

Summer Newsletter 2021



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Welcome to our Summer Newsletter 2021

Dear colleagues and friends, it is my great pleasure to write a few words of introduction to our FutureNeuro Centre Newsletter.

Why a newsletter?

Our research activities are regularly communicated via our website and social media channels but a newsletter is an opportunity to bring it all together and capture a snapshot of where we are and what's still to come.

The **SFI FutureNeuro Research Centre for chronic and rare neurological disease** was launched in 2017 and, since then, our team have been busy and productive. Our researchers are now publishing more than one article per week in scientific and medical journals – a total of 46 in 2021 already! We've hit all of our key funding targets including major awards from Europe and industry. We currently have 45 projects running in the FutureNeuro Centre and count 70 researchers across 7 academic institutions. Our research spans gene, drug and biomarker discovery, clinical genomics, modelling human brain disorders, and exploring the interface and interaction between patients, clinicians and technology. We also run an extensive education and outreach programme and continue to develop Patient Public Involvement (PPI).

What's inside this newsletter?

The newsletter spans our full range of activities, from new scientific breakthroughs through to funding successes and our public engagement activities. It would be impossible to feature everything so we've tried to select work that is recent, that highlights our newer areas of research and gives a sense of how much we are becoming a truly national centre.

We welcome lots of new people to the Centre, many of whom have started as remote workers. A special word of appreciation to our departing Funded Investigators;

Mary Fitzsimons who helped embed eHealth in the Centre and Prof. Sasi Balasubramaniam who brought cutting-edge molecular communications to FutureNeuro.

SFI would like us to begin planning for our refunding of the Centre, set to begin in 2023. This is a huge opportunity to build on what we have already accomplished as well as develop ambitious new programmes of research that address the unmet needs of patients and neurologists.

Finally, let me take the chance to thank all the researchers working on projects in FutureNeuro and Karina Carey and Alice Coughlan on the Operations team, led by Bridget Doyle supporting everything we do. Without your hard work and commitment, we couldn't achieve what we have. These past 18 months have created enormous strain on everyone and impacted how we operate. The effects of the lockdown and ongoing restrictions to laboratories and hospitals is a huge challenge. However, it has also been an opportunity, as you will see in our section focused on how clinical care has adapted during Covid times.

Read on and enjoy and a huge thank you to Ciara Courtney, our Communications, Education & Public Engagement Lead, for her help putting it all together.



Professor David Henshall.

Director of FutureNeuro and Professor of Molecular Physiology and Neuroscience at the Royal College of Surgeons in Ireland (RCSI), the University of Medicine and Health Sciences.



Diagnostics



Electrochemical detection of biomarkers

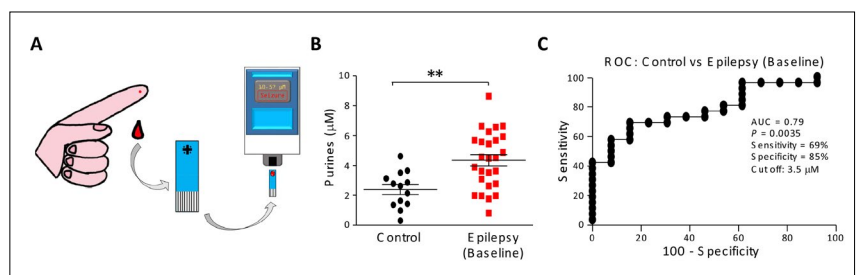
A key innovation in FutureNeuro's Diagnostics research programme is the development of prototype point-of-care devices that could be used for rapid testing of the circulating molecules (biomarkers) being discovered by the neuroscience teams. During 2021, Prof Robert Forster Dublin City University (DCU) leader of this research stream, published a series of studies reporting cutting-edge materials for the detection of biomarkers. You can read Prof. Forster's work below;

- [Wireless electrochemiluminescence at functionalised gold microparticles using 3D titanium electrode arrays](#)
- [Ferrocene-Containing DNA Monolayers: Influence of Electrostatics on the Electron Transfer Dynamics](#)
- [Electrochemiluminescence at 3D Printed Titanium Electrodes](#)



Elevated blood purine levels as a biomarker of seizures and epilepsy

Dr Tobias Engel and his team at RCSI together with researchers in UK, Germany and clinical colleagues in Beaumont Hospital, have discovered a biomarker that could lead to the diagnosis and detection of epilepsy via a novel, user-friendly point-of-care device which requires a drop of blood and gives results within minutes. The discovery was made by the measurement of the blood purine concentrations and were measured via a point-of-care diagnostic technology based on the summated electrochemical detection of adenosine. Measurements of blood purine concentrations were carried out using samples from preclinical models and in video-electroencephalogram (EEG)-monitored adult patients with epilepsy. The paper is published in *Epilepsia* [here](#).



Increased blood purine concentrations in patients with epilepsy (A) To measure blood purine concentrations in patients, blood was collected via finger prick and immediately analyzed via SMARTC hip. (B) Increased blood purine concentrations in patients with epilepsy when compared to control [n = 13 (Control) and 26 (Epilepsy, baseline)]. Baseline measurements from patients with epilepsy were taken following a seizure-free period of at least 24 h. Unpaired Student's t test ($t = 3.364$, $df = 37$, $p = 0.0018$). (C) ROC analysis showing that blood purine concentration changes have a 69% sensitivity and 85% specificity to diagnose epilepsy with a cut off of 3.5 µM (n = 13 (Control) and 26 (Epilepsy)). ** $p < 0.01$.

Therapeutics



Discovering a new mechanism to halt excessive inflammation in Multiple Sclerosis

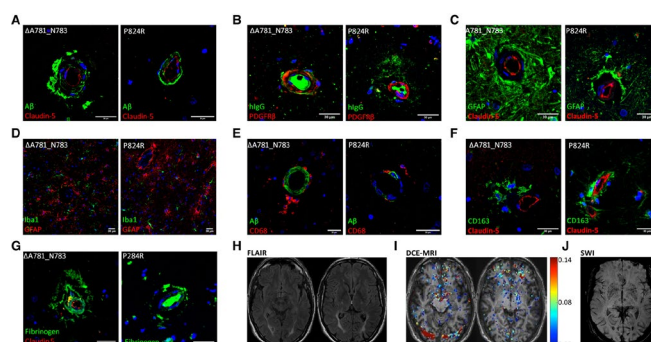
The team of Dr Claire McCoy at RCSI have found a new way to 'put the brakes' on excessive inflammation by regulating a type of white blood cell that is critical for our immune systems. The discovery has the potential to protect the body from unchecked damage caused by autoimmune and inflammatory diseases such as Multiple Sclerosis (MS). The paper is published in [Nature Communications](#).

In March, Dr McCoy and other researchers from across the country, established the All-Ireland MS Research Network (AIMS-RN, <https://aims-rn.org/>), the largest collaboration of MS researchers providing a unique opportunity for scientists, clinicians and people living with MS in Ireland to accelerate MS research. [Read more](#)



Identifying new mutations associated with early onset dementia

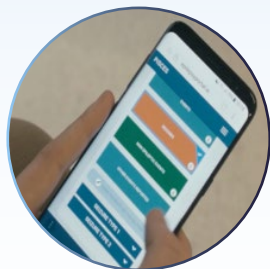
Dr Matthew Campbell and his research team in Trinity College Dublin (TCD) identified previously unreported mutations in a gene called colony stimulating factor-1 receptor (CSF-1R) in an ultra-rare form of Alzheimer's Disease. This discovery may lead to better understanding of how Alzheimer's Disease and other dementias occur. Read the full study published in [Embo Molecular Medicine](#) and the media coverage in [the Irish Times](#).



"These are a series of images of post mortem donor brain tissues from patients who lived with ALSP. Images show dysfunctional blood vessels in the brain as well as the infiltration of white blood cells from the circulation. The lower right images show brain scans from a living patient with ALSP. Images show that the small blood vessels in the brain are "leaky" and a dye injected into a peripheral vein is visible moving from blood to brain of this patient."

Matthew Campbell, PhD

E-Health



FutureNeuro epilepsy clinical network pivot to telecare during COVID and conduct research to support overhaul of patient interaction

Before the onset of the Covid-19 pandemic, telemedicine was already an important part of the FutureNeuro Centre. Building on the HSE-funded Epilepsy Lighthouse Project, FutureNeuro researchers developed a pilot ePortal, allowing people to access and co-author their own epilepsy care records. The redeployment of staff to Covid-care and the closure of outpatient services created an urgent need to provide safe remote patient care. With access to patient co-authored records within the National Epilepsy Electronic Patient Record (EPR), Profs Colin Doherty (St. James's Hospital) and Norman Delanty (Beaumont Hospital) moved 1,600 patient clinics on-line using a mixture of telephone and virtual appointments. Research by the FutureNeuro eHealth team into the facilitation of tele clinics demonstrated that telemedicine is seen by patients as an effective and satisfactory method of delivering chronic outpatient care. This paper was published in *Epilepsy Behav* [here](#). In addition to this, in June, the Economic and Social Research Institute (ESRI) published 'Advancing a Digital Healthcare Future for Ireland' citing the work of FutureNeuro. [See reference below and full report here](#).



Prediction of caregiver quality of life in Amyotrophic Lateral Sclerosis (ALS) using explainable machine learning

Dr Catherine Mooney and PhD Candidate Anna Markella Antoniadou (pictured) both from University College Dublin (UCD) and Prof Orla Hardiman (TCD) published a study in *Scientific Reports* on the identification of the predictors of a caregiver's quality of life and the development of a model which would alert clinicians when a caregiver is at risk of experiencing low quality of life. The data was collected through the Irish Amyotrophic Lateral Sclerosis (ALS) Registry, established by Prof Hardiman, and via interviews with 90 patient and caregiver pairs at three time-points. [Read more here](#)

“The Irish National Epilepsy Electronic Patient Record (EPR) and the subsequent development of the electronic patient portal (ePortal) have facilitated changes in patients care pathways and improved patient-clinician contact and has engendered greater patient self-management (Power et al., 2020). These structures provide Irish policymakers with a template for expanding an Electronic Health Record (EHR) to other patient populations, and ultimately to establish a national EHR.”

Advancing a Digital Healthcare Future for Ireland, ESRI Report June 2021.



FutureNeuro partners with SFI Insight Centre to secure €4.7M in global drive to train data analysts for neuroscience

The Marie Skłodowska-Curie Actions (MSCA) COFUND NeuroInsight Fellowship, led by Prof Gianpiero Cavalleri (RCSI), will see scientists from around the world working in Ireland to develop advanced data skills for research into neurological conditions. This exciting collaboration between FutureNeuro and the Insight Centre for Data Analytics will deliver an integrated and applied training programme for research fellows, building upon respective health and data analytics expertise available across both Centres. [Read more](#)



NeuroInsight will offer 24-month fellowships to 33 experienced researchers from around the world, who will work on projects across the two SFI Centres and gain practical experience through clinical, industry and patient-organisation placements. The programme will equip this future generation of research leaders with competencies in fields such as precision medicine and artificial intelligence. For expressions of interest in the NeuroInsight programme, visit [NeuroInsight](#) and for further details contact neuroinsight@rcsi.ie.



FutureNeuro to develop miniature brain implant to control seizures

Profs Jochen Prehn (pictured) and David Henshall are co-applicants on the PRIME project (Personalised Living Cell Synthetic Computing Circuit for Sensing and Treating Neurological Disorders), led by Prof Sasi Balasubramaniam (Waterford Institute of Technology) which was awarded €4.4M under the EU's Future and Emerging Technologies (FET) programme.

The programme will capitalise on a significant breakthrough discovery by Profs Prehn and Henshall who found that increases in tRNA fragments precede seizure onset in some patients- published in ([Scientific Report](#) and [Journal Clinical Investigation](#)). By understanding the role of tRNA in predicting seizure onset, the multidisciplinary team of researchers aim to develop a biological brain implant that will detect spikes in tRNA and then respond with a seizure-suppressing treatment.

The FET programme, funded under the EU's research and innovation initiative, Horizon 2020, invests in transformative research and innovation with a high potential impact on technology to benefit our economy and society. The project involves five other European academic and industry partners. [Read more](#)



MSCA RESEARCH FELLOWSHIPS

We are delighted to announce that two excellent early-career researchers were recently awarded highly competitive MSCA Individual Fellowships to undertake exciting projects within the FutureNeuro Centre.

Dr María Muñoz - “MiRNAs as therapeutics for neurorepair in Multiple Sclerosis”

Working with Dr Claire McCoy, Dr María Muñoz aims to identify microRNAs that have the potential to prevent and repair damage caused by multiple sclerosis. As part of her Fellowship, Dr Muñoz will also have the opportunity to spend time in the labs of both Dr Una Fitzgerald at NUI Galway and Dr Yvonne Dombrowski at Queens University Belfast.

Dr Mariana Alves – “Targeting the purinergic system for disease-modification in epilepsy”

Under the supervision of Dr Tobias Engel, Dr Mariana Alves will investigate new disease-modifying strategies to prevent the development of epilepsy based on purinergic signaling (a form of extracellular signaling involved in cell regulation). Having been awarded a Global MSCA Fellowship, which supports researchers to undertake a period of research outside of Europe, Dr Alves will spend 2 years working with Prof Detlev Boison in Rutgers University, USA, before returning to Ireland to complete her Fellowship with Dr Engel in FutureNeuro.



Developing a prognostic blood test for psychotic disorders

Prof David Cotter and his team in RCSI discovered that testing the levels of certain proteins in blood samples can predict whether a person at risk of psychosis is likely to develop a psychotic disorder years later. The study was published in the [JAMA Psychiatry](#).

Prof Cotter was also awarded a €1.3 million grant from Wellcome to expand his research to determine if this test is similarly accurate at predicting who will develop a psychotic disorder from other international groups of clinical high risk individuals. The ultimate goal is to develop a commercially-available test for use in clinical practice so people can be treated earlier and more effectively.



Bringing patient-centred disruption to clinical trials

In April, Prof Gianpiero Cavalleri led the launch of the Blockchain and AI enabled Stratified Trials System (BESTS). Funded by the Dept. of Trade Enterprise and Employment under the Disruptive Technology Innovation Fund, this €3.9M programme, in collaboration with industry partners Ergo, Microsoft and Akkure, is building and testing a patient-centric, trustworthy, GDPR-compliant platform to match and connect patients to clinical trials and other research studies. [Read more](#)

Joining the international EpiCare clinical network to treat rare neurological disease

We are pleased to announce that a FutureNeuro clinical site, Beaumont Hospital (Epilepsy Unit), led by Prof Norman Delanty, has been designated a collaboration partner in the [EpiCare](#) Network. EpiCare is the European Reference Network for epilepsy, which combines expertise from specialist centres across Europe, to develop and deliver highly-specialised diagnostics and care to improve interventions and outcome in individuals with rare and complex epilepsies.



This aligns well with the recently established FutureNeuro Epilepsy-Associated Gene-Ready Register (EAGER) Network. The register will enable study of the longitudinal phenotypic characteristics of patients with particular genetic mutations. Critically, it will also act as a link between patients, families, patient support organisations, clinicians, and biopharma to enable precision medicine trials in patients with particular mutations. We are grateful to Novartis Ireland for their support in establishing the EAGER Network.

For more information on funding opportunities with FutureNeuro, contact Dr Alice Coughlan (Research Funding Officer), alicecoughlan@rcsi.ie

Dates for your diary!

EPICLUSTER: Prof David Henshall, is chair of the European Brain Research Area (EBRA) EPICLUSTER which has established a collaborative framework for the coordinated actions of epilepsy research in Europe, based on shared partnerships and research priorities. The [EBRA](#) Epicluster virtual meeting 'Accelerating Patient Involvement in European Epilepsy Research' is taking place October 6th 2021. This is an opportunity for the network of researchers, clinicians, funders, patient advocates and policymakers to explore how the European Commission evaluates patient involvement in EU-funded research and the benefits for people with epilepsy and researchers.



Epilepsy and Climate

Does climate change matter to researchers, clinicians or patients with epilepsy? [The Epilepsy Climate Change](#) virtual conference will take place on November 25th 2021 to share knowledge about the effects of climate change on people with epilepsy. Pre-registration can be made [here](#).



FutureNeuro works closely with national and international companies to deliver collaborative projects, which address key clinical challenges and progress mutual research objectives to identify better diagnostics, improved therapeutics and person-centered eHealth. In recent months, we are pleased to have commenced new projects across our three themes with UCB, Janssen Pharmaceuticals, Neumirna Therapeutics ApS, Kahn Technology Transfer, STORM Therapeutics and UNEEG Medical A/S.



Partnering with UCB; FutureNeuro has extended its eHealth partnership with global biopharmaceutical company UCB to unlock the power of healthcare data to inform improvements in clinical care of people with epilepsy. Following on from an initial pilot project in 2018 to demonstrate the potential of the HSE epilepsy Electronic Patient Register (EPR) to provide insights into disease progression and responses to treatment, the new Epi-Dive study, led by Prof Colin Doherty (TCD and St. James's Hospital) will conduct a longitudinal analysis of patient data to address relevant clinical questions. The FutureNeuro-supported epilepsy EPR is a central repository of clinical records for over 10,000 patients across Ireland, many of whom have complex care needs and treated at one of the specialist care centres. The Epi-Dive project addresses the safe governance, protection and ethical requirements for the secondary use of patient data. While a partner in the project, UCB does not have access to patient data. FutureNeuro is also partnering with UCB in a preclinical project led by Prof David Henshall to examine blood-based diagnostics to support diagnosis of epilepsy and seizures.

UNEEG[™] medical

UNEEG Medical A/S: A new Diagnostics project with UNEEG will analyse the clinical utility of their implantable 24/7 EEG[™] SubQ device for seizure detection in two separate patient cohorts. It will report on the validity of the device for seizure detection in comparison to gold standard EEG continuous monitoring in the Epilepsy Monitor Unit in Beaumont Hospital. It aims to provide a complementary diagnostic tool for clinical care. The study is led by Prof. Norman Delanty, clinical neurologist and epilepsy lead in Beaumont Hospital. [Read more](#)



STORM Therapeutics; Led by Dr Gary Brennan (University College Dublin) and Prof David Henshall (RCSI), this study is exploring novel treatment options for epilepsy by focusing on gene regulation using RNA modifying enzymes developed by STORM, a biotechnology company focused on the discovery and development of small molecule therapies modulating RNA [epigenetics](#).

[Read more](#)

STORM have recently published their findings on RNA modification in the treatment of myeloid leukaemia in [Nature](#).

For more information on partnering with FutureNeuro, contact Bridget Doyle (Business Development Manager.) bridgetdoyle@rcsi.ie

New Tech and FutureNeuro

We were delighted to be part of the nearly €1.2 million SFI infrastructure award received by RCSI, to develop a high-resolution imaging system with an automatic microdissection and single-cell sequencing facility. The award will be embedded in the research infrastructure of FutureNeuro and other networks. The research infrastructure will provide new information on the molecular makeup of individual cells in complex tissues and structures, enable research towards personalised medicine and help in the development of novel diagnostics, therapeutics and biomaterials. [Read more](#)

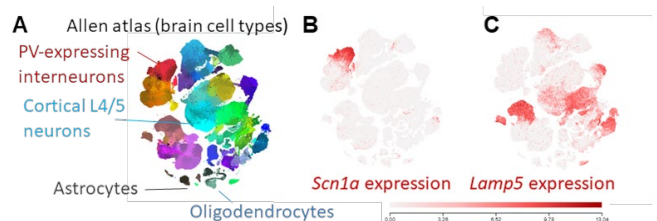


Image from the Allen Brain Atlas, generated using single cell sequencing technology.

Neurogenomics Clinical Conference

Our Neurogenomics conference on June 11th 2021 brought national and international researchers, clinicians, patient representative groups, virtually together to discuss many topical aspects of genomic medicine; from ethics, social and legal issues, diagnostics in the Irish Traveller community and paediatric and neuromuscular genomics.

Our international guest speakers included Prof Henry Holden – University College London (who spoke on what Ireland can learn from the UK experience with the 100,000 Genomes project), Dr Charles Stewart – Congenica (who gave the perspective of both a parent and bioinformaticist on neurogenomics) and Prof Stephen Kingsmore from Rady Children's Hospital San Diego (who spoke on rapid genome sequencing in new born infants with severe neurological disease).

Much of the panel discussion focused on the need for a national neurogenomics forum involving patients, policy makers and patient-representative organisations, to facilitate genome diagnostics at a national level. FutureNeuro is planning to host this PPI genomic forum in Q1 2022.



The poster for the National Neurogenomics Conference features a stylized blue brain graphic on the left. The title 'NATIONAL NEUROGENOMICS CONFERENCE' is prominently displayed in the center. Below the title, the registration link 'nationalneurogenomicsconference2021.eventbrite.ie' is provided. The conference details are organized into three columns: DATE (11 June 2021), VENUE (Virtual), and three sessions. Session 1 (9:00am - 11:50am) covers genetic disorders in Irish Travellers, lessons from the UK 100,000 Genomes Project, and genomic medicine. Session 2 (11:50am - 1:10pm) focuses on paediatric case studies, rare genetic movement disorders, and neuromuscular genetics. Session 3 (2:20pm - 4:20pm) addresses ethical, social, and legal issues, rapid-turnaround exome sequencing, and the future of genomic medicine in Ireland. The poster also includes logos for SFI, FutureNeuro, and various partner organizations, along with a 'PENDING CPD Points' badge.

NATIONAL NEUROGENOMICS CONFERENCE

Register at:
nationalneurogenomicsconference2021.eventbrite.ie

DATE
11 June 2021

VENUE
Virtual

SESSION 1 9:00am - 11:50am

- Genetic disorders in Irish Travellers**
Dr Sally-Ann Lynch, Mater Hospital, UCD
- Lessons for Ireland from the UK 100,000 Genomes Project**
Dr Henry Houlden, UCL, London
- Genomic Medicine – Navigating Between the Head and the Heart**
Dr Charles Stewart, Congenica, Cambridge

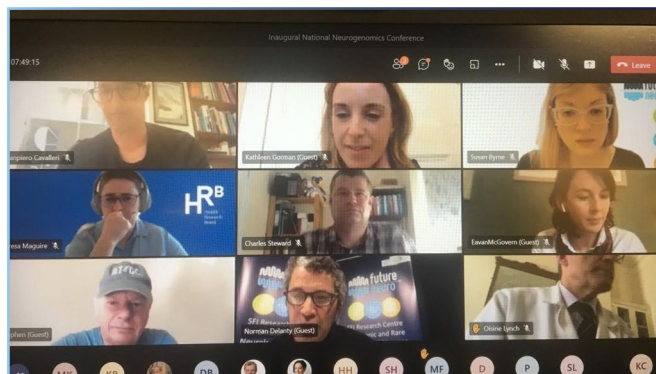
SESSION 2 11:50am - 1:10pm

- Paediatric case studies**
Dr Kathleen Gorman, Temple Street University Hospital / Dr Susan Byrne, FutureNeuro, Crumlin Children's Hospital
- Rare genetic movement disorders**
Dr Eavan McGovern, Beaumont Hospital
- Neuromuscular genetics**
Dr John McConville, Ulster Hospital, Belfast

SESSION 3 2:20pm - 4:20pm

- Ethical, social and legal issues in genomic medicine – the Irish context**
Dr Teresa Maguire, HRB
- Rapid-turnaround exome sequencing in critically ill neonates**
Dr Stephen Kingsmore, Rady Children's Hospital, San Diego
- Where now for genomic medicine in Ireland?**
Panel Discussion

PENDING CPD Points



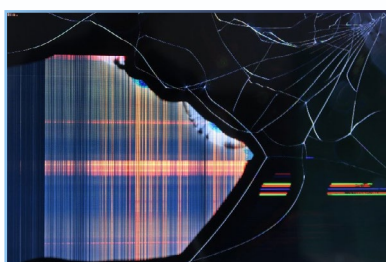
“Well done Norman and everyone in FutureNeuro. Thanks for the invite to a very successful event. Speakers were fantastic and great to see neurogenomics on the map.”

Dr Derrick Mitchell, CEO, Irish Platform for Patient Organisations, Science & Industry (IPPOSI)

Steam Art Collaboration

SFI Discover Primary Science and Maths Programme (DPSM) commissioned five artists, each paired with an SFI Research Centre to create an artwork which interprets a scientific concept. FutureNeuro was selected as a participating Centre.

Artist David Beattie has created Shifting Patterns of Light (pictured) along with members of the FutureNeuro team, Dr Susan Byrne, Dr Cristina Reschke and Dr Katie Benson. You can see this breathtaking work yourself by visiting the [virtual exhibition](#).

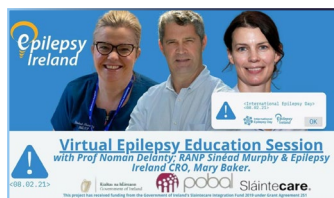


Cell EXPLORERS

We are so excited to be part of Cell EXPLORERS again this year. Cell EXPLORERS is a science education and outreach programme that promotes hands-on discovery of molecular and cellular biology. This year, we are reaching students all over the country with Fantastic DNA in a box via Zoom! [Read more](#)



In Spring, we partnered with Neurological Alliance of Ireland (NAI) for Brain Awareness Week and with Epilepsy Ireland and [Epilepsy Sparks for National Epilepsy Week](#). Our clinical researchers contributed to panel discussions on topics ranging from the Covid-19 pandemic and eHealth to Epilepsy research and awareness. FutureNeuro clinicians Profs Colin Doherty and Norman Delanty (pictured) also featured in Epilepsy Ireland's Virtual Education Sessions.



PPI Ignite Network

We are delighted to be part of the [HRB PPI Ignite Network](#). The initiative, in collaboration with the Irish Research Council (IRC), will see the development of a national network of Public and Patient Involvement (PPI) centres across 7 higher education institutions and 10 national partners on an all-island basis. The advancement of public, patients and carer's involvement in research will range from the generation of ideas to delivery of results. FutureNeuro are in the preliminary stages of establishing a patient advisory council and are exploring a broad relationship with a community group. [Read more](#)

Watch This Space

SFI Discover Epilepsy in English workshops are on the way! Participants can sign up to workshops that will help educate, equip and empower the public when it comes to epilepsy research and care. Building on the ["Epilepsy in English"](#) blog initiative.



For more information on Education and Public Engagement (EPE) opportunities or activities with FutureNeuro, contact Ciara Courtney, Communications, Education & Public Engagement Lead, ciaracourtney@rcsi.ie

Have a look at our new 'Getting to Know You' series on our website. This month, we spoke to Rachel Stewart, PhD student in NUIG, co-supervised by Prof Sanbing Shen and Dr Nicky Allen and funded by IRC/NCRC and FutureNeuro. [Read more](#)

