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More about our Research funding
<http://bit.do/epilepsyresearch>

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Dear Friend,

It is with great pleasure that we are once again bringing you this update on our Research activities here at Epilepsy Ireland, which you and hundreds of like-minded people across the country are generously supporting every year.

Our Research Funding Scheme, and epilepsy research in general in Ireland is thriving. We have a vibrant research community, whose work on a range of scientific and social issues is contributing greatly to international efforts to understand, treat and improve the lives of those living with epilepsy and their families. The ultimate aim of epilepsy research is to find a cure, and while this may be a long-term aspiration, there is still much work to be done in the short term.

Since 2009, Epilepsy Ireland has invested over €920,000 into Irish research efforts. This funding has led to important discoveries in gene activity; progressed understanding of epilepsy deaths; assisted researchers in attracting much bigger EU funding for continued research; influenced how health services are delivered and generated valuable information to assist people with epilepsy in their daily lives.

We focus our resources on high quality, peer reviewed research and on research that can have a direct practical benefits for people with epilepsy. Our most recent grant, investigating the ketogenic diet is explained on Page 2, and is something that can potentially have a huge impact on how epilepsy is treated in children in the future.

This award was made following our 2016 round of funding, which received a total of 11 applications, the highest since 2012. The quality of the applications was also higher than in previous years and it is regrettable that only one new project could be funded. However, we are now looking forward to funding our new 2018 proposals after an unprecedented response which can be read on page 2.

Your support makes this possible and I hope that you will continue to support our important research work into the future.

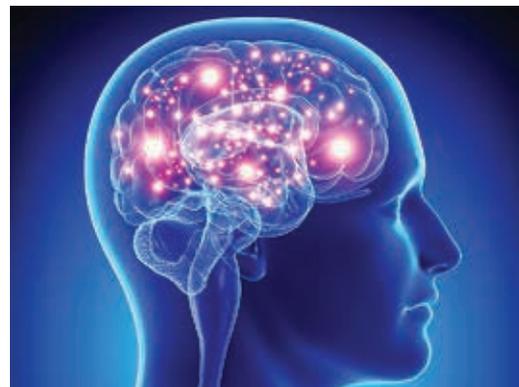
With best wishes
Peter Murphy
CEO, Epilepsy Ireland

WHAT IS EPILEPSY?

To have epilepsy is to have a tendency to have recurring seizures. Anyone can have a seizure, if the brain is exposed to a strong enough stimulus.

We know that about 1 in every 20 people will have a single seizure at some time during their lives.

Research by Epilepsy Ireland has determined that there are over 37,000 people with epilepsy nationwide. The significance of having a tendency to have seizures is individual and will depend on many things; for most people, epilepsy will only affect them for a short period in their lives. For some, however, the consequences can be more lasting. A minimum of 10,000 people still have uncontrolled epilepsy in Ireland and for this group in particular, the condition is a hidden disability. Although major strides have been made in recent times, there is still a stigma associated with the condition, a hidden burden which discourages many people from seeking the care and support they require.



ABOUT EPILEPSY IRELAND

Epilepsy Ireland is the national organisation supporting and representing people with epilepsy, their families and carers. Established in 1966, we provide a wide range of support and information services from our head office in Dublin and from nine locations around the country.

The charity also provides training programmes for both health professionals and for young adults with epilepsy; actively works to improve public understanding of epilepsy and funds high quality Irish research into the condition.

Our mission

We are committed to working for, and to meeting the needs of everyone with epilepsy in Ireland and their families and carers. To read more about Epilepsy Ireland's work why not read our Strategic Plan or 2016 Annual Report via the links below.

goo.gl/YBRdvy
goo.gl/x7k3Ru

HUGE RESPONSE FOR EPILEPSY IRELAND RESEARCH CALL 2017/18

Epilepsy Ireland's call for research proposals is now closed after an unprecedented response.

We have been overwhelmed by the high calibre of applicants from universities and institutions around the country and we are delighted to see the ongoing enthusiasm and expertise within the country for engaging in high-quality epilepsy research.

With 15 applications in total (from December 2017), there are unfortunately far more applications than we can hope to fund, and a shortlisting process will now begin to identify which applications will progress to the next stage. We look forward to funding the most impactful proposals in 2018 and bringing you further news in our next research newsletter.



Proposals address important questions in a number of target areas including epilepsy in pregnancy; psychosocial effects of epilepsy; SUDEP; intellectual disability and rare epilepsies. We are also delighted to have received three applications on the potential of cannabinoids (medical cannabis) in treating epilepsy, a theme which was included in our call for the first time this year. Epilepsy Ireland is committed to supporting Irish epilepsy research and since 2009, over €920,000 has been invested in a wide range of high quality projects, many in conjunction with the Health Research Board under the HRB/MRCG Joint Funding Scheme. After this research call, we hope to exceed the €1 million mark in 2018.

A massive thank you to all our supporters and donors who continue to support our efforts in researching causes, treatments and effects of epilepsy.

TALKING ABOUT EPILEPSY

Back in 2012, Epilepsy Ireland and the HRB made a grant of €92,990 to Dr Veronica Lambert from Dublin City University for her study “Demystify the veil of secrecy: a mixed method inquiry of parent-child dialogue about epilepsy and its associated stigma”.

The study, along with Dr Lambert’s other research in the area, explored how families living with childhood epilepsy communicate about the condition, and the challenges that parents and children face when it comes to discussing epilepsy and its associated stigma.

The innovative study generated numerous research papers and publications in leading medical and nursing journals and received worldwide attention. However, the work has also left behind a lasting legacy in Ireland through the development of a Community of Practice of Irish health professionals with a shared passion for ensuring that children with epilepsy and parents feel at ease when talking about their epilepsy with others.

This year, the new Community came together to develop and launch the “Talking about Epilepsy” website.

Informed by Dr Lambert’s studies in this area, the site provides information for children living with epilepsy and their parents when thinking about telling other people about epilepsy, and the myriad of issues that need to be considered. It also includes advice from an epileptologist, clinical nurse specialist, parent and a teacher, and some frequently asked questions & answers.

More information: www.talkingaboutepilepsy.ie

NEW FUNDING FOR STUDY ON SPECIAL DIET FOR CHILDREN WITH EPILEPSY

Epilepsy Ireland is delighted to announce that a new research grant has been awarded to Prof David Henshall at the Royal College of Surgeons in Ireland (RCSI).

The grant of €144,484 is co-funded by Epilepsy Ireland and the Health Research Board (HRB) and will support Prof Henshall’s three-year study entitled “MicroRNAs in the mechanism of ketogenic diet therapies and as biomarkers in paediatric epilepsy”.

The research aims to find out more about the ketogenic diet, a special high-fat, low-carbohydrate diet that helps to control seizures in some people with epilepsy, particularly children. The diet is very strict and must be prescribed by a health professional, but for many children who do not respond to epilepsy drugs, the diet can have excellent results in reducing seizures. Exactly why the diet works in epilepsy is not fully understood.

While half of children placed on the diet show an improvement, there is no way to know in advance which children will benefit and which won’t. Prof Henshall’s work will aim to solve this problem by investigating whether levels of molecules called microRNA in blood samples can predict which children with epilepsy will do best on the diet. If successful, this would eliminate trial and error and enable doctors to prescribe appropriate treatment faster than ever before.

Prof Henshall and his team at RCSI are regarded internationally as world-leaders in the emerging field of microRNAs in epilepsy. Work began on this project in early 2017 and we look forward to bringing you more news in future issues.

More information: goo.gl/rwWh7e



CAN DOGS PREDICT EPILEPTIC SEIZURES?

Epilepsy Ireland is delighted to support an extremely interesting study which is investigating whether untrained family pet dogs are able to predict epileptic seizures and to identify the trigger mechanisms used.

The study is undertaken by Neil Powell, School of Psychology, Queens University Belfast and supervised by Prof Peter Hepper. Epilepsy Ireland is providing a small grant of €2,500 for one year to support the work which will run until 2020.



The study will assess reported claims that some family dogs display warning behaviours prior to impending epileptic seizures in their owners. It will aim to capture video evidence of such behaviours in dogs and will attempt to identify the trigger bio-markers to which the dogs might be responding in the pre-seizure period.

Previous studies have demonstrated that dogs can be trained to 'alert' to imminent seizures, but the ability of untrained dogs is less understood. While some people with epilepsy get an 'aura' just before they have a seizure, the majority of people have no warning before a seizure strikes. As a result, accidents and injuries are very common, in addition to the fear of having a seizure that many people will endure daily. A warning such as that being studied here may provide people with the opportunity to avoid accidents while increasing the individual's sense of control over their lives.

The study also aims to understand the 'cues' used by dogs in predicting seizures and develop methods for people to shape their own animal's behaviour. Interim results of this study have been positive and we look forward to bringing you more news in future editions.

More information: goo.gl/wna7Pw

EPILEPSY IRELAND STUDY FINDS SPECIALIST EPILEPSY NURSES IMPROVES CARE AND REDUCES A&E VISITS

In February of this year, results of a three-year study funded by Epilepsy Ireland were launched that found Epilepsy Specialist Nurses (ESNs) had a very positive impact on the health of people with epilepsy. The study also found that ESNs were a cost effective way of delivering quality care to thousands of epilepsy patients and their families while reducing attendance at emergency departments.



The SENSE study was conducted by Prof Agnes Higgins, from the School of Nursing and Midwifery, Trinity College Dublin, and launched by Minister of State at the Department of Health Marcella Corcoran Kennedy (pictured above).

In the last decade, 16 ESNs were recruited by the HSE's National Clinical Programme for Epilepsy (NCPE). ESNs provide a range of services to people with epilepsy including nurse-led clinics, rapid access clinics, telephone advisory services and outreach services.

People with epilepsy reported:

- improved psychological well-being
- greater sense of involvement in their care
- being more prepared for tests and investigations
- stronger knowledge of epilepsy
- more confidence to self-manage their condition

It was found that ESNs:

- improved co-ordination and continuity of care,
- identified problems faster
- improved satisfaction with care;
- reduced attendance at emergency departments
- improved communication between healthcare professionals

Crucially, people with epilepsy who received care from an ESN had the same costs as those treated in a non-ESN site but experienced better outcomes with their epilepsy. The study highlights the positive and innovative work that is happening in the field of epilepsy to improve the quality of care for people living with the condition. It shows that the ESN model is highly beneficial, yet cost neutral. Epilepsy Ireland now hopes to use the study to ensure the ESN service is expanded nationally and with a focus on groups with specific needs such as women with epilepsy, adolescents, and people with an intellectual disability.

More information: goo.gl/rnkJPx

REPORT CALLS FOR GREATER AWARENESS OF EPILEPSY DEATHS

In 2015, Epilepsy Ireland and UK charity SUDEP Action launched the Epilepsy Deaths Register for Ireland (EDRI) thanks to the fundraising efforts of families who have lost a loved one (see Tour De Gaggs below).

The EDRI was set up to learn more about the reasons why people may die from epilepsy and to drive research in how risks can be reduced by providing an opportunity for families or professionals to register a death from epilepsy. The Register will also help treatment plans for those at the most risk of SUDEP.

In October 2016, data was released from the International Epilepsy Deaths Register which includes the new Irish Register. It was the first time that Irish figures had been included alongside information from the British and American Registers.

Some of the key findings from 527 registered deaths included:

- 56% of participating families did not know that you could die of epilepsy
- 20% of those that died from SUDEP may have forgotten to take their epilepsy medication in the days before they died
- 61% of families felt that the circumstances of death had not been adequately explained

The key message from the new data is one of raising awareness - both about the existence of risk and how to minimise the risk. It is still often incorrectly assumed that epilepsy is a benign condition, even by people with epilepsy and their families. However, many Irish families have experienced the devastation of SUDEP and are keen to raise publicity to avoid further untimely deaths. The risk of SUDEP is low but importantly, it is modifiable, through better awareness and education. The ongoing work of the Register, funded by donations from bereaved families will be critical to our work on this going forward.

More information: www.epilepsydeathsregister.org/ie

TOUR DE GAGGS - THE ALAN GALLAGHER MEMORIAL CYCLE

The 8th annual Tour De Gaggs took place last June. The event is an annual cycling challenge in honour of Alan 'Gaggs' Gallagher who passed away sadly in 2009. The cycle is from UCC Cork (pictured below) to Alan's hometown of Roscommon, taking in Limerick and Galway en route. The 300km challenge, organized by Alan's brothers Brian and Kevin, has helped raise awareness and research funds for the EDRI.

More information: goo.gl/9Qydrw



The How2Tell study at Trinity College on epilepsy disclosure, funded by Epilepsy Ireland in 2013 was launched recently. The study gathered experiences from people with epilepsy about the strategies they use in disclosing epilepsy to other people, such as work colleagues, employers, friends and family. As part of the study, a new phone app, website and printed materials were released to share people's experiences with the wider epilepsy population on an issue that has posed many difficulties for people with epilepsy traditionally.

Over the past twelve months, Epilepsy Ireland has also supported in non-financial ways, a number of other important epilepsy research projects including:

- A study on epilepsy terminology by Liverpool University highlighting the impact on people with epilepsy of using outdated terminology such as describing them as being "epileptic".
- A UCD study on the role of stress in epilepsy and how people with epilepsy adapt and cope with stress in their lives. By knowing more about this, we can add to the knowledge base and provide better supports and interventions to people with epilepsy and their families.
- The EPIC study, a collaboration by HSE, RCSI and Maynooth University which aims to understand how epilepsy services in Ireland can become more patient-centred. A more patient-centred service would improve quality and safety, and lead to better health outcomes, as well as result in more cost-effective service delivery.
- In 2016, the Health Service Executive (HSE) selected the national epilepsy electronic patient record (EPR) as a Lighthouse Project to demonstrate how eHealth technologies can help improve quality and safety in delivery of health care. Epilepsy Ireland is a proud partner in this project which also includes support from eHealth Ireland, HSE National Clinical Care Programme for Epilepsy, RCSI, Beaumont Hospital and Industry partner ERGO.

DRAW WINNERS

Time for a break winners

- January – Mary Maher
- February – Bridget McNicholas
- March – Fr. Michael Rodgers
- April – Kitty Doyle
- May – Mary Byrne
- June – Pauline McGuinness
- July – Andy + Mai Brady
- August – Ann Sexton
- September – Patricia Dunne
- October – Mary Durkan

All the funds from the draws go towards funding our research projects.

THANK YOU

It is our pleasure to bring you this update of our Research Funding Programme at Epilepsy Ireland. None of the work included here would be possible were it not for the support of donors and supporters like you. Thank you for your support, and for seeing the 'bigger picture' about the benefits of supporting high quality epilepsy research.

For more information about Epilepsy Ireland's research log onto: goo.gl/snzgVu