

Welcome to our annual newsletter. With 2023 under way, we take time to reflect over the past year and share our progress in the fight against

Motor Neurone Disease (MND), also known as ALS. 2022 was a busy year for

all of us at Research Motor Neurone, we are proud to report that our research efforts have continued at pace.

In this edition, we will keep you informed of the advancements we made over the past several months,

from new discoveries and innovative clinical trials to fundraising initiatives that aid our ongoing mission to further comprehend and treat MND.

Precision ALS Launch

A new €10m Ireland based project, Precision ALS, (www.precisionals.ie) which aims to develop new and innovative treatments for patients with MND launched in March at Trinity College Dublin (TCD). With funding from Science Foundation Ireland, Precision ALS brings together medical research, data science and artificial intelligence to build tools that enable clinical trials based on precision medicine, where treatments are personalised for individual patients.

The project is in partnership with TRICALS, an independent consortium of leading ALS experts, patients, and patient advocacy groups across Europe, as well as industry partners such as Biogen, Novartis, Takeda, IQVIA, Roche, and Accenture.

Led by two Science Foundation Ireland (SFI) research centres: the ADAPT centre for AI-driven digital content technology

and the FutureNeuro research centre for neurological diseases, clinical scientists, data scientists, and AI experts will collaborate on data-driven prediction models for the progression of the neuromuscular disease and data analysis that will help develop treatments.

According to the Director of Precision ALS Professor Orla Hardiman, there is an “increasing recognition of the need for precision medicine” in developing drugs for MND, or ALS, which only affects humans.

The research is supported by the Irish Government through an SFI investment of €5m, which will be matched by an additional €5m from industry partners.

We are proud to be part of this groundbreaking research that has the potential to change the lives of patients living with the disease, and we are excited

to see the impact it will have on the field of MND research. We will continue to keep you updated on the progress of Precision ALS.



Prof Orla Hardiman Leo Varadkar TD Prof Vinny Wade Prof David Henshall

PRECISION ALS



Awards

Over the past year RMN founder, Professor Orla Hardiman, was recognised and honoured with two significant and prestigious awards. The consultant neurologist at Beaumont Hospital and Trinity College Dublin's first professor of neurology, was named as “Researcher of the Year” by SFI for her significant contributions to understanding and treating motor neurone disease.

As a leading authority on ALS, as well as a researcher at the SFI research centers FutureNeuro and ADAPT. Professor Hardiman

also founded and leads the national ALS clinical and research program.

Professor Hardiman was also honoured with the Provost's Innovation Award at the 2022 Trinity College Dublin Innovation Awards.

The award recognised Professor Hardiman's exceptional record of clinical and academic excellence, as well as her significant international and interdisciplinary collaborations, her work as the HSE's national clinical lead for neurology, and her

dedication to improving the lives of those living with motor neurone disease through her innovative research and partnerships.



SFI Awards 036

Lara Mc Manus

Dr. Lara McManus, a Research Fellow at the School of Medicine, was awarded a highly competitive Royal Society University Research Fellowship in November of 2022. This fellowship, which is funded by Science Foundation Ireland, is designed to support outstanding scientists as they become leaders in their field. The fellowship which provides salary and research expenses for up to eight years, allows awardees to build an independent research career in Ireland or the UK. Dr. McManus will use her fellowship to focus on improving prospects for people living with motor neurone disease (MND).

One of the main challenges in treating MND is the lack of quantitative measures to detect early network disruption and measure disease progression. Dr. McManus's research aims to develop new markers of disrupted neuroelectric signalling that can detect early signs of motor unit dysfunction and provide a quantitative measure of both different subtypes of the disease and of disease progression within subgroups of those with ALS.

"The Royal Society University Fellowship Award combines my background in engineering with cutting-edge clinical neuroscience. I'm confident that the work



Lara Mc Manus

will radically change the lives of people with ALS by speeding up the development of new and better drugs," said Dr. McManus.



Conor Hayden

Conor Hayden

Conor Hayden, a PhD researcher in Trinity Centre for Biomedical Engineering, and Dr Deirdre Murray were announced as winners of the Trinity College Invention Challenge Prize.

Their submission an innovative device for motor neurone disease was recognised by the MED tec department of Trinity for innovation and developing solutions for those with this debilitating condition. Research and development of technological devices to aid those suffering from motor neurone disease (MND) is crucial in improving the quality of life for and in finding a cure for the disease.

With the development of new technology, patients can have access to devices that can help with mobility, communication, and other daily activities. Furthermore, technological advancements in research can also lead to the development of new markers that can detect early signs of the disease, which can help to delay the progression of the disease and improve the chances of survival. In addition, technology can help in the development of new drugs and treatments that can help to slow down the progression of the disease, and improve the quality of life for MND patients.

Successful Graduates Supported by RMN



Dr Emmet Costello

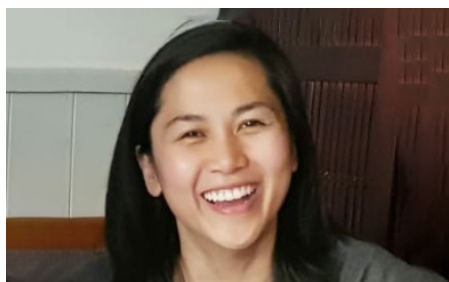
Dr Emmet Costello

Dr Emmet Costello completed his PhD this year. Focused on family members of people with ALS, its aim was to determine if they had particular cognitive or psychiatric traits that may be linked to ALS risk.

He found that as a group, relatives of ALS patients had deficits on tests that are often affected in ALS (e.g. verbal fluency), and they had particular personality characteristics. These findings were

stronger in relatives of patients with a strong family of ALS, supporting the theory that these results are related to ALS risk.

While still at a very early stage, these important findings could help researchers understand how ALS risk genes affect not just the patient, but also their broader family, and may help us discover new risk genes in future.



Dr Stacey Li Hi Shing

Dr Stacey Li Hi Shing

Dr Stacey Li Hi Shing, successfully defended her thesis and completed her PhD in the preceding year.

Through complex neuroimaging analyses, her work evaluated cerebral alterations of poliomyelitis survivors, decades after their original infection. She collected and analysed cross-sectional and longitudinal radiology data on a large cohort of poliomyelitis survivors to evaluate cortical, subcortical, cerebellar and white matter alterations.

Contrary to previous reports, Staceys work found no irreversible cerebral atrophy was detected and no underlying structural abnormalities to account for fatigue or cognitive impairment.

She has presented her findings at prestigious international conferences and had them published in high-impact peer-reviewed journals. Inspired by her experience in research, she has decided to pursue a career in neurology and has now started her medical internship.

Climb with Charlie

In autumn of 2021, Charlie Bird, a well-known Irish journalist and broadcaster, revealed that he had been diagnosed with motor neurone disease. Determined to help others despite his diagnosis, he organised a charity climb of Ireland's famous Holy Mountain, Croagh Patrick. The event exceeded his expectations and raised over €3 million for charities such as Pieta and the Irish Motor Neurone Disease Association. On April 2, 2022, Charlie successfully completed the climb with support from his family, friends, and a host of celebrities. The event sparked a nationwide outpouring of support, with thousands of people climbing local peaks in solidarity. For Charlie, the experience was deeply meaningful and captured the hearts of the Irish Nation.



Professor Orla Hardiman, Charlie Bird and IMNDA CEO Lillian McGovern

An incredible amount was raised from the event, with Research Motor Neurone benefitting directly from these funds. This money will now be used to launch an

innovative clinical trial for MND patients. The trial will be in partnership with other European countries and overseen in Ireland by Professor Orla Hardiman.

Charity Climb of Slieve Foye

The 'Climb the saddle of Slieve Foye for Seán Woods and Roy Taylor' event took place in April of 2022.

Inspired to raise funds after seeing Seán and Roy courageously battle motor neurone disease for the last number of years, teacher Paula Lavin organised the hike up Slieve Foy along with events in local schools with the hope of raising €10,000.

In the end she easily surpassed this amount thanks to the generosity of all those that supported the events and raised a staggering €37,720 for Research Motor Neurone. The success of the event and



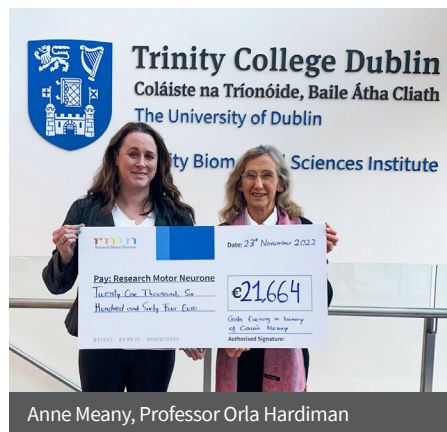
Climb of Slieve Foye

amount raised can only be described as a reflection of the dedication and hard work Paula poured into the event.

Gala Evening in Memory of Ciarán Meany

A charity evening in Aid of Research Motor Neurone was held in November 2022 by Anne Meany in memory of her late husband Ciarán Meany. Held in The Grand Hotel Malahide, it was a memorable evening that celebrated the memory of Ciarán whilst also raising much needed funds towards the fight against MND.

Dr Roisin McMackin, post doctoral researcher at the Academic Unit of Neurology at Trinity, spoke on the night on behalf of Research Motor Neurone. An amazing €21,645 was raised in total and is a testament to the hard work Anne put into ensuring the success of the event.



Anne Meany, Professor Orla Hardiman

Watch Your Back MND



Roy Taylor and Finbar Furey

Avid campaigners and fundraisers for MND since Roy's diagnoses with motor neurone disease in 2018. Roy and his son Terence Taylor continued their trojan work and support of RMN across all of last year.

Their events and initiatives linked to their ongoing Watch Your Back MND campaign, saw a charity event take place in April where Dundalk FC wore a one-off, charity jersey in the SSE Airtricity League game against Shelbourne at Oriel Park.

For the event each unique, player's jersey was auctioned ahead of the game. A bucket collection also took place during the night to raise awareness and funds for motor neurone disease. An incredible €9,526 was raised from the event itself.

October also saw the release of a truly special song 'Music's Door' a collaboration between Roy and his dear friend and fellow singer songwriter, Finbar Furey. The incredible duet, which received tremendous praise was written by Finbar himself, and was launched with a very special music video.

It aims to continue to raise much needed awareness and funds for Motor Neurone Disease after its release.

Speaking about the song launch Finbar Furey said "I'm honoured to share this song, 'Music's Door' with Roy Taylor, a wonderful singer and a very special person who is tragically suffering from motor neurone disease, and valiantly working to help raise awareness of this dreadful illness'.

We are sincerely thankful to Roy and Terence for their continued tireless determination to help everyone suffering with Motor Neurone Disease.



Roy Taylor

TRICALS Céad Míle Fáilte

The launch of the TRICALS project saw the largest European research alliance to find a cure for ALS to date. This project saw 48 top researcher centres in sixteen countries join hands with patient organisations and fundraisers to reach one common goal, find an effective treatment for ALS.

Inspired by the launch of TRICALS, the TRICALS Céad Míle Fáilte initiative was established. Its aim to raise 100K to contribute and support the top experts and researchers pooling their knowledge and findings in a concentrated push for a cure and to make a meaningful contribution to ridding the world of MND forever.

Last year in August marked a significant milestone moment of reaching that amount. This would not have been possible without the drive and determination of the late and sadly missed Fíona and her husband Fiachra Mac Domhnaill, the initiative's founders who pushed tirelessly since TRICALS Céad Míle Fáilte's inception to accomplish their

goal. For them to achieve this in such a short period of time is remarkable.

Sadly Fiona lost her fight against MND in January of this year. Everyone at Research Motor Neurone and the MND research group would like to acknowledge what a truly inspiring person she was and thank her, Fiachra, her family and anyone who supported the TRICALS Céad Míle Fáilte project. What they have achieved will make a significant difference towards the fight against MND.



Fiona and Fiachra Mac Domhnaill and Mark Heverin

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 2022 SUPPORTERS.

- Hähnel Industries - In memory of Mr Walter Hähnel
- Andrew O'Connel - Caragen
- Danny Houlihan - Pat Fogarty's Golf Classic
- Paula Lavin - St. Colmcilles GAA Club - Seán Woods & Roy Taylor Climb for RMN
- TRICALS Céad Míle Fáilte Initiative
- Peter Carr
- Norman McDonnell - Connect Credit Union, Blackrock Co. Louth
- Mark Kennan - The Round O Navan
- Gerry O'Connor
- Barry Brennan - Pump and Technical Services
- May Corr
- Nora de Búrca (Bequest donation), kindly shared by Ciarán, Aoife and Caitríona de Búrca.
- Stephanie Byrne
- Patrica McCarthy
- Damien Buckley - CTIL - Competition Team Ireland Ltd
- The Lough Ree Orca Swimming Group -Swim from Tarmonbarry, Co. Roscommon to Lanesboro, Co. Longford
- Partners at Law
- Eugene McCarthy - Big Band Afternoon Tea Dance
- Ann & Roger Barnes
- Sheane Motors - Mondello campaign
- Martin Connolly - Sean Woods & Roy Taylor Climb for RMN
- Lisa Kelly - VHI women's mini-marathon
- Irish Motor Neurone Disease Association (IMNDA)
- Charlie Bird - Climb with Charlie
- Roy and Terence - Watch your Back MND
- Anne Meany - Gala Evening in memory of Ciarán Meany