids were 5, 8 and 10. Our world had ended. There are risks with every medical condition - be diabetes, asthma and so on. Everyone seems to now know the risks, even with no-one in the family with those conditions, but no-one knows about SUDEP.

Inform yourself, question your medical team and have no regrets.

Mikayla is now 25 and a secondary school teacher. Matt is 22 and working in marketing. Dara is 19 and a carpenter apprentice. As for me, I've been so lucky to have met 2 great men in my life and have added Aiden to our family.

But...

I will never forget finding Noel.

I will never forget my screams.

I will never forget wailing as I counted to 30 performing CPR.

I will never forget the destruction on his family's face.

I will never forget my parents' anguish.

I will never forget telling my 3 children.

**I will never forget Noel.**



*We would like to thank Jenny for sharing her and her family's story with us, to raise awareness of SUDEP and to encourage the wider epilepsy community to learn more. As discussed on our previous page, it is vital information to know and we would encourage all our members to heed Jenny's advice and visit the SUDEP section of our website to learn more.*

*Noel Kelly - Ar dheis Dé go raibh a anam.*

▶▶ <https://bit.ly/SUDEI23>

### **Note:**

*If you have lost a loved one who lived with epilepsy - even where the stated cause of death isn't necessarily epilepsy-related – we are appealing to you to please consider providing details to the Epilepsy Deaths Register for Ireland. The register is a collaboration between Epilepsy Ireland and our colleagues in SUDEP Action. Knowing why people with epilepsy have died allows researchers to build a better picture of the condition and helps keep people safer in the future - potentially helping to prevent future deaths. To provide details of a loved one to the register, visit the website below.*

▶▶ <https://bit.ly/EDRIE123>

# INFANTILE SPASMS AWARENESS WEEK 2023

*While the year is drawing to a close, there is still another major awareness raising event between now and 2024 in the form of Infantile Spasms Awareness Week.*

Infantile Spasms Awareness Week takes place annually from December 1st to the 7th. Epilepsy Ireland have been members of the Infantile Spasms Awareness Network since 2021, and this will be the third year that we take part in the awareness raising activities associated with this important week.

Infantile Spasms are a rare but extremely serious type of seizure which occur in approximately 1 of every 2,000 children. The seizures themselves are extremely subtle in nature and can often be misdiagnosed or overlooked – and be mistaken for other conditions such as colic, reflux or a startle reflex.

However, if the spasms continue to be misdiagnosed and remain untreated, they can cause permanent and catastrophic damage to a child's developing brain.

Throughout Infantile Spasms Awareness Week, we will be joining with our colleagues across the globe to share further information about these types of seizures. The spasms are most likely to present in a child between 4 & 6 months of age –

although they can begin at any time in a child's first two years of life.

We will be appealing to new or prospective parents with the key message of STOP:

- S** – See the signs
- T** – Take a video
- O** – Obtain Diagnosis
- P** – Prioritise treatment

Encouraging people to be aware of the signs of Infantile Spasms will be paramount to our awareness raising activities. As noted, the seizures can often be overlooked and are extremely subtle in nature - with jerking of the mid-section, dropping of the arms or wide-eyed blinks some of the typical signs of Infantile Spasms. While sharing these key messages, we will also be sharing stories from families whose children have experienced Infantile Spasms to help encourage people to learn more. If you would like to share your experience of Infantile Spasms, please get in touch with our Advocacy & Communications Manager, Paddy McGeoghegan by emailing [pmcgeoghegan@epilepsy.ie](mailto:pmcgeoghegan@epilepsy.ie).

Please do share our posts on social media across **#ISAW2023** to help raise awareness and educate people about these types of seizures.

▶▶ <https://bit.ly/ISAW23EI>



## LAST CHANCE TO ENTER OUR RAFFLE!



With the big draw set to take place on 24th November, time is running out to enter our Annual Raffle!

This is the 14th iteration of the raffle, and last year – thanks to the support of our members – raised a massive €13,000 to help our continued journey towards a society where no person's life is limited by epilepsy.

Tickets are just €5 – and as well as being in with a chance of winning some incredible cash prizes, you will be helping to continue

our support and information services; training and education programmes; awareness & advocacy campaigns; and investment in Irish epilepsy research.

The top prize this year is €1,000 – so if you fancy having this fantastic amount in your back pocket in the lead-up to Christmas, get your tickets today! Even if you don't walk away with the top prize, there is fantastic runners-up prizes too with a 2nd Prize of €500 cash; a 3rd Prize of €250 cash (for THREE lucky runners up); and finally, a 4th Prize of a €200 voucher for Dunnes Stores – which is sure to come in handy for the Christmas shop!

You can get your tickets by getting in touch with Ashley by emailing [abutler@epilepsy.ie](mailto:abutler@epilepsy.ie) or by visiting our website – but do not delay, the closing date for online entry is the 22nd November!

▶▶ <https://bit.ly/AREI23>

## CHRISTMAS CARDS NOW ON SALE!

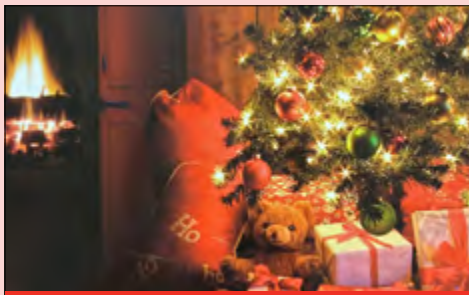
With mentions of the upcoming festive season throughout this edition of 'Epilepsy News', a reminder to our members that you can spread festive cheer and support the work of Epilepsy Ireland at the same time!

Our Christmas cards are now on sale, and if you send Christmas cards each year, please consider purchasing our cards to help continue our journey towards a society where no person's life is limited by epilepsy.

There are two different options to choose from – with each box containing 12 high quality cards with envelopes. If you would like to purchase our Christmas Cards, you can

do so by visiting our website or by getting in touch with Ashley by calling 01 455 7500 or by emailing [abutler@epilepsy.ie](mailto:abutler@epilepsy.ie).

▶▶ <https://bit.ly/EIXmas23>



# FREE TRAVEL CHANGES ANNOUNCED IN BUDGET 24

*We are very pleased to inform our members about progress on one of our most longstanding advocacy campaigns, that has been raised with us for many years.*

In the announcement of Budget 24, a commitment from Government was made to: *“to provide free travel for people medically certified unfit to drive.”*

This key line has essentially been the crux of our entire campaign over the last number of years. Currently, the Free Travel scheme is only accessible via other Departmental payments such as Invalidity Pension and the Disability Allowance. However, due to the individual nature of epilepsy, many people living with the condition may not qualify for these payments owing to the fact that they are working or do not meet the strict medical criteria. Despite this, many still face unique accessibility challenges as they may still be having active seizures, meaning they cannot drive. This results on a dependence on public transport for many people with epilepsy, which can be costly and can lead to many challenges for those living with the condition.

What has been announced in the budget will change this, by providing a direct access route to apply for the Free Travel scheme, alongside medical evidence confirming that a person is unable to drive for a specified period.

This announcement is one that we have fought hard for over many years, and we are pleased to finally see a Government commit to resolving the issue.

As the Free Travel scheme is the responsibility of the Department of Social Protection, the Minister responsible for introducing this change is Minister Heather Humphreys.

Since we first met with the Minister on this matter back in early 2022, we have always had a strong sense that she understood the challenges facing people with epilepsy regarding travel.

On several occasions the Minister noted in the Dáil that she had someone close to her affected by driving restrictions due to epilepsy. However, understanding and acting are two different entities – and we are incredibly grateful to the Minister for acting in support of our campaign and securing this commitment as part of the 2024 Budget.

In a departmental press release about her Department’s priorities for Budget 24, the Minister specifically highlighted the progress on this issue and the work of Epilepsy Ireland in securing this change, commenting,

“

*I am particularly pleased to expand my Department’s Free Travel Pass to support people who are medically certified as unable to drive. I want to acknowledge the work of Epilepsy Ireland who I have engaged with over the last two years on this matter. This is a small change but it will make a big difference.*

”

While this welcome commitment has been made as part of Budget 24, and has secured Government approval, it is not expected to come into effect until July 2024; as per a Departmental press release and subsequent parliamentary questions responses in the Dáil. While we will obviously be continuing to liaise with the Department and Minister



**Minister Heather Humphreys, who has secured the all important changes to the Free Travel scheme in Budget 24.**

on this, to push for its introduction as soon as possible, we do have some insight and explanation as to why this lead-in time is required.

The changes can only be enacted by the passage of the Social Welfare Bill via the Oireachtas – which as per the evidence of previous years, will take the rest of the year. It is only when this is passed that the changes officially come into effect. Following this, the processes which are currently in place with the Free Travel scheme will need to be amended to allow the change to take effect. We understand this will include changes to the application form; changes to the IT system to allow for the assessment of medical evidence; and to put the staff resources in place to assess and process new applications to the Free Travel scheme. It is important to note that while we have always focussed on epilepsy, the changes announced take account of anyone who is deemed medically certified unfit to drive. This means that the numbers entering the scheme could be much larger than the estimate of epilepsy specific new entries to the scheme that we have quoted throughout our campaign. In short, all the above will take time but as noted, we will be in close contact with the Department and Minister regarding this, pushing for this to be implemented asap.

While we have specifically highlighted the contribution of the Minister in securing this change, we would also like to acknowledge the significant support that this campaign received from TDs & Senators from all parties and none, from constituencies across Ireland. There are much too many to name individually, but the support received was crucial in helping secure this much-needed change.

Last but not least, we would like to thank our members for supporting this campaign. Throughout this process, you have used your voice to contact your local representatives to help amplify our calls and bring it to a local level. What has been announced in the budget would not have been possible without you.

In a year which we have achieved considerable progress on several advocacy campaigns – including the introduction of deferred leaving cert exams for students who have experienced seizures before/ during their exams; Government approval for an inquiry into the historical licensing and prescribing of Sodium Valproate; and now these new measures to be introduced to the Free Travel scheme – it is clear that this progress would not have been possible without our supporters getting behind our campaigns and this shows how positive changes can be achieved by working together.

As further details on the implementation of the amended scheme becomes available, we will share these to our website, social media channels and in future editions of 'Epilepsy News'.

In the meantime, thank you again for your support and together, we can achieve a society where no person's life is limited by epilepsy.

▶▶ <https://bit.ly/EIFT23>

# INTERNATIONAL EPILEPSY CONGRESS REPORT

*As many of our members will be aware, the International Epilepsy Congress took place in Dublin in early September. The congress is organised biennially by our colleagues in the International Bureau for Epilepsy and the International League Against Epilepsy.*

This marked the first time the congress took place in Ireland since 1997 and we were delighted to have the largest international scientific epilepsy meeting back this year. The congress had over 3,400 delegates attend from 120 countries – so Ireland was very much the focus of the global epilepsy community at the beginning of September.

We were pleased to play a leading role in the Congress, and to assist our colleagues in the ILAE and IBE in the lead-up to the Congress – and on these pages, we have outlined some of our highlights from what was an incredible event!

## **First-ever public events!**



Prof Sándor Beniczky speaking at Night 2 of our Public Events

Historically, the Congress has been exclusively for scientific and medical professionals but as part of the preparations for the Congress, we pushed to have a public-facing element to the congress to make it more accessible to those who matter the most – people with epilepsy and their families.

Thankfully, our colleagues in the ILAE and IBE agreed that this would be a welcome addition to the Congress' activities and with that, we arranged and hosted these first-ever public events!

The events took advantage of the fact that some of the leading minds from the global epilepsy community were based in Ireland for the week, and a number of delegates who were presenting at the main congress, agreed to speak at our events on topics such as the genetics of epilepsy; the relationship between sleep and epilepsy; precision therapies for epilepsy and much more!

With close to 400 people attending across our two-night event, and approximately 300 tuning in online each night, it is fair to say that the event was welcomed by the entire epilepsy community. We received fantastic feedback from the event, both at home and abroad – with the below being our favourite!

*“As a person living with epilepsy for the last 20 years, I learnt more in that conference in those two days than I’ve done in the last 20 years. Can I just say that it wasn’t just a brilliant idea, it was a magnificent one. The appetite for information was met by those who live with the condition. So heartfelt congratulations for not only having the foresight to understand the need for information but to keep your promise and deliver. I hope it’s the start of something positive that started in Dublin and will ripple worldwide.”*

We are proud to have hosted these first-ever public events and are hopeful that they will become a fixture of the congress as they travel across the globe in the years ahead,

with a legacy forever linked to Ireland. If you were unable to attend this event, you can now watch it back on our website. We would like to thank all our speakers who took the time to take part in these events; all those who attended; and our colleagues in the IBE & ILAE for making these events possible.

▶▶ <https://bit.ly/IEC23Dub>

## Global Youth Summit



Some of the Global Youth Summit attendees – including a few familiar faces!

As part of the Congress, our colleagues in the International Bureau of Epilepsy arranged a global youth summit. The Summit brought together inspiring young people with epilepsy, from all over the world – including 8 Irish/Epilepsy Ireland delegates and Golden Light Winner Wayne. The event not only highlighted the challenges faced by young people living with epilepsy but also provided a platform for them to share their experiences, knowledge, and advocate for a better future. While we're obviously biased – we were so proud of the contributions made by our delegates Jack, Cara, Lucy, Melissa, Jonathon, Sophie, Grace, and Rachel at the summit. With sessions on self-care; challenges with epilepsy; and epilepsy research; our delegates made an enormous impact and were certainly an inspiration to others in attendance. Thank you to all our delegates for taking part!

## Wayne is a Golden Light!



Wayne O'Reilly (Right) with fellow golden light awardees Walter & Fides

At the opening ceremony of the Congress, longstanding Epilepsy Ireland volunteer Wayne O'Reilly – who has fronted two International Epilepsy Day campaigns in recent years – was presented with a "Golden Light" award. The award was in recognition of Wayne's enormous contributions to epilepsy awareness in Ireland. While we announced the news of Wayne's award in the last edition of 'Epilepsy News', we had to mention it again in this edition! A huge congratulations to Wayne again!

## Taoiseach's Opening Address

With the international epilepsy community in attendance, and all eyes on Ireland, it was fantastic to have An Taoiseach provide a welcome message to all delegates. However, we were particularly pleased to have the Taoiseach specifically reference the impact and importance of the work of Epilepsy Ireland as part of his address to the international epilepsy community – in which he acknowledged our history of working alongside policy makers and Government to better the care of people with epilepsy in Ireland. However, this was not the last involvement of the Taoiseach at the Congress – and you can read more about his further involvement overleaf.

▶▶ <https://bit.ly/LVIEC23>

# EI MEET WITH TAOISEACH AS PART OF STATE RECEPTION FOR IEC2023

*With the International Epilepsy Congress taking place in Dublin in September, and with Epilepsy Ireland playing a leading role in the organising of the congress, we were delighted to be invited to meet with the Taoiseach as part of a State Reception to celebrate the occasion of the congress taking place in Ireland.*

The reception was attended by leading international delegates attending the IEC; members of the organising committee of the congress; our colleagues from the International Bureau for Epilepsy and International League Against Epilepsy; as well as key representatives from the Irish epilepsy community – including Epilepsy Ireland, the Irish Epilepsy League and FutureNeuro.

Epilepsy Ireland were represented at the reception by our Chairperson Cathy Grieve; our CEO Peter Murphy; and our Advocacy & Communications Manager, Paddy McGeoghegan.

The reception allowed us an opportunity to briefly discuss some key issues directly with the Taoiseach as head of Government – and to acknowledge his kind words about Epilepsy Ireland at the opening ceremony of the congress.

In his address at both the opening ceremony of the Congress, and at this private State Reception, the Taoiseach acknowledged the important work that Epilepsy Ireland does as well as recognising the challenges which can exist for those living with epilepsy. We hope that this acknowledgement is a sign of renewed focus from Government to help address the many issues which can face the entire epilepsy community.

Following our meeting, we wrote to the Taoiseach to expand on some of the points

which we had the opportunity to raise directly with him, and some of those that we did not – particularly focussing on Ireland's commitment to realise the vision of the World Health Organisation Intersectoral Global Action Plan on Epilepsy and highlighting key areas facing the epilepsy community which can be progressed under this plan.

In our correspondence to the Taoiseach, our CEO Peter Murphy wrote, *"While much work has been done over the past decade to improve the care and lives of people with epilepsy, progress cannot stop now and the IGAP is a golden opportunity to do this. However, we need the support of Government to progress and address the points above, and the many others which have not been listed. The will, determination, skills, and knowledge exist on the ground, and with appropriate supports and a co-ordinated approach, much more can be progressed within the framework of the IGAP to deliver a truly excellent service to those living with epilepsy."*

To read the letter to the Taoiseach in full, visit our website.

▶▶ <https://bit.ly/SRIEC23>



Some of the Irish delegates at the State Reception - (L-R) Dr Cristina Ruedell Reschke (FutureNeuro), Paddy McGeoghegan (EI), Peter Murphy (EI), Cathy Grieve (EI), An Taoiseach, Dr. Peter Widdess-Walsh (Irish Epilepsy League), and Prof David Henshall (FutureNeuro).

# 45 FOR EPILEPSY: MOVE AND MAKE A DIFFERENCE!



**Epilepsy Ireland**

**45 for Epilepsy: Move and Make a Difference**

December 11th to 17th

**SIGN UP NOW!**

wherever is convenient for you and that you enjoy it – just remember to link it into that all important number!

Keep an eye on our Facebook page for the launch of this challenge during the week of the 13th of November. Sign up to the challenge group on Facebook and set up a fundraising page.

In the 45 Challenge's Facebook group, you will be able to share your training and fundraising progress alongside the community of Epilepsy Ireland supporters who will be moving and making a difference alongside you this December!

*Before the year is out, we want to set our members the challenge of taking part in the 45 for Epilepsy: Move and Make a Difference!*

This December, we are launching this new challenge called aiming to raise funds for Epilepsy Ireland and to show support for the 45,000 people living with epilepsy in Ireland!

The challenge will take place from the 11th – 17th December so there's plenty of time to sign up and take part and do one last good deed before the festive season to ensure you're Mr. Claus"nice" list!

Whether you choose to walk/run/cycle/row/hike 45km over the course of the week, do 45 mins of exercise or 45 reps of exercise each day, we're asking you to challenge yourself and fundraise for Epilepsy Ireland as part of the 45 Challenge! The main thing is that you set a challenge that works for you,

The funds raised via this new challenge event will go towards supporting our community services, training and education programmes, advocacy & awareness campaigns, and epilepsy research – bringing us further towards a society where no person's life is limited by epilepsy.

We can't wait to see what 45 themed challenges our members come up with, and remember, we are here for further information and support that you might require.

To learn more about the **45 for Epilepsy: Move and Make a Difference** challenge, please reach out to our new Fundraising & Development Executive Roisin Dolan, by emailing [rdolan@epilepsy.ie](mailto:rdolan@epilepsy.ie) or by calling 085 871 4580.

*Thank you in advance for your support!*

# STAND UP CAMPAIGN – #EPILEPSYDAY 2024

*We are delighted to let our members know that work on our campaign for International Epilepsy Day 2024 is well and truly underway!*

As our members will be aware, International Epilepsy Day is our biggest awareness raising day of the year – where we seek to increase public knowledge and awareness of epilepsy, a condition that affects over 45,000 people in Ireland. Our members will also be aware that the materials we use for the campaign are *usually* a closely guarded secret until the day itself. . .but as you might have guessed, we're going to take a slightly different change in approach for next year!

An unexpected opportunity arose in recent months to avail of free advertising space, kindly donated to us by the National Transport Authority – and we decided to grasp this opportunity with both hands and release parts of our campaign early for the big day next year.

The eye-catching campaign features two Epilepsy Ireland volunteers – the fantastic Lucy Prevo & Paul Guy - and encourages everyone to visit our website to learn more about how to correctly respond to a seizure and learn the key words of **Time, Safe, Stay** – by asking the public a simple question:

*"If I fall down, will you stand up?"*

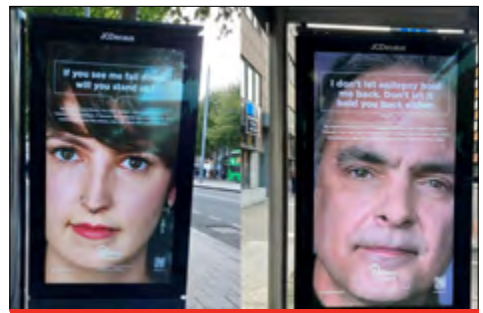
This is a question that many people with epilepsy ask themselves every single day. Anxiety and worry about how the public respond to a seizure is a common concern brought up by our service users. Not only that, but there are still misconceptions out there amongst the public about how to respond to a seizure. This campaign

confronts this directly, and we hope it will help in increasing public awareness of seizure first aid. Another element to the campaign encourages the public to not let a person's epilepsy hold them back from responding correctly.

This initial phase of our campaign used outdoor billboard advertising featuring Lucy and Paul to promote these key messages. Our plans are constantly developing, but the intention is to go much wider with this campaign with national outdoor advertising, and much more alongside that – including a few additional faces to be added to the awareness raising efforts – but we'll keep them a secret for now!

Keep your eyes peeled on our website and social media channels for more on this campaign and our plans for **#EpilepsyDay 2024**. In the meantime, save the date of 12th February 2024 as that is when the big day will happen next year – and encourage your friends, family, and colleague to learn more about seizure first aid and Time, Safe, Stay by visiting our website.

▶▶ <https://bit.ly/TSSEI23>



Lucy & Paul's posters in locations around Dublin.

## STAND UP CAMPAIGN – PAUL’S STORY



Paul pictured with Paul!

*While we were shooting our new awareness campaign for #EpilepsyDay24, we spoke with all those featured about their journey with epilepsy so far. In this edition of 'Epilepsy News', we are featuring Paul's story. Paul is a Marketing Director of a global tech company and is a person living with epilepsy and he explained to us why he wanted to take part in such a public-facing campaign...*

I was 17 when I first experienced it. On the day I started my Leaving Cert, I collapsed at school. My parents didn't know what was going on. Back then, very few people understood epilepsy. Doctors said it was a chemical imbalance, but no one identified it as epilepsy.

Later in my career when I joined an architectural practice, my boss' brother was on the board of a private hospital and he saw first-hand my situation after seeing the many seizures I had in work, put me in contact with a doctor who specialised in epilepsy.

Within 3 minutes he diagnosed me with epilepsy.

I was both delighted and annoyed because for so many years no-one recognised it. But I'm so much better today.

I want to help change perceptions of epilepsy. When you have a seizure, people don't know what to do. Medical experts can talk about the condition, but most of them don't have it. As someone with epilepsy, I can share my experiences with the world and that's what I'm doing by being part of this campaign.

Epilepsy affects families, friends and colleagues too. My kids have seen me having full-blown seizures. I was in a boardroom once, presenting to clients, when I felt a seizure starting. I couldn't tell them because I couldn't speak. So, I quickly wrote on a piece of paper - I'm having a seizure and can you help me. They were great. Once people know more about epilepsy and how to help, they're very supportive. It's simple – Time the seizure, keep them Safe by clearing any danger from the area and Stay with them for support.

People like me with epilepsy need to share our stories and debunk misconceptions. I'm not defined by epilepsy and I don't let epilepsy hold me back – so it shouldn't hold you back either!

*Thank you Paul for sharing, and for being part of this campaign! If you'd like to follow Paul's advice and get involved by sharing your story for #EpilepsyDay 2024, please get in touch with our Advocacy & Communications Manager Paddy McGeoghegan by emailing [pmcgeoghegan@epilepsy.ie](mailto:pmcgeoghegan@epilepsy.ie). Key to our awareness-raising activities in the lead-up to the day and on the day itself is sharing the lived experience of epilepsy, so please get in touch. You can see examples of previous personal stories by visiting our website.*

▶▶ <https://bit.ly/EIawa23>

## EVENTS



### *Our National Information Officer Geraldine will be updating attendees with the latest info on Seizure Detection Devices*

In the last number of years, there has been a huge increase in the availability and types of seizure detection devices.

These devices have the potential to allow a person to lead a more independent life, learn more about their own individual condition, and to alert a loved one or carer to the fact that a person having a seizure – allowing for seizure first aid to be given as soon as possible.

However, as with all things technology, this is a constantly evolving space. One of the most common queries our team of Community Resource Officer's receive from people with epilepsy and their family members, is about these devices. This is why we are delighted to arrange this online session with our National Information Officer, Geraldine Dunne.

As part of this session, Geraldine will discuss the types of alarms that are available in Ireland; prices that are involved; and other considerations which should be accounted for when assessing whether an alarm would be suitable for you or your loved one. There will also be an opportunity for questions and answers. However, please note that due to

the individual nature of epilepsy, no specific recommendations can be made on the best alarm that will suit an individuals' need – the purpose of the event is to ensure that you have the most accurate and up-to-date information to help inform your decision.

Geraldine delivered a similar session at our National Conference in 2021, which was well received by all those in attendance and those who watched it back. This event will take place online on the 29th November at 6:30pm. If you'd like to join us, visit our zoom registration page!

▶▶ <https://bit.ly/SDDEI23>

### **Creative Workshops for siblings of children with epilepsy**

Throughout the year, we have run creative workshops for siblings of children with epilepsy. We know that epilepsy is a condition that can affect the entire family unit. When caring for a child with epilepsy – especially where the condition is complex - there can be a knock-on impact for that child's young siblings. At this event, not only will the children have fun but also have an opportunity to discuss concerns they might have about their sibling's long-term health condition – alongside other children in a similar situation to them. The event is for children aged 8-12, and the next workshop takes place on the 12th December at 7:00pm. Email our Community Resource Officer Pam on [pobrien@epilepsy.ie](mailto:pobrien@epilepsy.ie) if you would like to register.

### **2024 Events**

A reminder to members that the majority of our events are added to the events section of [www.epilepsy.ie](http://www.epilepsy.ie) year-round; so keep an eye on this section of our site for details of events like the above and many more!

# YOUR LOCAL COMMUNITY RESOURCE OFFICER



*Our Community Resource Officers are here for you to provide support and information about the condition for people with epilepsy, their families, their carers, and the wider community. If we can be of assistance, get in touch!*

## **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.

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

Our Community Resource Officer for the South East, Joanne Lynch is on extended leave until December 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**

Our Community Resource Officer for the Midlands, Cliona Molloy is currently on extended leave. Please contact our Head Office on 014557500 and you will be redirected to another member of our Community Resource Officer team.

## **Limerick, Clare & Tipperary North**

Margaret Dixon  
mdixon@epilepsy.ie  
0858766629

## **Cork**

Sharon O'Connell (North Lee & North Cork)  
soconnell@epilepsy.ie  
0858766626  
Niamh Jones (South Lee & West Cork)  
njones@epilepsy.ie  
0858766628

## **South Dublin & Wicklow**

Carina Fitzgerald  
cftzgerald@epilepsy.ie  
0858766587

## **North Dublin & Kildare**

Agnieszka Polak  
apolak@epilepsy.ie  
0858063959

## **Kerry**

Pam O'Brien  
pobrien@epilepsy.ie  
0858766627

## FUNDRAISING

### Rick's Christmas Appeal!

We are delighted to have our Patron, Rick O'Shea, supporting our cause through his annual book club appeal! Many of our members will be familiar with Rick and his broadcasting career – but may not be aware that he runs Ireland's largest book club! The club has over 40,000 members and every year, during the festive season, they come together to raise funds for worthy causes across the country. Over the past 5 years of the club's fundraising efforts, just under €200k has been raised. We are privileged and delighted to be selected as one of the chosen charities this year! We continue to be in Rick's debt for his continuous support of EI during his long tenure as our patron. To support the appeal, visit the group's dedicated GoFundMe page.

▶▶ <https://bit.ly/ROSBC23>

Pic: Epilepsy Ireland Patron, Rick O'Shea

### Well done Mark!

Many of our members will be familiar with the incredible efforts of Mark McGuire to raise funds for EI in the name of his son Ciarán – given we featured their story in previous editions of 'Epilepsy' news. Mark decided to take on Kilimanjaro, the world's tallest free-standing mountain! Did he complete the challenge?! Of course he did – and he even had time to unfurl the EI flag atop the mammoth mountain!

Mark raised an incredible €8,271 for Epilepsy Ireland in Ciarán's name. Mark recently and Ciarán recently presented the funds raised to our Advocacy and Communications Manager, Paddy McGeoghegan. During the presentation, an impromptu game of indoor football broke out – Ciarán is one to watch for the future, as he nutmegged Paddy more times than he'd care to admit...!!

Thank you to Mark, Ciarán and everyone who donated to this incredible fundraiser!

*Pic: Mark and Ciarán presenting the funds raised to Paddy*

*Pic: Mark at the peak of Kilimanjaro!*





## Thank you Sophia!

At the International Epilepsy Congress, we got to meet Sophia & Andréa Glennon and have an official presentation of the funds they raised as part of the VHI Women's Mini-Marathon! Sophia and a small army of her family and friends took part in run and the fundraising efforts – raising a massive €5,430.

Thank you Sophia, Andréa and everyone involved in this monumental effort!

Pic: Andréa, Sophia and our Fundraising & Development Manager Cian

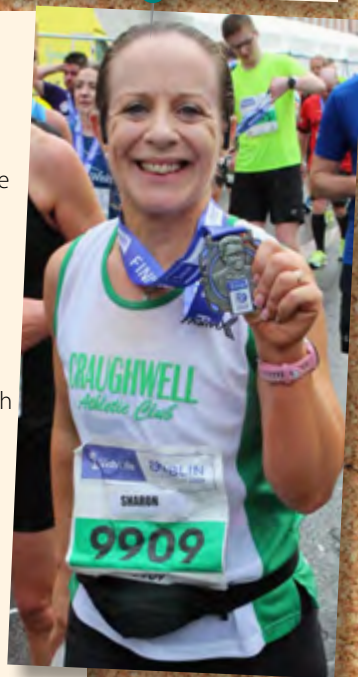
## Dublin City Marathon & Craughwell Fun Roast!

A huge thank you to everyone who took part in the Dublin City Marathon recently in support of Epilepsy Ireland. There are two many incredible participants to thank individually and while final totals are still being tallied at the time of print, an incredible amount has been raised collectively in support of our work. We will share further details on this in the next edition of 'Epilepsy News'

A special mention to Sharon Gilligan, who ran the race in memory of her sister Margaret – and certainly got her entire community behind her! Sharon's efforts in the marathon were further supported by Epilepsy Ireland being one of the organisations benefiting from the Craughwell Fun Roast! The 6th iteration of the roast took place on the Halloween Bank Holiday weekend, and involves huge efforts from the local community. We were delighted to meet with some of those involved in organising the Roast, with our Fundraising & Development Manager Cian, attending the official launch of the event.

While final tallies of the total amount raised are not available at the time of print, we wanted to say a huge thank to Sharon and all involved in the Craughwell Fun Roast!

Pic: Sharon at the finish line after completing the Dublin City Marathon!



## Mizen to Malin for EI!

Huge congrats to Andrew Fitzpatrick, Gavin O'Leary, Shane O'Connor and Tom Carroll who cycled the length of the country from Mizzen to Malin in support of EI and our colleagues in the Irish Cancer Society! The lads absolutely smashed their original fundraising target of €5k, raising a total of €7,585 – with half going towards supporting our work!

Well done and thank you to everyone involved!

Pic: The lads at the finish aka Ireland's most northerly point!





HAPPY CHRISTMAS  
TO ALL OUR MEMBERS, SUPPORTERS  
AND VOLUNTEERS

—

THANK YOU FOR EVERYTHING IN 2023,  
AND WE LOOK FORWARD  
TO CONTINUING OUR WORK  
WITH YOU IN 2024!



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

