Epilepsy Ireland

2019 RESEARCH NEWSLETTER

INSIDE THIS ISSUE

Contact Us
Please get in touch with us:

By Post: 249 Crumlin Road, Dublin 12
By Phone: 01 4557500
By Email: Info@epilepsy.ie
Website: www.epilepsy.ie

facebook.com/epilepsy.ie
@epilepsyireland

More about our Research funding
https://goo.gl/rVFVLk

More about how we use our funds:
https://goo.gl/rVFVLk

CHY Number: 6170
Registered Charity Number: 20010553

PQASSO QUALITY MARK LEVEL 1 NCNO

MEMBER OF CHARITIES INSTITUTE IRELAND
Best Practice in Transparency and Accountability

Dear Friend,

Once again, I am delighted to share with you this update on the research activities supported by Epilepsy Ireland.

Alongside our work to support and represent people with epilepsy and their families, enabling Irish epilepsy research is one of our organisation's key objectives.

Internationally, epilepsy research is flourishing. Research teams are regularly announcing new genetic advances; proposing new targets for the next generation of epilepsy drugs and developing new technologies to better diagnose and manage seizures. The treatments that exist today only control seizures for about two thirds of people with epilepsy and for the other one third whose seizures are not currently controlled, these discoveries and advances are very badly needed.

Ireland is punching well above our weight in terms of our contributions to global epilepsy research. Earlier this year, a new Science Foundation Ireland research centre called FutureNeuro was opened at RCSI which will focus on a world-class programme of research into epilepsy and motor neurone disease. Epilepsy Ireland maintains strong links with FutureNeuro and has supported the ongoing work of the centre's principal investigators over the past decade.

This includes our most recent award which is outlined on page 5 and which will investigate the potential links between bacteria in the gut and autoimmune epilepsy. We have also recently began supporting a study on how new web-based technologies can improve the lives of people with epilepsy.

These new grants now mean that Epilepsy Ireland has invested over €1 million into Irish research efforts since 2010. As a small organisation with limited funds for research, we are very proud of this contribution and you can read more about what has been achieved by our investment inside.

Our research funding is only possible because of the generosity that you and hundreds of similarly minded people show each year. Whilst the long-term goal of a cure for epilepsy may be some way off, the work being undertaken today builds on that of yesterday to deliver a brighter future for people with epilepsy. With your continued support, we hope to announce a new call for applications in September 2019. I hope that you will be able to continue supporting our research funding efforts in 2019 and beyond. Thank you for all your support to date.

With best wishes
Peter Murphy
CEO, Epilepsy Ireland

EPILEPSY IRELAND REACHES €1 MILLION MILESTONE FOR RESEARCH FUNDING

A new research grant awarded under the latest round of the Epilepsy Ireland Research Funding Scheme (see page 5) has resulted in a significant milestone – since the establishment of the Scheme in 2009, we have now committed over €1million in funds to Irish epilepsy research!

In total, we have funded 11 Irish based projects since 2010 at RCSI, Trinity College, University College Dublin and other leading research institutions. Many of these projects have been co-funded by the Health Research Board under the Medical Research Charities Group Joint Funding Scheme. Projects have investigated a wide range of important issues including epilepsy genetics, molecular mechanisms involved in epilepsy, health services research, psychosocial issues and sudden death in epilepsy (SUDEP).

Our Scheme was set up to provide epilepsy researchers in Ireland with an avenue to access funding for world-class research. We have focused not only on the scientific quality of proposals received but also on their relevance to people with epilepsy and on their potential to deliver tangible benefits to the lives of people with epilepsy.

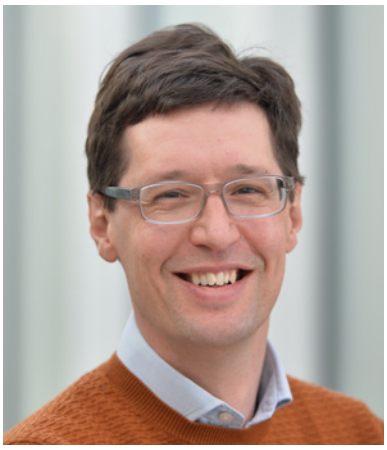
We are very proud of the impact that has been made, which would not have been possible without the generosity of hundreds of donors over the past decade who have donated or fundraised for our work. Thank you to everyone who has supported this work and we hope that you can continue to do so.

IMPACT OF EPILEPSY IRELAND'S RESEARCH FUNDING SCHEME

- Over €1,000,000 invested in Irish epilepsy research
- Enabled participation by Irish researchers and Irish patients in large-scale international genetics studies
- Led directly to important genetic and gene activity discoveries
- Supported Irish research teams in achieving major national/ international research funding (for example www.epimirna.eu and www.futureneurocentre.ie)
- Progress in understanding the causes of SUDEP
- The Epilepsy Deaths Register for Ireland is one of a growing number of international registries to drive further SUDEP research
- Studies on epilepsy prevalence and the impact of Epilepsy Specialist Nurses have shaped the provision on health services for people with epilepsy in Ireland
- Led to new supports for people with epilepsy and their families, for example, the How 2 Tell project.
- Helped ensure that State research funding has been invested in epilepsy, one of the most common brain conditions
- Publications in leading medical journals including Epilepsia; Nature Genetics; Brain; J Neuroscience and The Lancet

Read more about the projects funded via this link: https://goo.gl/MQqZtD

THE IMPORTANCE OF IRISH RESEARCH



Dr Gianpiero Cavalleri, Royal College of Surgeons in Ireland

To celebrate our €1million funding milestone we speak to four researchers who have received grants from Epilepsy Ireland to discover more about what was achieved by our investment and how it benefits people with epilepsy and their families.

PROJECT: A PHARMACOGENOMIC STUDY OF CHRONIC REFRACTORY EPILEPSY (FUNDED 2009; €147,000)

What did your research project achieve?

Our project explored the contribution of genetic factors to treatment-resistant epilepsy. The work supported the generation of dense genetic signatures for treatment resistant epilepsy. These datasets were further analysed to identify new risk genes for epilepsy, and to identify genetic predictors for severe skin reactions relating to the use of Tegretol.

Why is epilepsy research important?

In order to create more effective treatments for epilepsy, we need to improve our understanding of the brain generally, and how epilepsy develops specifically. This is what research is about – improving our understanding of complex systems and situations, in a manner that leads to better treatment and care, and ultimately, a cure for epilepsy. Research can span from how healthcare is delivered at a population level, right down to how our cells behave at a microscopic level.

Why is it important for Epilepsy Ireland to continue to fund research?

Research is essential if we wish to see an improvement in the lives of people with epilepsy. However, traditionally, epilepsy is very underfunded compared to other neurological conditions. This not only slows progress but also limits our ability to get the best researchers working to solve epilepsy. Ireland is becoming globally recognised for epilepsy research, and a significant part of that success is due to support from Epilepsy Ireland. That research success allows Irish researchers to compete for, and attract more money to research from overseas – e.g. from the European Union, from international epilepsy charities and national funders such as the Health Research Board. This is illustrated through the establishment by Science Foundation Ireland of the FutureNeuro Centre of Excellence, which is studying epilepsy as a key condition of interest.

PROJECT: HOW2TELL: DEVELOPMENT OF AN EVIDENCE-BASED EDUCATIONAL RESOURCE FOR SELF-DISCLOSURE STRATEGIES FOR PEOPLE WITH EPILEPSY (FUNDED 2014; €149,000)

What did your research project achieve?

Using the experiences of adults (aged 18+ years) with a range of forms of epilepsy and personal backgrounds, How2tell developed a set of multi-media educational resources on self-disclosure. The resources including the How2tell website, app and booklet, assist people to develop effective strategies, so it is less challenging to tell others that 'I have epilepsy'. How2tell gives practical information in the following areas: how to become comfortable with your epilepsy; decide why, who and when to tell; use different opportunities to tell; tell people depending on who they are and deal with people's reactions.

Dr Naomi Elliott, Trinity College Dublin

Why is epilepsy research important?

Epilepsy research is important in understanding how it affects people's lives and to developing resources that will help people with epilepsy manage their condition in everyday life situations. There are many gaps in what we know about epilepsy, so research is important in growing knowledge that is evidence based which is then used to inform educational resources that assist in supporting the day to-day living of people with epilepsy.

Why is it important for Epilepsy Ireland to continue to fund research?

Epilepsy Ireland has an invaluable role to play in setting the research priorities for people with epilepsy in Ireland. Members of Epilepsy Ireland therefore, can influence the decisions regarding what research is important and can make a difference to managing epilepsy in their everyday lives.

THE IMPORTANCE OF IRISH RESEARCH

Professor David Henshall: Royal College of Surgeons in Ireland

PROJECTS:

(1) MICRORNAS IN THE MECHANISM OF KETOGENIC DIET THERAPIES AND AS BIOMARKERS IN PAEDIATRIC EPILEPSY (FUNDED 2016; €145,000)

(2) GENOME-WIDE DNA METHYLATION ANALYSIS (FUNDED 2012; €75,000)

Why is epilepsy research important?

Funding excellent science can make a big difference to the lives of people living with epilepsy. The more we understand what causes epilepsy and what maintains the brain in this epileptic state, the closer we get to developing better treatments or a cure. I'm very optimistic right now because of various technologies that will help accelerate discovery. This includes: ways to study the behaviour of brain circuits; create models of the human brain from skin cells and measure every single molecule in a brain cell.

What did your research project(s) achieve?

My team has been fortunate to twice receive funding from Epilepsy Ireland. The first project looked at how gene activity is controlled in brain cells. We found a chemical coating around certain stretches of DNA that blocked the genes from working – genes were being silenced that should normally be switched on. Some others were switched on when they should be off. We're now looking at ways we might be able to control the on-off switches. In the second project we're searching for tiny molecules made by the brain in blood samples from children with complex epilepsy. We think finding these may speed up or simplify diagnosis. We're also trying to understand how the ketogenic diet works and whether some of the same molecules in the blood might help predict who responds best to the diet.

Why is it important for Epilepsy Ireland to continue to fund research?

For various reasons, epilepsy research has been historically under-funded relative to other brain diseases. Also, a number of pharmaceutical companies have halted their epilepsy research. It is critical that those gaps are filled. While we can never be certain what research discoveries will lead to, the funding from Epilepsy Ireland can make a real impact. Any progress in our understanding of this disease could one day improve the lives of people living with epilepsy.

PROJECT: THE PREVALENCE OF EPILEPSY IN IRELAND STUDY (2009)

Dr Christine Linehan: University College Dublin

Why is epilepsy research important?

There's a large and diverse range of research in the epilepsy field. Basic science, for example, explores causes and manifestations of epileptic seizures. Epidemiology studies the prevalence and trajectory of epilepsy among the population. Social science research unravels the complex impact of epilepsy, not only on the individual but also on family and other natural supports. In combination, these research studies promote an evidence based approach to our understanding and treatment of epilepsy, ensuring good data drives our efforts to not only reduce if not eliminate seizures but also reduce the considerable psychosocial impact of epilepsy.

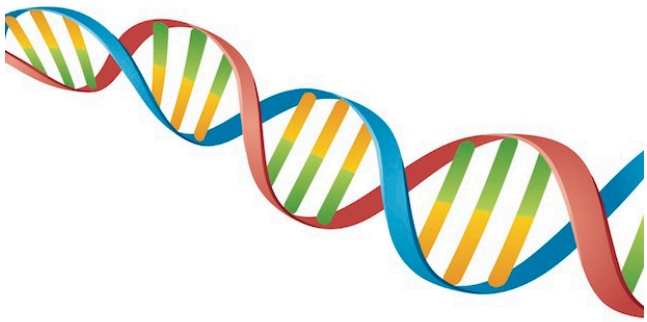
What did your research project(s) achieve?

I am indebted to Epilepsy Ireland for funding my doctoral study which estimated the prevalence of epilepsy in Ireland, and to the UCD Centre for Disability Studies for their support. Our data revealed that approximately 37,000 individuals over the age of five were living in Ireland have epilepsy. 10 per 1,000 individuals over 18 self-reported ever having epilepsy, and 8-9 per 1,000 individuals over five years were being treated for epilepsy with anti-epilepsy medication. The study was published in 2010 and is distinguished as the first nationwide study of prevalence in Europe and provides valuable data for planning and treatment purposes.

Why is it important for Epilepsy Ireland to continue to fund research?

Epilepsy Ireland has funded a number of high-profile research projects led by many of our key academic institutions including UCD, TCD, DCU and RCSI. The undertaking of these studies is vital, not only for the insights they provide into their respective areas, but also because they contribute to a growing critical mass of researchers in Ireland working within the epilepsy field. A number of these studies have enabled Irish researchers to successfully apply for bigger funding grants to continue and develop their work. Epilepsy Ireland's research funding ensures that Ireland remains an important contributor to epilepsy research. Epilepsy Ireland fosters a collaborative and active environment for clinicians and researchers to work alongside each other to enhance our understanding of the cause and impact of epilepsy.

NEW GRANT TO INVESTIGATE AUTOIMMUNE EPILEPSY



A new Epilepsy Ireland research grant has been awarded to the Royal College of Surgeons in Ireland to investigate possible links between auto-immune epilepsy and bacteria found in the gut. The study is funded under the 2017/2018 round of the Epilepsy Ireland Research Funding Scheme and will be led by Prof. Gianpiero Cavalleri of FutureNeuro.

The total grant is for €148,998, over three years. 50% of the funding is made available by the Health Research Board (HRB) through the Joint Funding Scheme operated by the HRB and the Medical Research Charities Group, of which Epilepsy Ireland is a member. Epilepsy Ireland will fund the other 50% through our fundraising efforts.

Prof. Cavalleri's project, entitled The Microbiome as an Environmental Trigger for Autoimmune Epilepsy is one of 14 new projects that have been supported by the HRB and research-funding charities like Epilepsy Ireland this year.

Prof. Cavalleri explains the new study: "Autoimmune epilepsy is a rare form of drug-resistant epilepsy characterised by frequent seizures in later life. Patients may respond to immune therapy, but causation of disease is poorly understood and more targeted treatments are required. This gap in knowledge is the major priority for epilepsy specialists, and the area of greatest interest to patients. Recently, it was found that people with this condition often carry a set of genes related to the way the immune system sees foreign bugs. However, the majority of people who carry those genes do not develop autoimmune epilepsy. This has led to the idea that autoimmune epilepsy develops as a result of an environmental factor which interacts with this genetic predisposition. We propose that certain bacteria present in the gut (the microbiome) might be providing the environmental trigger that, alongside specific genes, causes autoimmune epilepsy."

"We propose to recruit 100 individuals with a specific form of autoimmune epilepsy, and their siblings who haven't developed the disease. We will collect saliva and stool from each individual, to extract human and bacterial DNA, respectively. Using state of the art DNA sequencing techniques, we will characterise the nature and number of bacteria present in the gut of people with autoimmune epilepsy and their genetically-related, but unaffected siblings. We will compare these profiles to see if the gut of people with autoimmune epilepsy has a distinctive microbiome profile. Identifying an environmental trigger behind autoimmune epilepsy would represent a major step forward both in our understanding of autoimmune epilepsy and also for epilepsy in general, as it would represent the first link between gut microbiota and epilepsy, a link that is increasingly being made for other central nervous system diseases. In addition, it may guide a set of treatments targeting the bacteria, or the immune response to the bacteria."

Speaking about the new research project Epilepsy Ireland CEO Peter Murphy said: "This project is very relevant to Epilepsy Ireland's research priority area of rare epilepsies. It represents a new, important and potentially highly rewarding area of research. Currently, knowledge of autoimmune epilepsy is weak. In the event of a significant finding, this research might lead to significant benefits for patients, for example identifying the cause of autoimmune epilepsy or preventing severe epilepsy in patients who are genetically at risk. There are also very real opportunities for new treatments that could arise from this work, and we are delighted to be able to target our funds towards such innovative work here in Ireland".

SUPPORTING TECHNOLOGY TO IMPROVE EPILEPSY CARE

Mary Fitzsimons from the Royal College of Surgeons in Ireland

Epilepsy Ireland has agreed to provide support to a new research project which will explore how new technology can help foster a culture of trust, transparency and collaboration within epilepsy health services to improve health and well-being.

Over the past decade, the National Epilepsy Clinical Care Programme has developed a secure web-based electronic patient record (EPR) which allows authorized medical professionals to access patient health records when and where needed. Compared to traditional paper-based records, the EPR offers many advantages in terms of speed and quality of care.

A recent development is a new "e-portal" which allows epilepsy patients to access and interact with their own health records via a mobile device. It enables people to upload information on their seizures, quality of life, and medicine compliance. It is hoped that when fully developed and rolled out, the e-portal will improve patient empowerment, address the power balance between patients and doctors, and better co-ordinate the patient's care.

In 2018, Epilepsy Ireland agreed to co-fund a major new piece of research on the role the e-portal can have in the development of meaningful partnerships between healthcare professionals, patients and families.

The new study will measure patient, carer and healthcare professional perspectives on the usability and usefulness of the epilepsy ePortal.

E-health is widely regarded as the future of healthcare delivery, not just in epilepsy but across the spectrum and this project will add to the body of knowledge on what is an emerging innovative technology.

The project is funded by the Health Research board under the Applied Partnership Awards 2018. €20,000 is provided in co-funding by Epilepsy Ireland over two years.

2018 DRAW WINNERS

Time for a break winners

October: R. Hatton,
September: M. Ross
August: N.Collins
July: D. Barron
June: Kathleen McCaulfield
May: Eithne Payne
April: Ann Quinn
March – Fr. John Beatty
February – Tommy Donlon
January – John Conlan

Why not enter the 'Time For A Break' draw to be in with a chance of winning a hotel break every month. Contact info@epilepsy.ie.

DONATE NOW

Support Epilepsy Ireland's work by donating via this link: https://goo.gl/76BDd4

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: https://goo.gl/EvvGrt