RESEARCH BULLETIN

An update on Epilepsy Ireland's activities in supporting Irish epilepsy research

ABOUT EPILEPSY AND EPILEPSY IRELAND

Epilepsy is a neurological disorder, characterised by recurrent, unprovoked seizures. The condition affects over 45,000 people in Ireland, including an estimated 10,000 - 15,000 children. There are approximately 2,000 new diagnoses annually, and up to 15,000 people are living with uncontrolled seizures.

For this group in particular, the consequences of epilepsy can be long-lasting and significant. It can affect the person's education, employment, social functioning, self-esteem and independent living.

People with epilepsy must also cope with the physical impact of seizures, the side-effects of medications and for many, the social stigma and economic impact that can be associated with it. Its individualised impact on those who live with it means that it is often considered as a hidden disability. There is also an increased risk of mortality associated with epilepsy with an estimated 130 epilepsy-related deaths in Ireland each year.

Epilepsy Ireland's vision is to achieve a society where no person's life is limited by epilepsy. Since 1966, we have remained committed to working for and meeting the needs of everyone with epilepsy in Ireland, their families, and carers.

Our Mission is to empower all those affected by epilepsy to achieve their full potential by:
- providing high-quality community-based support and education,
- raising public awareness,
- conducting effective advocacy,
- supporting epilepsy research.

For further information on epilepsy and all of Epilepsy Ireland's activities, supports and services, visit our website www.epilepsy.ie.

FOREWORD

A Chara,

I am delighted to once again introduce the latest edition of our Research Bulletin, bringing you updates on the progress of the projects you have helped support, as well as insights into our broader research activities.

Since 2009, Epilepsy Ireland has invested over €1.5 million in impactful research aimed at better understanding, treating, and supporting the 45,000 people living with epilepsy in Ireland and the many millions worldwide.

This is a considerable commitment for an organisation of our size and would not be possible without your continued generosity. As I write, we are preparing to increase this investment in the coming year.

Later this year, we will launch our 9th Research Funding Call under the Health Research Charities Ireland/ Health Research Board (HRCI-HRB) Joint Funding Scheme. This scheme enables charities like Epilepsy Ireland to secure matched government funding for innovative research that directly benefits the people they represent - people with epilepsy and their families in our case. It is a highly competitive process, but thanks to your support, we have the opportunity to be part of it and to fund new, groundbreaking projects. We look forward to announcing new research investments in the next edition of our Research Bulletin!

In addition, we are actively exploring research partnerships through the Research Ireland Enterprise Partnership Scheme, which supports early-career researchers working on specific projects in a range of different fields of expertise. We have already seen several success stories from participating in this scheme - one of which you'll read about in this bulletin!

Also in this edition, we highlight a major study on Sudden Unexpected Death in Epilepsy (SUDEP) in Ireland, which made national headlines and is now the foundation of a new Epilepsy Ireland advocacy campaign. We also chat with Postdoctoral Researcher Dr. Jade Parnell about her work on the EPIKNOW project and we share an update on the completion of a research project you helped fund—and how it has paved the way for further studies.

We hope you enjoy reading about the impact of the research you have supported, as well as our other activities within the world of epilepsy research. As always, thank you for your continued support. If you have any questions or comments, please feel free to contact me at pmurphy@epilepsy.ie.

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

Peter Murphy

Peter Murphy
Chief Executive Officer,
Epilepsy Ireland

EPILEPSY IRELAND SUPPORTED STUDY ESTABLISHES INCIDENCE OF SUDEP IN IRELAND

In October 2024, a major new study which you helped make possible, published its findings which for the first time, establishes the incidence of Sudden Unexpected Death in Epilepsy (SUDEP) in Ireland.

SUDEP is when a person with epilepsy dies suddenly and without an obvious cause. It happens without injury, drowning, or another known medical reason. There may or may not be evidence of a seizure, and it often occurs during sleep.

SUDEP is the most devastating aspect of epilepsy but until now, there was no data available on how many people died from SUDEP each year in Ireland.

In 2020, Dr Yvonne Langan from the Department of Neurophysiology at St. James's Hospital, working in partnership with researchers from the Health Research Board (HRB), began a study to gather this data. The study was funded by Epilepsy Ireland, the Irish Institute of Clinical Neuroscience and Jazz Pharmaceuticals.

Using data from all deaths referred to coroners in the reference year of 2019, the researchers identified all those with a history of epilepsy, and then worked to identify all deaths which met the criteria for SUDEP.

The following are the key findings from this research:

- A total of 33 cases of definite SUDEP were identified in 2019
- This included 21 men and 12 women
- The age range of those who died ranged from 9 – 81 years old. The median age was 45.

Using established data on the prevalence of epilepsy in Ireland, we now know, thanks to your support, that the incidence rate of SUDEP in Ireland is 1:1,400 per annum. In other words, for every 1,400 people with epilepsy, one person dies from SUDEP each year.

Knowing this information is vitally important. It will help doctors, researchers, and people with epilepsy understand how common SUDEP is and guide efforts to reduce the risk, improve care, and encourage informed decision making.

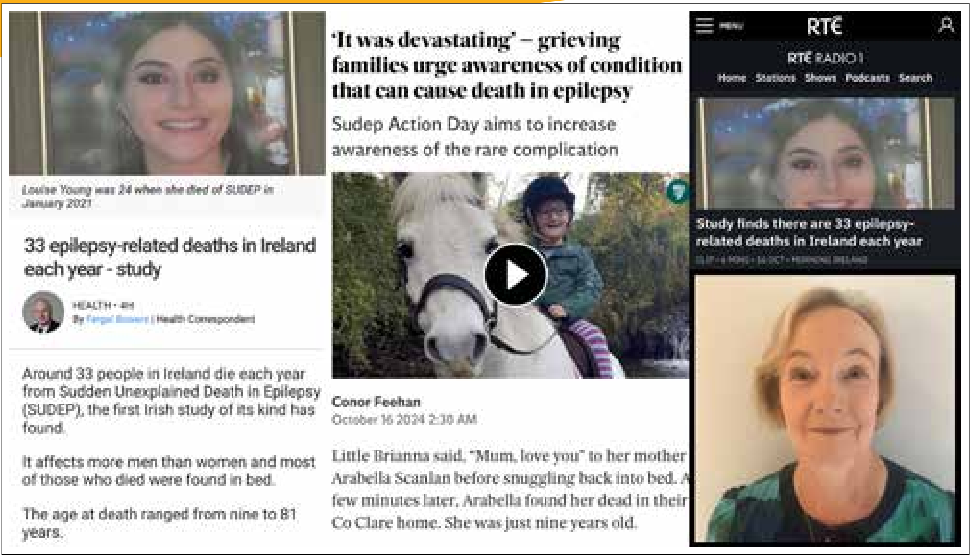
Epilepsy Ireland has also launched a new advocacy campaign calling for targeted action to reduce the incidence of SUDEP. While the exact mechanism behind why SUDEP happens is not yet fully understood, we do know that the better a person's epilepsy is controlled, the lower the risk of SUDEP. A number of other risk factors can also be reduced.

Armed with accurate scientific data, we can now push for action to reduce these numbers, for example by campaigning for improved access to specialist care and treatments in order to increase the likelihood of becoming seizure-free.

The study's publication, and the launch of our campaign received significant attention last October with features across RTÉ News, including the 6.1 News, and politicians of all parties and none voicing support for our campaign.

CONTINUING RESEARCH

It is important to note that this is just the first set of findings from the research which you have supported. Dr Langan is continuing her work to establish the



Louise Young was 24 when she died of SUDEP in January 2021

33 epilepsy-related deaths in Ireland each year - study

HEALTH • 4H
By [illegible] | Health Correspondent

Around 33 people in Ireland die each year from Sudden Unexplained Death in Epilepsy (SUDEP), the first Irish study of its kind has found.

It affects more men than women and most of those who died were found in bed.

The age at death ranged from nine to 81 years.

'It was devastating' – grieving families urge awareness of condition that can cause death in epilepsy

Sudep Action Day aims to increase awareness of the rare complication

Conor Feehan
October 16 2024 2:30 AM

Little Brianna said, "Mum, love you" to her mother Arabella Scanlan before snuggling back into bed. A few minutes later, Arabella found her dead in their Co Clare home. She was just nine years old.

Study finds there are 33 epilepsy-related deaths in Ireland each year

Some of the mainstream media coverage from the study, featuring the experience of bereaved families and study lead, Dr. Yvonne Langan pictured in the bottom right.

incidence of **total** epilepsy-related deaths in Ireland.

This includes deaths not only due to SUDEP, but also those as a result of status epilepticus (a prolonged seizure), seizure-related injuries, drowning etc.

Looking at international data, we estimate that that there are over 130 total epilepsy-related deaths in Ireland annually, but this is just an estimate. We hope that later this year, accurate data will help to further amplify the need for action to tackle epilepsy-related deaths in Ireland.

For too long, much of the action and communication around SUDEP in Ireland has come from Epilepsy Ireland, often supported by the fundraising efforts of bereaved families. This shouldn't need to be the case, and we hope that this research will act as catalyst for a more strategic approach from the Department of Health, HSE, clinicians and policymakers to improve access to specialist epilepsy care and save lives.

We would like to thank Dr Yvonne Langan and Dr Ena Lynn and colleagues at the HRB for their outstanding and continuing work on this important topic.

Again, this work would not have been possible without your support. Our thoughts remain with all those who have lost a loved one due to SUDEP or an epilepsy-related death and we hope that renewed efforts will lead to fewer families being faced with the devastation that this can bring.

Ar dheis Dé go raibh a n-anamacha.

To read more about this study and our new SUDEP advocacy campaign, visit the 'Advocacy' section of www.epilepsy.ie.

EPILEPSY IRELAND PARTNERS WITH FUTURENEURO ON MY MOVING BRAIN!

We are excited to continue collaborating on various projects with our colleagues at FutureNeuro, the Research Ireland Centre for Translational Brain Science.

At FutureNeuro, many of their world-class researchers and projects focus on epilepsy. While most of our collaborations ae centred on epilepsy research that you have helped fund, some have a broader reach, engaging the wider community. One such example is My Moving Brain!

Led by FutureNeuro and funded by Research Ireland, this two-year project includes Epilepsy Ireland as a named partner. The project aims to highlight the connection between brain health and sport while promoting the inclusion of people with epilepsy and other neurological conditions in sporting activities.

Epilepsy is not a barrier to a person's participation in sport in most cases. However, we have encountered instances where individuals were excluded from sporting activities because of their condition. Often, this is simply down to a lack of awareness of the condition and when simple safety measures are put in place, a person with epilepsy can fully participate.

To raise awareness, challenge misconceptions, and encourage greater participation, the project will include five regional workshops and educational sessions over the next two years. Events will feature the lived experience of epilepsy and other neurological conditions, as well as medical professionals, coaches, teachers, patient advocates and researchers.

From an Epilepsy Ireland perspective, this will be a wonderful opportunity to inform and raise awareness of those involved in local sporting activities about epilepsy.

The first event took place in Dublin in November 2024, with the next one due to take place in Cork in March 2025.

The Dublin event included inputs from Epilepsy Ireland volunteers, Dr. Michael McKillop MBE (Former Paralympic gold medallist and world champion) and Emma Beamish (former Ireland international cricketer) speaking about their lived experience of epilepsy and how they did not let the condition hold them back from achieving their goals.

With sports coaches, local clubs and others living with neurological conditions in attendance, this was an important message to share to help foster a more inclusive society for people with epilepsy and other brain conditions who wish to compete and participate in sports.

We look forward to continuing our work with FutureNeuro on this important project. Please follow our website (www.epilepsy.ie) and social media channels for more details on upcoming My Moving Brain events and come along to see My Moving Brain in action!

Some of the EI & FutureNeuro team with Dr. Michael McKillop (centre) and Emma Beamish (end)

EPILEPSY IRELAND FUNDED RESEARCH LEADS TO NEW PROJECT FOCUSED ON DOGS

Long-term supporters of our research activities will be familiar with a project we previously supported in Queen's University Belfast by Dr. Neil Powell which published its findings in 2021 and found that untrained pet dogs can display seizure-alerting behaviours when exposed to seizure-related odours.

At the time, this research led to national media coverage and captured the attention of the entire epilepsy community.

New research is now aiming to further capitalise on the initial work you helped to fund.

We are delighted to collaborate with researchers from Dublin City University which aims to develop a seizure-predicting dog collar. The project has received funding of just under half a million euro via the Research Ireland Frontiers for the Future programme and is being led by Prof. Alan Smeaton and Tomás Ward of Insight DCU.

The project will involve cross-collaboration amongst several organisations and centres – including the Research Centre for Data Analytics at DCU, Irish Dogs for the Disabled, Beaumont Hospital, and of course, Epilepsy Ireland.

The researchers will team up man's best friend with cutting-edge technology to develop wearable sensors for dogs which it is hoped will support patients with epilepsy. Placed in the collar, the sensors will automatically capture a dog's behavioural changes/ movements in real-time when the dog is exposed to a pre-seizure scent. Using machine learning, an alert will then be transmitted to the person with epilepsy or a carer, to warn them of seizure.

In theory, this should enable the person to seek assistance or get themselves into a safe space before the seizure happens, to minimise risk of seizure-related injuries.

There is a huge interest within the epilepsy community on how technology can be used to help warn of an impending seizure – and equally, there is also huge interest in similar approaches using dogs, particularly since the Queen's/ Epilepsy Ireland study from 2021.

A reliable method of seizure prediction and detection is the holy grail for many people living with epilepsy as well as the parents of children with the condition. This is especially the case where seizures involve the loss of consciousness, with a high risk of injury.

We at Epilepsy Ireland are thrilled that the project has received such significant state funding – it shows clearly how relatively modest investments you help to enable can create a ripple effect and inspire larger follow-on projects. We look forward to working with the research team as the project progresses.

LET'S TALK ABOUT EPIKNOW WITH DR JADE PARNELL!

For this edition of our Research Bulletin, we sat down with Dr Jade Parnell to discuss the EpiKNOW project - which you have helped to fund.

Jade is a Senior Postdoctoral Fellow at the Royal College of Surgeons in Ireland, working on the EpiKNOW Project since it began in August 2023.

The project is led by Dr Aisling Walsh from the Department of Public Health & Epidemiology at RCSI. It aims to understand the health information needs of women with epilepsy from preconception to postpartum, both in terms of what is available and what needs to be developed in order to fill identified gaps in information.

Jade recently spoke to EI's Advocacy and Communications Manager Paddy McGeoghegan to discuss her work on EpiKNOW, and the progress which has been made so far.

PMG: Why is this research important?

JP: This research is important because there are approximately 10,000 women of childbearing age living with epilepsy in Ireland and women with epilepsy have expressed a need for information to support them during the stages of preconception (before pregnancy) to postpartum (after pregnancy).

PMG: Can you tell us about the progress of the research so far and what are the plans for the year ahead?

JP: The research will conclude in August this year. So far, we have investigated what information is available online for women with epilepsy during these stages and the quality of these resources. We have also interviewed 34 women with epilepsy and 23 health professionals in Ireland. The information from these interviews has directly fed into the final stages of this project, which is to have women with epilepsy, their family members, and health professionals in Ireland complete a survey to find out what type of resources they would prioritise. The most preferred resource will then be co-developed with women with epilepsy and health professionals in the spring/ summer of this year.

PMG: What has been your favourite aspect of working on this project?

JP: Whilst there are many things I enjoy about this project, if I had to pick one, it would have to be working with the women. From the interviews with women with epilepsy and the wonderful PPI (Patient & Public Involvement) panel we have, it's a lovely reminder that this project is going to help these women feel more informed and supported.

PMG: Patient and Public Involvement (PPI) is a relatively new approach to research where researchers work in close partnership with patients across all stages of the research process. Can you tell us a bit more about the PPI Panel and why PPI is important in research?

JP: As mentioned, we have a fabulous group of women with epilepsy who are part of the PPI panel for this project. We meet online once every three months and, after having a bit of a catch-up, get the chance to hear from these women regarding their feedback on elements of the project. They're great and really help ensure what we do is relevant for women with epilepsy. We all get something out of it, so I call that a win-win! Its important other projects do this, especially when considering how our research will help others. Yes, we want to help, but there is an important distinction

(L-R) Epilepsy Ireland Advocacy & Communications Manager, Paddy McGeoghegan, Postdoctoral Fellow Dr Jade Parnell, PPI Panel member Claire Mulcachy and her twin sister Jane.

between doing 'for' and doing 'with.' Having representation within research is vital which is why PPI panels are so important.

Thank you, Jade, for taking the time to speak with us and provide some insight on this ongoing research! As Jade mentioned, the project is moving into a new phase with the issuing of a survey of healthcare professionals, women with epilepsy, and family members/ friends of women with epilepsy. If you fall into any of these categories – or know someone who does – please stay tuned to www.epilepsy.ie for details on the survey.

Claire Mulcahy is a member of the PPI panel for this project and she also spoke to Paddy about what it is like to part of a PPI panel:

"It's been such an interesting project to be part of and to meet women with epilepsy from across Ireland on the PPI panel, all of whom are at different stages of live and have unique perspectives. We've seen how the points we have made on the panel from our lived experience perspective have been reflected in the questions the research is asking. By involving our lived experience as part of the project and the work it is doing, it can only strengthen its findings and hopefully amplify its impact for women with epilepsy both now and in the future".

Thank you, Claire, for participating in the study and for sharing your perspective.

Thank you again to all our readers and supporters who have helped make this research possible. We firmly believe this work has the potential to make a huge impact on the future care of women with epilepsy in Ireland, who are planning pregnancies in the future.

We look forward to reporting about the completion of this project and its findings in the next edition of our research bulletin.

STUDY ON CIRCADIAN BIOMARKERS IN DRAVET SYNDROME COMPLETES

As noted on page 7, while your support for our research investments is crucial, an often-unseen outcome of these investments is how the projects we fund can lead to further, bigger investments to delve deeper or take the research in new directions.

Dr Radharani Benvenutti's Epilepsy Ireland funded research on circadian biomarkers in pre-clinical and clinical Dravet Syndrome is a great example of this in action. Thanks to your support, Epilepsy Ireland co-funded Dr Benvenutti's research from 2022 to 2024, through a total investment of €32,509.

Dravet syndrome is a very difficult to treat epilepsy syndrome characterised by seizures that start in the first years of life. People with this condition commonly present with nocturnal seizures, sleep problems and are at high risk of sudden unexpected death in epilepsy (SUDEP) that most commonly happens at night.

Dr Benvenutti's research investigated whether this may be associated with circadian rhythms. The circadian system acts as an internal clock synchronizing many functions in our bodies, setting their rhythms. Until now, the precise mechanisms of the disruption of the circadian system in Dravet Syndrome was poorly understood.

While there have been many distinct findings from this research, the core finding indicated that the circadian clock is disrupted in specific areas of the brain, and that neuroinflammatory pathways which are regulated by this 'clock' may have a key role in the mechanisms leading to Dravet Syndrome. This pre-clinical work could in time lead to new treatment targets which would offer hope to all those affected by this life-limiting condition.

These are significant findings – which are not only of great interest to Epilepsy Ireland, but also to families of those who are affected by Dravet Syndrome.

While the Epilepsy Ireland funded aspect of this research has now been successfully completed, it does not mean that Dr Benvenutti's work has ended. In 2024, she secured a $250,000 in research grant funding from the Dravet Syndrome Foundation in the United States to help continue her investigations in this area. Dr. Benvenutti has noted that the findings from her initial EI-supported study were instrumental in securing the new funding.

While the funding you helped to provide appears modest in comparison to the US grant, the latter would not have been possible without Epilepsy Ireland and our supporters.

This is a great example of how Epilepsy Ireland's support can provide an opportunity for a young researcher to establish their career and make an impact in the world of epilepsy research. We hope that this will lead to a long, successful and brilliant career in working to improve the lives of people with epilepsy, not just in Ireland, but across the globe.

RESEARCH NEWS IN BRIEF!

Did you know?

While this bulletin highlights some recent research updates, you can find full details of all our investments in epilepsy research in the 'Research' section of www.epilepsy.ie.

With your support, we look forward to adding several new projects to the list by the end of the year!

Epilepsy Research Matters Event

As this edition of our Research Bulletin goes to print, we are busy planning our Epilepsy Research Matters event which takes place in Dublin on 12th March 2025.

This event is a continued collaboration between Epilepsy Ireland and FutureNeuro, featuring a showcase of some of the incredible epilepsy research projects which are taking place in Ireland – including those projects you have helped to fund!

We can feature research events like this or events like My Moving Brain regularly on our website. Keep a close eye on the 'Events' section of www.epilepsy.ie to see how you can attend - and potentially meet some of the researchers you have helped support!

Time For a Break!

A huge congratulations to all the recent winners of our monthly Time For a Break monthly draw, which helps support our investments in epilepsy research. The full list of our 2023 & 2024 winners are included on the top right – we hope all our winners enjoyed their breaks!

2024 Winners

- Jan: M Quinn
- Feb: W Moore
- Mar: A Dalton
- Apr: M. Manning
- May: F. McCarthy
- June: P. Cleere
- July: P. Galvin
- Aug: P. Gillick
- Sept: J. Fitzgerald
- Oct: M. Cunningham
- Nov: P O'Rourke
- Dec: E.Kenny

2023 Winners

- Jan: N. Bolger
- Feb: M. Smith
- Mar: E. O'Connor
- Apr: I. Agar
- May: A O'Sullivan
- Jun: M Brady
- Jul: M & B Kennedy
- Aug: W. Fitzgerald
- Sep: F. Galvin
- Oct: C. Carolan
- Nov: B McNicholas
- Dec: J Ryan

THANK YOU!

For the final time in this edition of our Research Bulletin, we want to express our heartfelt gratitude for your continued support of Epilepsy Ireland's research efforts. Your support makes our investments in epilepsy research possible, and as we hope this edition has shown, these investments are driving progress that could make a real difference in the lives of people with epilepsy.

Thank you for being part of this journey. Together, we can achieve a society where no person's life is limited by epilepsy.

If you would like to help continue all of Epilepsy Ireland's activities in supporting people with epilepsy and their families across Ireland, you can make a vital donation by scanning the QR code below.

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