

Thank you to all those who took part in our research to enable scientific breakthroughs by our team.

The MND research team would like to sincerely thank all of those who have volunteered to participate in our

ongoing research. In 2021, with your help, we have made ground-breaking discoveries from our electrophysiology, psychology, brain scanning, genetics, physiotherapy and caregiver wellbeing research studies. If you wish to learn

more about findings of research you have participated in already, or wish to take part in our research in 2022, please email academicneurology@tcd.ie

Brainwaves Provide a Key to Understanding MND

One of the problems in finding new treatments for MND is that the condition is different in different people. To try to understand this, we have used new technologies that collect and analyse brain waves using EEG (electroencephalogram). Mr. Stefan Dukic (right), supervised by Dr. Bahman Nasserolelami, Fr. Tony Coote Assistant Professor in Neuroelectric Signal Analysis, Professor Hardiman, and Professor van den Berg, her colleague in the University of Utrecht, has used EEG to identify four different patterns of brain wave activity that link to different types of MND. Finding these different types of brainwave patterns is a major breakthrough that will help us to reach our aim of finding the right drug, for the right patient in the right time at the right dose.



REVEALS Study

The REVEALS (Registry of Endpoints and Validated Experiences in ALS) study began in March 2018 and data collection was completed in 2020. REVEALS was a Europe-wide study to better understand the impact of MND on breathing, cough and the ability to manage chest secretions and infections. Breathing was measured in detail every three months during clinic visits.

The study was led by Research Motor Neurone and Professor Orla Hardiman along with a team of physiotherapists – Dr. Deirdre Murray, Dr. Dara Meldrum & Ms. Rachel Tattersall. The findings from REVEALS will help us to find drugs that improve respiratory muscle strength. We would like to thank all the people who took part in this study and will report the final results in 2022.

REVEALS
POWERED BY TRICALS

IMPACT ALS

IMPACT ALS was an anonymous online survey of people living with ALS, and their caregivers, designed and conducted by Prof. Miriam Galvin and Mr. Mark Heverin. The survey was available online between October and December 2020 and was funded by RMN with support from the pharma companies Biogen, Ionis and Cytokinetics. Early analysis took place during 2021 and provided important insights into aspect of MND that doctors do not always recognise. The results have been shared with the European Regulatory Authority (EMA), and will help us to shape new treatments and interventions that reflect the patient and caregiver perspectives.

Watch Your Back MND

After being diagnosed with MND in April 2018, Roy Taylor continues his fight against Motor Neurone Disease with his Watch Your Back MND campaign for RMN.

This year saw Roy along with his daughter Ella Taylor release the beautiful song and video "I Can't Wait for Tomorrow". Roy and 12-year-old Ella continue their journey together through life's door. An unbreakable bond like no other.



Roy and Ella Taylor

MIRANDA

The team of Professor Miriam Galvin, Professor Orla Hardiman, Dr. Dara Meldrum and Dr. Deirdre Murray (MND clinic and the MND research team at TCD) was awarded €1.5 million from the Health Research Board, under the Collaborative Doctoral Awards (CDA) 2021 scheme. The programme, entitled Multidisciplinary Innovation and Research

Advancing Neurological care in a Digital Age, (MIRANDA) links clinical research and practice through novel and emerging telehealth solutions in patient-focussed research. This programme will enable different clinical specialties to develop essential research skills and integrate research with clinical practice. As we are

capitalising on existing collaborations with European centres, our PhD researchers will develop smart technologies to enhance knowledge, minimise burden for healthcare professionals, patients and families, and expand the benefits of cutting-edge multidisciplinary care.

Clinical Trials – Lots of New Drugs

This year is full of hope and optimism. We are participating in seven new clinical trials, in addition to completing the TUDCA study. Pharma sponsored trials that are currently recruiting include COURAGE (Cytokinetics) and MERIDIAN (Apellis) trials. We will be recruiting to ADORE (Ferrer) and PHOENIX (Amylyx) in late spring.

The Doddie Weir Foundation and the Irish Motor Neurone Disease Association are helping to support the MAGNET and LIGHTHOUSE trials, which are scheduled to start recruiting in the summer. We are also participating in two exciting gene therapy studies for people carrying the C9orf72 gene that is associated with MND. And we anticipate more trials later this year, as many promising new drugs are being developed. While not everybody is suitable for clinical trials due to strict criteria for enrolment, we will do our very best to make sure that

everybody that is eligible will have an opportunity to find out about the trials, and to participate if they wish to do so.

The clinical trials team is growing, but we must also say goodbye to Liz Fogarty. After ten years our clinical trials coordinator and clinical research nurse, Liz has decided to take a well-earned rest, although she will continue to help oversee the team and make sure that her high standards are maintained. We would like to thank Liz for her dedication, hard work, and leadership over the past decade. As is usually the case for exceptional people, Liz's job needed three people to replace her – two fantastic nurses – Toyosi Atoyebi and Rachel Nolan, and a superb manager, Niamh Ní Obáin. The clinical trials team is also supported by nurses Olivia Grogan and Triona Banneman, and by our talented and dedicated doctors, Dr. Sinéad Murphy, Dr. Amina Coffey and Dr. Sarah Darcy.



Liz Fogarty at her retirement



Valerie O'Carroll

Valerie O'Carroll/ Valerie's Warriors for Walk With Me For MND

Valerie O'Carroll, living in Clondalkin for the past 39 years, Manager of Ballymun Child & Family Resource Centre (FRC) for 12 years. She was diagnosed with MND in October 2019. Valerie and BCFRC organised many Walk for MND events throughout the last couple of years to raise awareness of Motor Neurone Disease. The Walk With Me For MND in November 2021 had 121 FRCs participating in the fundraising event, which raised €11,000 for RMN.

www.idonate.ie/fundraiser/11401195_valerie-s-warriors.html

Successful Graduates Supported by RMN

Dr. Róisín McMackin

Róisín McMackin used electroencephalography (EEG) and transcranial magnetic stimulation (TMS) to study how ALS affects brain activity, and to investigate if measurements of brain activity abnormalities can be used to detect ALS and predict how symptoms will progress. Róisín is now continuing to develop this research, as part of the Signal Analysis Strand of the Academic Unit of Neurology, and aims to develop these measurements as tools to improve prediction of how ALS affects each individual, as well as to improve how we test potential new drug therapies.



Dr. Róisín McMackin

Dr. Eoin Finegan

Dr. Eoin Finegan completed his PhD on the characteristic differences between PLS and ALS including the unique brain regions affected in each condition and distinctive progression over time. Dr. Finegan wishes to acknowledge the outstanding contribution of Irish PLS patients to this project.



Dr. Eoin Finegan

Dr. Marie Ryan

Dr. Marie Ryan completed her PhD this year. Her research found that although the risk of developing ALS among first-degree relatives of people with ALS was very low (~1%), this risk may manifest in subtle cognitive changes and higher levels of psychiatric distress observable among relatives of those with ALS compared with healthy controls.

Her research highlights the complex nature of epigenetic interactions in ALS risk and suggests that family units may play an essential role in future research. Determining how this disorder may be subcategorised by susceptibility gene and affected biological pathways is hoped will ultimately lead to the development of new and more effective treatments.



Dr. Marie Ryan



Dr. Síle Carney

Dr. Síle Carney

Dr. Síle Carney is a psychologist who successfully defended her PhD this year. Her research focused on the psychological needs of MND family caregivers.

Dr. Carney started her clinical training in September 2020, and continues to focus her research on the experience of family caregivers, as well as building clinically meaningful management strategies for caregivers of neurodegenerative diseases.

The Careys Foundation Support

The Careys Foundation, a charitable arm of the Carey Group, a leading family-owned construction business, operating across the UK and Ireland, made RMN its chosen charity for three years starting from 2019.

Established in 1969 by the three Carey brothers, the Carey Group has continued to evolve and grow developing new capabilities through innovation and learning. It has always taken a keen interest in charitable work.



The Careys Foundation Support

Noel Kavanagh

Raising awareness of the need for further research into Motor Neurone Disease absorbed the last three years of Noel Kavanagh's life. His book, a penetratingly honest account of his life, *From Living the Dream to Living with Motor Neurone Disease*, sold out in under three months, proceeds going to fund research into the disease. Fortunately he lived to see its success before he died 16 December 2021 at the age of nearly 76. Noel aided in the further development of Predictable software so that other MND patients could benefit from this in the future. Noel and his family raised over €25,000 for RMN and €20,000 for IMNDA.

Qualifying in veterinary medicine in 1969 he became a specialist of the Royal College of Veterinary Surgeons (RCVS) and developed and patented autogenous vaccines in Oldcastle, Co. Meath, and lectured worldwide. Noel was the most published specialised practicing vet. Noel was a keen sportsman and competed at many sports including motor car and bike racing in his younger days and more recently enjoyed cruising on his boat in the South of France.

He is sadly missed by his wife Caroline and daughters Kirsten and Naomi and extended family.



Naomi, Caroline, Noel and Kirsten at the Charity Ball in the Shelbourne, Sept 2019

WE SINCERELY ACKNOWLEDGE THE SUPPORT OF THE MANY PRIVATE INDIVIDUALS AND ORGANISATIONS WITH THE VISION TO HELP US FIND SOLUTIONS FOR THE ULTIMATE BENEFIT OF PATIENTS WITH NEURODEGENERATIVE DISEASES. OUR SPECIAL THANKS TO THE FOLLOWING 2021 SUPPORTERS:

- Roy and Terence Taylor (Watch Your Back MND Initiative)
- Noel Kavanagh Book Sale Fundraising
- Analogue Devices International Unlimited
- Irish Motor Neurone Disease Association (IMNDA)
- Eleanore O'Connor (El and Nick's Lockdown Quiz)
- Maggie Fernandez (Chloe and Rocio's hair raising fundraiser)
- Damien Buckley (CTIL - Competition Team Ireland Ltd.)
- Deirdre Cassidy (1 Million Steps for Mammy)
- O'Carroll (Walk With Me For MND)
- Andrea O'Connor (Walk with me for MND campaign)
- Hähnel industries in memory of Mr Walter Hähnel
- Frank Newman Golf Charity (Stackstown Golf Club)
- Pat Fogarty's Golf Classic
- Careys Foundation
- Dundalk Golf Club
- GT Office Design
- Dell Technology
- Theresa O'Leary/Joe Carty
- Walk While You Can
- Eugene/Maeve McCarthy
- Malcolm McGrath (1000KinMay)
- Mike Reidy (The Run Limerick)
- Tricals Céad Míle Fáilte
- Phil Nolan (Kanturk Golf Club)
- Eithne Nic Dhomhnaill
- Christina McCarthy
- Rise Global
- Ann Sirr (In memory of Maurice Sirr)
- MRIL
- Tayto Park, Asbourne Visitor Centre
- Clare McKenna
- Discissio Consulting LTD
- Daragh Noone
- Hayes Family Charitable Trust
- Iris O'Brien Foundation

Anna Costello of Newhall, Ennis, Co. Clare, who died of MND, left a major bequest to benefit our research. Our team will do everything possible to justify the trust Anna put in us and in her belief that further research into this terminal condition can help make MND a manageable disease and bring hope.