EPILEPSY NEWS

Issue 100 Autumn 2023

The official Epilepsy Ireland members' newsletter

In this issue:

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- Michael's story
- Wayne is a Golden Light

…much much more!

NOTE FROM THE EDITOR

Welcome to the Autumn Edition of Epilepsy News! It is hard to believe that we are staring into the final quarter of the year, but all the team here at Epilepsy Ireland are excited by what is yet to come in 2023!

Throughout previous editions of our Newsletter, we have mentioned how a major event in the form of the International Epilepsy Congress is coming to Ireland this year. This event is now very much on the horizon and is mere days away at the time of print! We are hugely excited by this event coming to Ireland and we are delighted to have been so closely involved in organising same alongside our colleagues in the International Bureau for Epilepsy and the International League Against Epilepsy – particularly in arranging the first ever public-facing events as part of the congress. You can read more about these in this edition of our newsletter and you'll find a special Congress Flyer enclosed outlining further detail on some of the incredible speakers who will be joining us.

In this edition, you will also read about a major step forward in our campaign with OACS Ireland surrounding Sodium Valproate. In July, the Government officially green-lighted the establishment of an inquiry into the historical licensing and prescribing of Sodium Valproate in Ireland. While this announcement does not signal the end of this campaign, it is a significant and monumental step after over a decade of campaigning. Staying with advocacy campaigns, you'll also read about a powerful statement of support for our campaign around access to the Free Travel scheme.

In addition to all the above, we have a fantastic personal reflection from Cork man, Michael Mulcahy, who was only recently diagnosed with epilepsy – but has immediately recognised the importance of speaking about his epilepsy to others. Michael's piece will undoubtedly be an inspiration to all those who may have been recently diagnosed or who are hesitant in speaking about epilepsy so be sure to read!

Finally, in this edition, you'll also read about how after 25 years, we are this year saying goodbye to our QQI Level 5 course Training for Success. While we are sad to see TFS ending, the course coming to an end is ultimately a positive reflection of societal changes and we can be proud of the impact the course has had for so many.

All this, and much more – including **some** of the incredible efforts that YOU have undertaken to help continue our journey towards a society where no person's life is limited by epilepsy.

As always, we remain here for support and information that you or your family may need on your respective journeys with epilepsy – do not hesitate to get in touch with your local Community Resource Officer!

Hope to see you at the congress!

Paddy McGeoghegan

Advocacy & Communications Manager

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Front Page Image:
Mark McGuire, the main man Ciarán, and family & friends before one of Mark's training treks before he takes on Kilimanjaro! Good luck Mark! You can find out more about this challenge by visiting our website.

▶▶ https://bit.ly/MMGCEI23

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WELCOME CIAN!

We have a new face to introduce to our members, in the form of our new Fundraising and Development Manager, Cian Dikker.

Cian took up his new role in mid-June, filling a vital role within our charity which had been vacant since October of last year. Cian has a wealth of experience in the non-profit and fundraising sector – joining us from Focus Ireland where he worked on major gifts, corporate fundraising, trusts, foundations, and legacies. Prior to that Cian held a similar role in the Central Remedial Clinic, while he also previously held a fundraising position at Spina Bifida Hydrocephalus Ireland.

We have no doubt that Cian would love to hear from our members if you have any suggestions, ideas or connections which might help us achieve one of our key strategic aims in increasing and diversifying our income as we seek to support our work towards a society where no person's life is limited by epilepsy.

Cian can be reached by emailing cdikker@epilepsy.ie or by calling 0858808012.

Welcome Cian to the team!

Our new Fundraising and Development Manager, Cian Dikker.

NEWS UPDATES

Toy Show Funding

We are delighted to confirm with our members that Epilepsy Ireland was one of the 147 organisations to benefit from the RTÉ Toy Show Appeal.
Last year, the appeal raised just under €4m and we have no doubt that our members would have generously contributed towards that figure, so we're delighted that the importance of supporting children with epilepsy was recognised within these awards.

Funding of €26,000 was allocated and the funds will be invested in further supporting children with epilepsy and their families on their journeys with epilepsy.

We would like to thank the RTÉ Toy Show Appeal and the Community Foundation of Ireland for their support; and of course, we would like to thank the Irish public for their generous support of the appeal. You can read more about this funding allocation by visiting our website.

▶▶ https://bit.ly/EITSA

Annual General Meeting 2023

The Annual General Meeting of Brainwave The Irish Epilepsy Association (trading as Epilepsy Ireland) for the year ending 31.12.22 was held virtually on July 6th.

Chairperson Cathy Grieve outlined our activities during 2022 and how we continued our journey towards a society where no person's life is limited by epilepsy during the first year of our new Strategic Plan 2022-2026. Treasurer Paul Kehoe presented our financial statements, outlining how Epilepsy Ireland generated and used funds during the year.

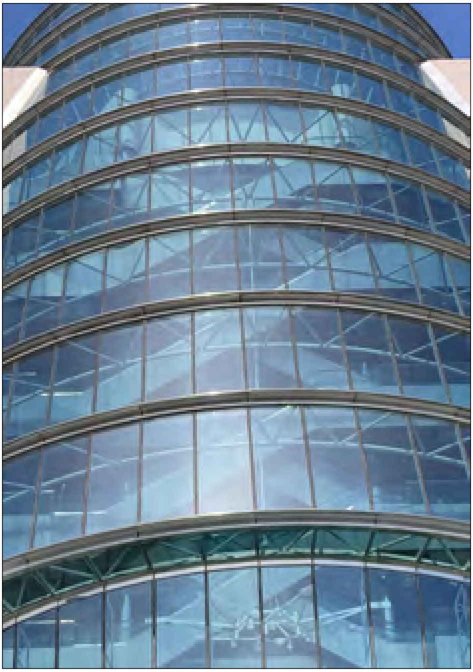
We also welcomed two new board members who have been elected for a four-year term. Mark Curran and Nicola Saarsteiner bring a wealth of legal experience to our board, with both being practising barristers. Nicola may be familiar to many of our members, as a long-time, active volunteer for Epilepsy Ireland since being diagnosed with the condition in 2003.

The Chairperson also thanked three voluntary board members for their years of service to Epilepsy Ireland - Mark Dowdall, Chairperson of the charity from 2013 to 2019; Derry Gray who served on the Board from 2014 and Chair of our Finance & Audit sub-committee, Shane O'Brien. All three stepped down at the AGM and we would like to thank them all for their years of service and dedication.

Recordings of the Chairperson's and Treasurer's reports from the AGM can be viewed on our website.

▶▶ https://bit.ly/EIAGM23

Our new board members, Nicola Saarsteiner and Mark Curran



Last chance to join us for the International Epilepsy Congress!

As mentioned in the notes from the editor, we are on the cusp of a global epilepsy event taking place right here in Ireland – with time running out to join us at the public events!

We have enclosed a special Congress Flyer alongside this edition of our newsletter, and you will see that we have an incredible array of speakers lined up to discuss a range of topics – including the ketogenic diet, complex and rare epilepsies, the genetics of epilepsy, exercise and epilepsy, when surgery should be considered and so much more! This is a unique event and is an opportunity to hear from some of the leading global epilepsy experts right here in Ireland. We would love to have a full house to help welcome these speakers at what is the first ever public-facing events of the International Epilepsy Congress so please join on one of the nights or both!

You can find further details on how to register on our website (including an online registration link for those who can't attend in person).

We're really excited by this event and hope you are too – we look forward to welcoming to you to the Convention Centre in September!

▶▶ https://bit.ly/IEC23Dub

New Study suggests why CBD might stop seizures

A study recently published in the medical journal Neuron, has providing further information on how cannabidiol (CBD) works to potentially prevent seizures. In recent years, numerous studies have been carried out on the use of CBD treatments in drug-resistant epilepsies – many of which have showed positive findings.

However, the exact mechanisms as to why CBD can reduce seizures has never been fully understood. The study published in Neuron could offer a new explanation.

The study, which was conducted by researchers in the US, found that CBD acts as a blocking agent against a molecule called LPI (lysophosphatidylinositol). LPI has been found to strengthen nerve signals in the brain, which could lead to seizures. The study has also suggested that LPI could weaken other signals that help to prevent seizures. Therefore, when the CBD works to block this LPI molecule, it can help to prevent or reduce seizures.

Further information on the study and its findings; as well as further information around the use of medical cannabis in epilepsy can be found by visiting our website.

▶▶ https://bit.ly/CBDNeuron

GOODBYE TRAINING FOR SUCCESS!

TFS Course Manager Maire Tansey with the award she received in 2021; It's not goodbye as Maire will be moving to a new role within Epilepsy Ireland.

After nearly 25 years, this year we will be saying goodbye to Training for Success (TFS).

'Training for Success' first began in 1998 and was specifically targeted at people living with epilepsy whose education or employment prospects may have been impacted by their condition. The course offered participants an opportunity to develop their skills for entry into the workforce or further education – skills which may not have been developed fully due to their epilepsy – for example, frequent hospital visits for teens during their secondary school years.

The course found it's home in IT Sligo, now Atlantic Technological University Sligo, and grew to become a QQI Level 5 accredited course which acted as a springboard for so many people with epilepsy to pursue further education or enter the workforce.

TFS was the only course of its kind in Europe and in 2013, was recognised via the STAR awards, which awards invaluable collaborative work undertaken by adult learning initiatives. In 2021, current course Manager Maire Tansey, won a European Federation of Neurology Associations Advocacy (EFNA) Advocacy Award for her and the course's work in action against stigma.

While we are sad to be saying goodbye to something which has been a fixture of our service for so many years, it is heartening to think that we live in a much different society than that when TFS first began in 1998.

There is now an abundance of different adult learning education courses available across the country; and while there is still work to be done, there is a much more inclusive structure in third level institutions which can help assist people with epilepsy to pursue their chosen course. In addition, attitudes to epilepsy have shifted dramatically over the past two decades – perhaps best seen in a finding from a public awareness survey we did last year in which 80% of respondents said they did not view epilepsy as being a barrier to the workplace.

These societal changes and availability of a wider array of courses has seen interest in Training for Success falling over the last number of years. In addition, recent changes with IT Sligo becoming a Technological University would have seen the course change significantly, losing some of it's most unique aspects.

While it is ultimately a difficult decision to say goodbye to something which we know has had such a positive impact on people's lives, we are confident this is the correct decision with Course Manager, Maire Tansey, who has been part of the TFS team for over 20 years commenting, "It is sad to see TFS ending but there are positives to be taken. Attitudes have changed, as has the availability of other opportunities for people with epilepsy – opportunities which did not exist back in 1998. We can all be proud of the impact the course has had; and the changes it has helped bring about for people with epilepsy across Ireland. Training for Success was ultimately a success itself, and leaves behind a fantastic legacy."

While TFS may be ending, it will lead to another aspect of our existing service being further enhanced. When TFS officially ends, Maire will be moving to a new role within Epilepsy Ireland which will lean on her 20+ years of supporting people with epilepsy. Maire will join Epilepsy Ireland's training department – adding a vital extra resource to a much depended on service. Since 2009, Epilepsy Ireland have offered Training in Epilepsy Awareness and the Administration of Buccal Midazolam. The delivery of this course has been co-ordinated by our Training and Quality Manager and supported by our Community Resource Officer team. From its humble beginnings, approximately 3,000 professionals are now being trained by Epilepsy Ireland every year. With Maire joining the team, we hope that the extra capacity will lead to more numbers trained, more sessions delivered and ultimately an increase in the understanding and awareness of epilepsy from professionals across Ireland.

We would like to thank all our former students of TFS; the excellent tutors; committed staff members; our supportive funders at Mayo Sligo Leitrim Education and Training Board, as well as Atlantic Technological University for being the home of TFS for almost 25 years and for helping make TFS the success it truly was.

Goodbye Training for Success and thank you!

Are you a former student of TFS and would you like to share the impact the course has had on your life? Get in touch with us by emailing our Advocacy & Communications Manager, Paddy McGeoghegan by emailing pmcgeoghegan@epilepsy.ie.

MICHAEL'S STORY

In April of this year, Michael Mulcahy from Cork was diagnosed with epilepsy. Michael is 55 years old and is living proof of how epilepsy can affect anyone at any stage of life, at any time. While it can be a process for many in becoming open about their epilepsy, Michael, despite being early in his journey with epilepsy, immediately realised the importance of being open and honest about the condition and took to social media to share news of his recent diagnosis with his friends, family, and colleagues. Michael has now shared an amended version of this with us, which you can read below…

Regardless of how worldly wise we are or feel we are, regardless of what age we are, or regardless of what we have or don't have in life, there are certain things in life that when they happen to you that you have to decide on how to deal with them. Every one of us faces these decisions on the journey of life and some are minor, and some are major.

For the many people that I am privileged to call friends, they will know that sharing things in life is often for me more about the positives than the negatives. If sharing something about myself can help someone else, then happy days in my world!

At 6am on April 22nd at home while in bed, I experienced an issue that I now know that I was fortunate to survive – thanks to the quick thinking of my husband Jonathon and the incredible response of the emergency services.

While at that point we didn't know what had happened, in consultation with my GP, it was very quickly decided that we needed to know more. Just a few days after the incident, a barrage of tests and procedures at the Medical Assessment Unit of Bon Secours Hospital, Cork followed. Initially, we had thought what I had experienced was cardiac – but a visit from my neurologist set out more clearly what the line of thinking was.

None of us are ever really prepared to hear something that hasn't figured in our mindset before, that is relatively new to us and that takes the wind out of our sails because of elements of it. And yet, being told that 'this can be managed' doesn't quite hit the mark that you want it to hit when you hear it first.

My neurologist sat with me and explained that the 'issue' that I experienced was an epileptic seizure, and a severe one for a first-time full seizure as it lasted for up to or longer than 30 minutes. Again, and as I've said above, I was lucky that Jonathon was next to me and acted as he did on that Saturday morning.

My neurologist spoke at length to Jonathon about what had happened before he gave us his diagnosis. He told us how he feels that my condition can be managed with Anti-Seizure Medications and explained that as with all new medications, it's a bit of trial and error to see how they suit me and to see which (if any) of their side effects might affect me.

I know I will have to make some changes to my lifestyle and some change of stress levels and other things and looking on the bright side of this new part of my life, perhaps that's not a bad thing in hindsight.

From sharing my posts on social media about epilepsy, I've been taken aback by just how many people there are living with epilepsy – and I've learnt more about the misunderstandings and stigma that still unfortunately exists. I've been through Epilepsy Ireland's website and been in touch with their services as I know I'm early on in my journey and may need support and information in the time ahead.

> “*From sharing my posts on social media about epilepsy, I've been taken aback by just how many people there are living with epilepsy – and I've learnt more about the misunderstandings and stigma that still unfortunately exists.*”

In those early days post-diagnosis, I discussed with Jonathon on how to approach this diagnosis and we quickly decided that I'd be as open and honest with this news and diagnosis as if this helps someone else, then it will be worth sharing. If you're at the beginning of your journey like me, know that you're not alone – and that there's over 45,000 people like us across Ireland. Reach out to the team at Epilepsy Ireland for information and support – that's what they're there for!

To conclude for now, it's been an eventful, frightening and emotional time since my diagnosis, but I've been surrounded by support and love at every point when sharing my news and I'm hugely grateful for that - and even more grateful to be still here to tell the tale, as I know now that so many people who have experienced my type of sleep seizure sadly haven't come through them. I want to take this opportunity to thank my husband Jonathon, my family, friends, and colleagues for all their support. No doubt I'll need a bit of support and encouragement from people who care, who listen and who find time for others in the months and years ahead, which is why I felt it was so important to be open about my diagnosis from the outset. Equally so, I want to be there to support anyone that experienced something like I did, because once you come through it and can have it managed, life can reposition itself.

Thank you for reading, and I hope my story was of some help to someone out there!

Thank you, Michael, for sharing such an important message at such an early stage of your journey with epilepsy – we have no doubt that your words will be of huge support to many people in a similar situation to you. As Michael said, if you are newly diagnosed – or if you need any support on your journey with epilepsy – get in touch with our team; we are here for you.

If you would like to share your story in a future edition of Epilepsy News, contact our Advocacy & Communications Manager Paddy McGeoghegan by emailing pmcgeoghegan@epilepsy.ie.

SUDEP ACTION DAY 2023

A very important day for the entire epilepsy community is on the horizon in the form of SUDEP Action Day 2023 – with the day taking place this year on Wednesday 18th October.

SUDEP Action Day is a day in which we raise awareness of Sudden Unexpected Death in Epilepsy and remember those who have sadly been lost due to SUDEP and other epilepsy-related deaths.

SUDEP is a rare but devastating aspect of epilepsy and while there is a lot we still do not know about SUDEP, there are factors which we know contribute to increased SUDEP risk. SUDEP Action Day aims to educate the epilepsy community about SUDEP, so they are aware of these risks and can discuss them with their medical team.

The day is also an opportunity to highlight the existence of the Epilepsy Deaths Register for Ireland. The register is a very important tool for researchers aiming to learn more about and prevent SUDEP & other epilepsy-related deaths. The information provided about a single person could provide vital clues for researchers and scientists as they continue this important work. As part of SUDEP Action Day we will be appealing to people that may have lost a loved one due to SUDEP or an epilepsy-related death – even if their stated cause of death is not epilepsy-related – to provide details about their loved one to the register. This information could help learn lessons from those who have passed away, in the hope of saving future lives.

https://bit.ly/EDRI23

In addition to the above, we have also been seeking responses to a new survey we have issued in relation to awareness of SUDEP amongst the epilepsy community. A similar survey released in 2020 found that 81% of people with epilepsy believed that SUDEP risk should be discussed with them, whether they were at high risk or not. We are seeking to measure if there have been any changes to attitudes towards SUDEP, and to ascertain if people are more aware. We would greatly appreciate if you could complete the survey at the link below as it will provide vital insights to us as we aim to increase awareness of SUDEP on SUDEP Action Day.

https://bit.ly/SUDEPEI23

Finally, if you have been bereaved by SUDEP and would be interested in telling your loved one's story on SUDEP Action Day, please contact our Advocacy & Communications Manager Paddy McGeoghegan by emailing pmcgeoghegan@epilepsy.ie.

We would appeal to our members to please join with us on SUDEP Action Day and to remember those who have sadly passed away. We would encourage all our members to visit the SUDEP section of our website to learn more about how risks can be reduced.

https://bit.ly/SUDEI23

WE WANT TO HEAR FROM YOU!

WE WANT TO HEAR FROM YOU!

Scan the QR code and tell us more about your experience of Epilepsy Ireland to help us plan for the future to continue our journey towards a society where no person's life is limited by epilepsy.

To best support and represent people with epilepsy and their families, and to continue our journey towards a society where no person's life is limited by epilepsy, it is very important that we understand the needs of the epilepsy community and measure the satisfaction of those who engage with our organisation.

While people with epilepsy and their families have always been central to the work we do and why we do it, the importance of this was officially recognised as part of our Strategic Plan 2022-2026 which was launched last year. The new plan contained a new Strategic Aim stating:

"Centre people with epilepsy and their families in the work of Epilepsy Ireland."

With this in mind, we would greatly appreciate a moment of your time to help provide feedback on our activities by completing a survey which is targeted at not only people with epilepsy and their families who have used our service, but also our wider stakeholders with whom we engage with on the behalf of people with epilepsy and their families.

We have designed a survey to help capture the experiences of those who have engaged with our organisation to better understand the impact of what we do.

The survey is totally anonymous and the amount of time it will take is dependent on how much you want to say but we would greatly appreciate you taking the time to complete the survey for us.

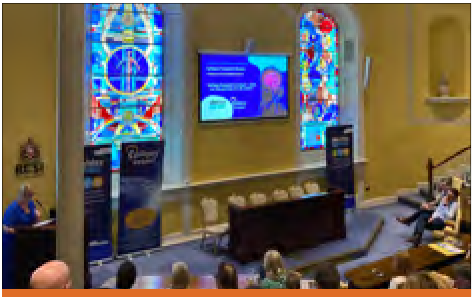
Your responses will help us plan for the future, further understand the needs of people with epilepsy and their families and identify how our services and activities could potentially be improved or adapted. This will ensure that we better serve our community in keeping with the aims of our Strategic Plan (2022-2026).

To complete the survey, please visit the SurveyMonkey website below, or scan the QR code in the image alongside this page.

▶▶ https://bit.ly/EIExpSur

Thank you in advance for taking the time to complete. Together, we can achieve a society where no person's life is limited by epilepsy.

EVENTS ROUND UP AND UPCOMING EVENTS!



Our Training & Quality Manager, Edel Curran expertly MCing our Epilepsy Research Matters event back in May!

As our members are aware, we have various events running year-round on various topics of interest to the entire epilepsy community. On this page, we have featured some of our recent events where recordings are now available or other events that are coming up which might be of interest to you or your family member!

Epilepsy Research Matters

Back in May, together with our colleagues in FutureNeuro, we held a special event focussed on epilepsy research. The event featured leading scientists, clinicians and researchers investigating epilepsy in Ireland and highlighted some of the incredible research that is underway to drive new discoveries in epilepsy. You can now watch the recording of the event by visiting our website. A huge thank you to all those who attended on the night and to all our fantastic speakers.

▶▶ https://bit.ly/ERMEI

Epilepsy and Menopause – A special event for women with epilepsy

With a new campaign recently launched by the Government aimed at taking the mystery out of menopause, we were delighted to show our support for this campaign through this special event for women with epilepsy that we held back in May. The event covered a range of topics, specific to women with epilepsy who may be peri-menopausal or menopausal, and if you did not get to attend on the night it is well worth a watch back on our website to learn more.

▶▶ https://bit.ly/EiEvents

Teen Time!

As highlighted in the last edition of Epilepsy News, beginning in September we will be holding a special monthly event for Teens with epilepsy during the academic year. These sessions will act as platform for teens to discuss their journey with epilepsy; or their lives in general; and allow them to meet with other young people living with epilepsy in Ireland. We're really looking forward to hosting this new event and hope to see plenty of teens attend. Further information about Teen Time and registration details can be found by visiting the events section of our website.

▶▶ https://bit.ly/TTEI

Other Events!

A reminder that the majority of our upcoming events can be found by visiting the Events section of www.epilepsy.ie. We have upcoming support groups for people with epilepsy; creative art sessions for siblings of children with epilepsy; STEPS programmes and information sessions for Teachers and SNAs – alongside much more! If you have any further questions on any of our upcoming events, contact your local Community Resource Officer – their details are on the back page.

FAMILY FUN DAY!

After taking place in Dublin Zoo last year, we were delighted to head South this year for our annual Family Fun Day – with Fota Island Wildlife Resort in Co. Cork being the venue for this year's event!

Families often tell us that their child who lives with epilepsy has never met or interacted with another person with epilepsy and our Family Fun Day is an annual event offered by our service aimed at bringing families from across Ireland together in a fun environment – where those affected by the condition can meet with others in a similar situation, in a fun environment.

The event is one of the most popular events we hold year on year and this year was no different! The day was attended by a number of our Community Resource Officers and 152 people from across Ireland – with our Community Resource Officer Pam revealing herself as an expert face painter at the event!

As you can see from the pics included in this page, the kids in attendance (and some of the big kids from Epilepsy Ireland) had a fantastic day!

We are already looking forward to our next Family Fun Day in 2024 and keep an eye on our website and social media channels for further details! A huge thank you to all our members who attended – we hope you enjoyed the event as much as we enjoyed hosting you!

SODIUM VALPROATE INQUIRY GIVEN GREEN LIGHT

Stephen Donnelly
@DonnellyStephen

Today Government approved my request to establish an inquiry into the use of sodium valproate in Ireland. My thanks to @oacsireland @epilepsyireland and all stakeholders. A step forward for the women and families affected.

The 11th of July was a significant day in our longstanding campaign alongside OACS Ireland concerning Sodium Valproate, with the Government officially signing off on the establishment of an inquiry into the historical licensing and prescribing of Sodium Valproate in Ireland.

The decision follows years of campaigning by both Epilepsy Ireland and OACS Ireland, advocating for such a measure to be taken – and marks Ireland finally falling in line with other European Jurisdictions who have already held similar inquiries.

Sodium Valproate (Epilim) is a medicine licensed in Ireland to treat epilepsy and bipolar disorder. If a woman becomes pregnant while taking Epilim, their baby is at risk of serious birth defects and developmental disorders. 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. While these risks are now well established and known, for decades, women on the drug were not made aware of the risks – despite evidence emerging from the 1960s onwards that the medication could potentially have this impact. It was not until 2014 and again in 2018 that any real, formal measures were taken to warn women on the drug about its potential impacts.

In the period from when the medication was first licensed to when warnings first began to be issued, the HSE estimate that up to 1,250 families have been impacted by exposure to valproate in pregnancy. Families affected want to know how and why this was allowed to happen, and it our hope that this inquiry will begin the process of better understanding this.

On the establishment of the inquiry, our CEO Peter Murphy said, ""The decision by cabinet paves the way for the State to begin the process of understanding the history of sodium valproate, and the impact that exposure to the drug has had for an estimated 1,250 families in Ireland. Other European countries including the UK and France have already taken action on this issue, and we hope that Irish families will soon have their voices heard, and in time, the answers they rightly deserve.

"By documenting the regulation and practices around the prescribing and dispensing of sodium valproate, alongside a thorough review of the development of scientific data over time, a clearer historical picture will emerge not just for those impacted but to inform recommendations to ensure that this never happens again. It is vital that public trust in how our medicines is regulated and prescribed is maintained. It is equally vital that we do all possible to ensure the safety of women who continue to be prescribed the medication to this day, as well as their future children".

It has been an extensive process to get to the official announcement of this inquiry. Our members will be familiar that the Minister for Health first gave a commitment to holding an inquiry back in 2020 and in the three years since, there has been marked by lengthy and frustrating delays in getting the inquiry established with extensive discussions on the form of the inquiry and its terms of reference. We have been working together with our colleagues in OACS Ireland to have this inquiry established, and commenting on this recent development, OACS Chairperson Karen Keely said, "While we would have favoured the establishment of a Statutory Inquiry to fully investigate the history of the licencing and prescribing of Sodium Valproate in Ireland, we were left in no doubt during our prolonged negotiations that the terms of reference agreed by Cabinet were the only terms on offer. Our members reluctantly agreed to proceed with a non-statutory inquiry.

"While the structure is not what we would have chosen at the beginning of this process, we sincerely hope that this inquiry will, through transparency and public interest, act as a vehicle to finally answer our long-standing questions and give a voice to those who have been harmed, some catastrophically over the years. Families are trusting that the process, under the guidance of an independent Chair, will strike at the heart of key issues such as how and why this was allowed to happen; why it took so long for effective preventative regulatory steps to be put in place; and whether the steps taken by the State over time were in line with the progression of scientific knowledge.

"Cabinet approval for an inquiry is an important development for all the families in Ireland whose children have been left with devastating birth defects and neurodevelopmental delay as a direct result of their mothers taking sodium valproate during pregnancy. It has taken over a decade of our lives to get to this stage and we are pleased to be moving forward at long last."

With the Government now approving an inquiry, we have moved into a new phase of our campaign. We eagerly await further information on the Chair that will be appointed to lead this inquiry – while we will also be working with the Department of Health to ensure that the appropriate supports are put in place to ensure the maximum participation of families affected in the inquiry.

We would like to thank the Minister for Health for honouring his commitment to hold this inquiry; all TDs and Senators who have continually raised this issue over the years; and of course, would like to thank you, our members, volunteers and supporters for helping amplify this campaign in every possible way by raising with your local representatives at every opportunity.

We look forward to the swift establishment of this essential inquiry and to working with the Chair when they are in place. As soon as any further updates are available on this ongoing campaign, we will share these in future editions of our Newsletter and on our website and social media channels. To learn more about the history of this campaign, visit the 'Advocacy' section of our website.

PLEASE CONTACT YOUR HEALTHCARE TEAM IF YOU HAVE ANY CONCERNS. DO NOT STOP TAKING VALPROATE WITHOUT FIRST SPEAKING WITH YOUR PRESCRIBER.

▶▶ https://bit.ly/EISV23

SEPTEMBER IS MYLEGACY MONTH

September is MyLegacy Month, a time when we highlight the impact of legacy giving. MyLegacy Month appeals to the public to consider including a gift to their chosen charity, after they have looked after their family and friends.

Every year, we are privileged to have incredible people leave the gift of a legacy to Epilepsy Ireland in their will. These extraordinary gifts support the future of critical services we deliver that are needed by people living with epilepsy and their families; power the advocacy needed to secure healthcare and legislative change and fund the ground-breaking research that will change the lives of people with epilepsy in future.

Leaving a gift in your will means that you can contribute to the work of Epilepsy Ireland that costs you nothing in your lifetime but will mean everything to someone with epilepsy in the future. You will have the benefit of being part of a special community of supporters, knowing that you will be changing many people's lives and assisting us with our work towards a society where no person's life is limited by epilepsy.

Each gift, whether big or small, will make a vital and cherished difference.

How you can include Epilepsy Ireland in your will

- Leave a specific sum, a pecuniary gift. Each such gift is a secure contribution to help achieve our vision of a world where no person's life is limited by epilepsy.
- Leave a share of your estate not promised to family or friends, a residuary gift. A gift like this can have a wonderful impact on innovative research, service delivery, and advocacy.
- You may pledge a specific item from among your assets, such as property, shares, or jewellery, to Epilepsy Ireland.
- To include Epilepsy Ireland in a will you have already written, you can add a codicil. This is a simple addition and becomes a permanent part of your will.

If you are considering leaving a gift in your will to Epilepsy Ireland, we are very grateful. Even if you are only at the very early stages of planning, we would be pleased to hear from you and answer any questions you may have.

If you choose to share your intentions with us, we can work closely with you to ensure your wishes are met, keep in touch with you about our work, and most importantly, we can thank you for your support.

Please look out for posts about legacy month on our social media and share these to highlight the importance of legacy giving.

If you would like to discuss Legacy giving and the prospect of a gift to Epilepsy Ireland without obligation, please contact our Fundraising & Development Manager Cian by emailing cdikker@epilepsy.ie or by calling 085 880 8012.

By leaving a gift in your will, you can secure the future of Epilepsy Ireland's services.

Your gift will ensure that we can continue to work towards a society where no person's life is limited by epilepsy.

epilepsy Ireland

To discuss further in total confidence and without obligation, contact Cian by calling 085 880 8012 or by emailing cdikker@epilepsy.ie

OIREACHTAS COMMITTEE ON SOCIAL PROTECTION SUPPORTS EI FREE TRAVEL CAMPAIGN

In a major boost to our ongoing campaign to improve access to the Free Travel scheme for people with epilepsy, we were delighted to have the Oireachtas Committee on Social Protection support our campaign as part of their recent pre-budget submission to the Minister and Department of Social Protection.

Epilepsy Ireland have regularly liaised with all members of the Committee, highlighting the impact this issue has on people with epilepsy and their families, seeking their support in having it addressed. Recently we made a further submission to the Committee as part of their pre-budget consultative process, and we were delighted to see our proposals included within their final document as a priority recommendation.

Our members will be very familiar at this stage with what we are proposing and why. However, to have the Committee now echoing this is an important development as it adds further pressure on the Minister, Department and Government to hopefully act on this longstanding issue.

While the support of the Committee is important and gives us a powerful ally in addressing this campaign, ultimately rectifying this issue will be a matter for Government.

At the time of print, we still await a final report from the Department of Social Protection regarding our proposals to improve access to the Free Travel scheme. This report has been expected since the end of last year but frustratingly, has yet to be finalised or shared with Epilepsy Ireland.

Given the amount of time which has gone into the report's preparation, and the fact that several deadlines have now been missed, we can only hope the delay is because the report contains positive steps forward on resolving the issue.

For our member's information, we have included an entire written Parliamentary Question Dáil response on this report which was raised with Minister Heather Humphreys by Deputy Aindrias Moynihan.

Deputy Aindrias Moynihan: To ask the Minister for Social Protection if the report being compiled by her Department on expanding the free travel scheme for people who have been excluded from driving with epilepsy is available; and if she will make a statement on the matter. [33085/23]

Deputy Heather Humphreys; Minister for Social Protection: The Free Travel scheme provides free travel on the main public and private transport services for those eligible under the scheme. There are over one million customers with direct eligibility. The estimated expenditure on free travel in 2023 is €95 million. It is important to note that, in general, access to a free travel pass for those aged under 66 is a secondary benefit linked to a person being in receipt of certain primary Social Protection payments such as Disability Allowance, Invalidity Pension, Carer's Allowance, Blind Pension and Partial Capacity Benefit. As many illnesses or physical conditions have an impact ranging from mild to severe, entitlement to these social welfare schemes is not provided on the basis of a diagnosis but on the basis of the impact of that diagnosis on the individual concerned and in the case of Disability and Carer's Allowance to an assessment of their means. In this way, resources can be targeted to people in most need.I am aware of an ongoing campaign by Epilepsy Ireland. I fully recognise the issues and difficulties that can arise due to a person being diagnosed with epilepsy and who is unable to drive as a result of their condition. I have met with representatives of Epilepsy Ireland to discuss its proposal in detail and following the meeting I asked my Department officials to examine the issues raised in relation to access to the Free Travel scheme. As previously advised to the Deputy, I am awaiting a report from my officials on the issues raised by Epilepsy Ireland. I expect to receive the report shortly and will carefully consider its contents and any recommendations that it may contain. I hope this clarifies the matter for the Deputy.

We hope that the report mentioned is available soon so we can continue to move forward with this campaign and seek progress on same. We will use all avenues available to us to further advance this issue and we have wrote to the Minister on two separate occasions now stressing the need for a further update and response. We will provide further updates in future editions of our newsletter and on our website and social media channels.

In the meantime, we would appeal to all our members to continue to raise this directly with your local TDs and Senators. With the Dáil now in recess and the budget approaching, it is a perfect opportunity to remind elected representatives within your community of the impact of this issue and how it is affecting people with epilepsy in every constituency in Ireland. This can help greatly in helping draw further attention to this issue, which will hopefully lead to it being addressed eventually.

You can find further information on this campaign, as well as a template letter which can be sent to your local elected representatives, by visiting the Advocacy section of our website.

We would like to thank all our members for their continued support for this campaign.

▶▶ https://bit.ly/EIFT23

WAYNE IS A GOLDEN LIGHT!

We are delighted to share with our members that at this year's International Epilepsy Congress, there will be an Irish recipient of the International Bureau for Epilepsy's Golden Light Awards in the form of Wayne O'Reilly from Wexford!

The IBE Golden Light Awards are bi-annual awards that recognise young people affected by epilepsy – either because they have epilepsy or have made a significant positive impact on the lives of others who have the condition.

As part of the awards process, Epilepsy Ireland could only put forward one nomination. At Epilepsy Ireland, we are fortunate to have incredible volunteers who go above and beyond to help raise awareness of epilepsy, and to support the work of Epilepsy Ireland. We are in a privileged position in that we were spoilt for choice on who to choose, but in the end, we put forward Wayne given his immense contributions in support of Epilepsy Ireland over the years as he is the definition of an incredible volunteer!

Whenever we have sought his involvement, the word "no" has not been in Wayne's vocabulary.

Wayne is 30 years old and has been living with epilepsy since 2016. Since being diagnosed, Wayne has been an incredible advocate for epilepsy awareness and Wayne has shared his personal story of his journey with epilepsy on our social media channels, directly with the media AND has fronted two of our #EpilepsyDay campaigns – most notably in 2022 when he donned a suit of armour to become "Sir Wayne of Wexford" in the name of epilepsy awareness.

Alongside his awareness raising efforts, Wayne has also been more than willing to put his shoulder to the wheel to help support Epilepsy Ireland's fundraising activities.

As part of the nomination process, we highlighted some of Wayne's contributions to the IBE judging panel – and are delighted that they agreed his work is more than worthy of recognition. Wayne is just one of three recipients of the award this year – which saw incredible young people from across the globe being nominated.

Wayne will officially receive his award at the opening ceremony of the International Epilepsy Congress in September and we are delighted to have his outstanding contribution to EI acknowledged at such a prestigious event. It is an added bonus that it is happening on home soil!

We are sure our members will join us in offering a huge congratulation to Wayne and we would like to thank him once again for his contributions to Epilepsy Ireland over the years!

EI CALL ON GOVERNMENT TO ACT ON WHO IGAP

In advance of the International Epilepsy Congress in September, we have written to the Taoiseach calling for national and international action on the Intersectoral Global Action Plan on Epilepsy and other neurological conditions.

The plan was adopted by the WHO back in June of 2022 and Ireland, as a European Union Member State, agreed to the actions of the plan.

Some of the key points of the plan are summarised below:

- To raise the prioritisation of, and strengthen governance for, epilepsy and other neurological disorders.
- To provide effective, timely and responsive diagnosis, treatment, and care for all patients.
- To implement strategies for promotion and prevention of epilepsy and other neurological disorders.
- To foster research and innovation into, and strengthen information systems, for epilepsy and other neurological disorders.
- To strengthen the public health approach to epilepsy.

The plan aims to improve the lives of all those living with epilepsy and neurological conditions across the globe and calls on member states to implement several key initiatives and policies to help achieve this.

With the eyes of the global epilepsy community on Ireland with the upcoming International Epilepsy Congress taking place in Dublin, we have highlighted in our correspondence how this represents a perfect opportunity for Ireland to take initial steps to make the goals of the plan a reality in Ireland. By doing so, we would set a global example to other countries in beginning the work required to implement the plan in Ireland.

While there has been major developments and improvements in epilepsy care in Ireland over the past decade, there is still much work to be done. For example, we need to better integrate clinical genetics into epilepsy diagnosis and treatment; expand our epilepsy surgery programme; embed new e-health technologies into clinical practice; and there is an urgent need to tackle preventable epilepsy deaths including those from Sudden Unexpected Death in Epilepsy (SUDEP). This can all be achieved if the IGAP is to be fully implemented in Ireland.

In our correspondence, we have proposed the establishment of a working group of all stakeholders in the epilepsy community to come together to work on these key issues, and the many more which are facing the entire epilepsy community in Ireland.

The Congress represents a perfect opportunity for the Government to announce action on these issues and we hope that they will do just that.

You can read our correspondence in full by visiting www.epilepsy.ie.

Thank you, Chloe!

A massive thank you to Chloe Coyne from Clara in Co. Offaly who held a fantastic coffee morning in support of Epilepsy Ireland recently, raising €547.65 in support of our work. Chloe is pictured here presenting the funds raised to her local Community Resource Officer, Cliona Molloy. Speaking about why she arranged her fundraiser, Cloe said, *"Since I was very young, I was diagnosed with epilepsy so it's a condition I have had to live with all my life. When I was looking at organising a fundraiser, Epilepsy Ireland was the obvious choice. The support, advice and research that Epilepsy Ireland provides for families is invaluable."*

Coffee Morning in Memory of Jamie Bonner

A huge thank you to Máire Bonner, Forbairt Na Rosann Dungloe and everyone involved in supporting and donating to an incredible coffee morning in memory of the late Jamie Bonner. Through everyone's fantastic efforts, a massive €2,135 was raised in support of Epilepsy Ireland in Jamie's name. Máire and some of the Forbairt Na Rosann team are pictured here presenting a cheque with the total funds raised to our local Community Resource Officer for the North-West, Agnes Mooney.

Jamie Bonner - Ar dheis Dé go raibh a anam.

Thank you Integer!

We were delighted to travel to Integer New Ross in May to thank them for the incredible amount that they raised in support of Epilepsy Ireland over the course of 2022.

The Integer team, through several initiatives, raised a massive €20,000 for Epilepsy Ireland – specifically for the Louise Young Seizure Alarm & Research fund – which was set up in memory of the late Louise Young who passed away due to SUDEP in 2021.

The research aspect of this fund is currently underway and when we move into the next phase of this, the funds raised by the team at Integer will go a long way to ensuring the long-term viability and sustainability of the fund – alongside the incredible amount which has already been raised by Louise's family, friends, and colleagues. A huge thank you to everyone involved in raising these funds for Epilepsy Ireland in Louise's memory.

Pic: Louise's mother Tina and all the Integer Team presented the cheque with funds raised to our Advocacy & Communications Manager Paddy.

VHI Women's Mini-Marathon

We are in the envious position of not having enough room in this edition of our Newsletter to thank everyone individually who supported our work via the annual VHI Women's Mini-Marathon in June – but is no exaggeration to say we had a small army taking part in support of EI!! It was fantastic to see so many taking part this year and all we can say is a HUGE THANK YOU to all the incredible women who took part. While totals are still being calculated, it is estimated that everyone's efforts have collectively raised over €11,000!! You can see ***some*** of our incredible runners in the accompanying pics!

Cork City Marathon 2023

Much like the VHI Mini-Marathon, all we can say once again is a massive thank you to everyone who took on the challenge of running the race in support of Epilepsy Ireland. Again, there are a number of incredible individuals who took part, and we cannot thank you all enough. Through their collective participation, just over €6,000 was raised in support of our journey towards a society where no person's life is limited by epilepsy!

Pic: All smiles at the end of the Cork City Marathon!

2023 Annual Raffle!

Enclosed with this Newsletter, you will have received details and tickets for our Annual Raffle. The raffle has been a fixture of our fundraising activities over the last number of years – raising just under €13,000 last year thanks to your support. Once again, we are appealing for your support this year for our raffle, with the funds raised helping continue our journey towards a society where no person's life is limited by epilepsy. If you have any questions about the raffle, contact Ashley by emailing abutler@epilepsy.ie.

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

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If you need information or support on your journey with epilepsy, we are here for you. Get in touch with your local Community Resource Officer.

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

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