2024
NEWSLETTER

Motor Neurone Disease Research

Trinity College Dublin
The University of Dublin

rmn
Research Motor Neurone

Welcome to our annual newsletter. As we move further into 2025, we take this opportunity to reflect on the achievements of the past year and share the latest developments in our ongoing fight against Motor Neurone Disease (MND), also known as ALS.

The past year has been a busy and impactful one for all of us at Research Motor Neurone. We are pleased to report that our research continues to make significant strides, driving us closer to new breakthroughs and improved treatments.

In this edition, you'll find updates on recent progress, including exciting scientific discoveries, innovative clinical trials, and the inspiring fundraising efforts that support our mission. Your continued support is invaluable in the pursuit of better treatments—and, ultimately, a cure — as we work toward a future free from MND.

Dr.Dara Meldrum Honoured for Innovation

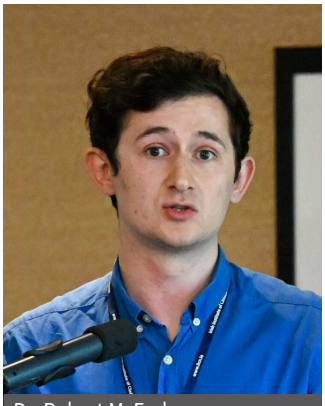
During 2024, Dr. Meldrum, a physiotherapist and Associate Professor at the Academic Unit of Neurology, School of Medicine, Trinity College Dublin, and founder of Vertigenius, was awarded the "TCD Innovation Campus Company Founder Award" in recognition of her contributions to digital health and vestibular rehabilitation.

The award celebrates her innovative mobile health platform, Vertigenius, which leverages wearable sensors and digital exercises to support individuals experiencing dizziness, vertigo, and balance disorders. Vertigenius is a spin-out company from the ADAPT Centre. As both a researcher and clinician, Dr. Meldrum merges academic expertise with hands-on patient care to advance digital and telehealth solutions. Vertigenius enhances the rehabilitation process by offering a technology-driven, user-friendly approach that benefits both patients and healthcare professionals. In addition to this achievement, Dr. Meldrum was also honoured with the "Women in Life Sciences Award" at the Life Sciences Awards 2024, which recognises outstanding contributions to Ireland's medtech sector.

The judges praised Dr. Meldrum for her "outstanding academic and professional accomplishments". They also recognised her significant impact and potential to inspire other women in science noting "Her recognition at the Life Science Industry Awards underscores the importance of continued investment in medical technology and the crucial role women play in advancing scientific innovation."

Dr. Meldrum with her Life Sciences award

Dr.Robert McFarlane Awarded Target ALS Neurology Resident Grant


Dr. Robert McFarlane

Dr. Robert McFarlane is a Neurology registrar with a keen interest in neurodegenerative diseases and epidemiology. He is currently working as a research registrar and PhD student at Trinity College Dublin, where his research focuses on the European epidemiology of Amyotrophic Lateral Sclerosis (ALS) and the clinical application of statistical models.

In 2024, Dr. McFarlane was selected as one of the recipients of the "Target ALS Neurology Resident Grant", an initiative that supports early-stage clinician-scientists conducting groundbreaking research in ALS therapeutics and biomarker development. This program aims to drive innovation in diagnostics, treatments, and drug development for ALS.

Dr. McFarlane's project applies machine learning techniques to identify distinct sub-populations of ALS patients who share biological characteristics. By creating data-driven patient sub-cohorts, his research aims to refine targeted drug development and develop "digital twins"—a cutting-edge approach designed to optimise clinical trial recruitment and outcomes. His work has the potential to significantly improve the precision and effectiveness of future ALS treatments.

Fraser Holden

Fraser Holden

It is with great sadness that we acknowledge the passing of Mr. Fraser Holden in 2024. Fraser was a tremendous supporter of Research Motor Neurone (RMN) who dedicated himself to raising awareness and funds for MND research in a truly unique and inspiring way.

Diagnosed with Motor Neurone Disease in 2022, Fraser had spent 30 years as an architect before the progression of the disease made it impossible for him to continue in his profession. Undeterred, he turned to art, using eye-tracking technology to create stunning pieces that captivated not only the MND community but art lovers worldwide.

During 2023 Fraser generously utilised this talent to produce artwork that was sold to benefit Research Motor Neurone. Since his passing his art has continued to contribute to research into MND through donations of proceeds of art pieces that were sold to Trinity College Dublin during 2024.

He will be remembered not only for his incredible artistry but also for his strength, generosity, and commitment to making a difference. His artwork remains as a powerful and lasting reminder of his extraordinary resilience, transforming personal challenge into a source of beauty, hope, and inspiration for so many.

Our thoughts are with Fraser's family, friends, and all those who had the privilege of knowing him. His legacy will continue to inspire for years to come.

A Night of Music and Generosity: Michael Walsh's Fundraising Success

Professor Hardiman and Michael Walsh

In October 2024, Michael Walsh hosted an unforgettable evening of live music, laughter, and community spirit at The Sugar Club in Dublin. Featuring, M:Brace – Michael Walsh & Band, along with special guests, the event brought people together to support Research Motor Neurone (RMN) and Cancer Research.

The night was a resounding success, with attendees enjoying fantastic performances while contributing to vital MND and Cancer Research through ticket sales and donations. In the lead-up to the event, a coffee morning also helped boost fundraising efforts, further strengthening the support for these crucial initiatives.

Thanks to the overwhelming generosity of those who attended and donated, Michael Walsh far surpassed the initial target he had set and raised an incredible €8297.50 each for both charities. This remarkable achievement highlights the power of community and the impact of coming together for a meaningful cause. A huge thank you to Michael Walsh and everyone who supported these events.

Maeve's Morning for MND

Maeve's Morning for MND was a heartwarming coffee morning and raffle held at Kinlough Community Centre in North Leitrim. The event was the brainchild of Maeve Kilgannon, who wanted to give back to Research Motor Neurone and IMNDA, two organisations that she credits at providing invaluable support since her diagnosis in 2022.

With the help of her family, Maeve formed a dedicated committee to bring the event to life. Their efforts resulted in an incredible raffle featuring 83 prizes. Some of the amazing prizes featured included a cookery course with Catherine Fulvio and tickets to Mrs. Brown's Boys. Despite the weather on the day (which coincided with the arctic winds of Storm Darragh) the whole team was Overwhelmed by the support of those who

Meave and Katie Kilgannon

attended, the turnout was truly inspiring. Supporters braved the weather to enjoy coffee, cakes, and Christmas cards on offer, generously donating to the cause. Thanks to the incredible community spirit, the event raised over €11,000 to support Research Motor Neurone's vital and groundbreaking work.

Fingal County Council Donates €10,000 to RMN in Memory of Roy Taylor

Terence Taylor Center with Fingal County Council Members

We are deeply grateful to Fingal County Council's Fingal Helping Hand Fund for their generous donation of €10,000 to Research Motor Neurone (RMN) in memory of the much-missed Roy Taylor. During 2024, a cheque was presented to Roy's son, Terence Taylor, who continues to be an inspiring advocate for both RMN and the MND community. The donation will directly support vital research efforts in the fight against Motor Neurone Disease (MND).

Established in 2005, the Fingal Helping Hand Fund is a remarkable initiative run by Fingal County Council employees. It provides financial assistance to registered charities and worthy causes, funded through voluntary payroll contributions from both current and retired council employees. We extend our heartfelt thanks to Fingal County Council and its employees for their unwavering commitment to supporting important causes.Their generosity is helping to drive lifesaving research and bring hope to those affected by MND.

Successful Graduates Supported by RMN in 2024

Dr. Marjorie Metzger

Dr. Marjorie Metzger successfully completed her PhD under the supervision of Dr. Bahman Nasseroleslami and Prof. Orla Hardiman. Her work was funded by the Thierry Latran Foundation. During her PhD, she collected and analysed EEG data at rest, measuring the spontaneous electrical activity of the brain. Her work focused on finding quantitative biomarkers of cognitive and behavioural impairment in ALS. Such impairments in ALS can manifest as difficulty concentrating, fixation on repetitive tasks, trouble with speech or language and changes in personality or social behaviour, affecting up to 50% of individuals with the disease.

Dr. Metzger used advanced EEG techniques to track changes in brain activity over time, revealing distinct patterns of neural dysfunction linked to cognitive decline, behavioural symptoms, and survival rates, offering valuable insights into ALS progression with potential future applications in personalised care.

In 2024, she published two articles in high-impact peer-reviewed journals, presented her research at relevant international conferences in the US and Korea and was awarded a 2024 Milton Safenowitz Postdoctoral Fellowship to pursue her research in the field of MND.

Dr. Soroj Bista

Dr. Saroj Bista successfuly earned his PhD under the supervision of Dr. Bahman Nasseroleslami and Prof. Orla Hardiman, funded by IRC Postgraduate Scholarship program. His PhD focused on understanding brain networks of people with motor neurone disease (MND), using non-invasive techniques like EEG (to measure brain activity) and EMG (to measure muscle activity). The overarching aim of his work was to identify abnormal brain networks that could serve as early indicators for diagnosis, prognosis and stratification of people with MND.

Dr Bista improved a method for estimating brain-muscle communication (Cortico-muscular coherence) and used it to demonstrate that in primary lateral sclerosis (PLS), brain areas not typically involved in unilateral movement are abnormally involved. He revealed that people with ALS have abnormal motor planning — the brain's preparation phase before performing a movement— and demonstrated that abnormal motor planning networks could help develop better diagnostic tools. He has published his findings in high-impact peer-review journals and presented his work to the scientific community at relevant international conferences.

Rosie Giglia

Rosie Giglia completed and submitted her PhD thesis under the supervision of Dr. Bahman Nasseroleslami and Prof. Orla Hardiman. Her work was funded by the Irish Research Council, Research Motor Neurone, and the FutureNeuro Centre.

Her project took EEG biomarkers of cognitive dysfunction in ALS and investigated their applicability to cognitive dysfunction in multiple sclerosis to understand whether cognitive changes in these conditions are related to shared or distinct neural dysfunction.

She was also named as the overall winner of the 2024 Trinity College Dublin postgraduate teaching award for her contributions to undergraduate teaching during her PhD.

The Trinity Teaching Award for Postgraduate Students aims to identify and recognise individual postgraduate students who make a substantial contribution to undergraduate student learning. Under the terms of the scheme, Schools nominate postgraduate students that they believe merit recognition for undergraduate teaching /demonstrating.

Aileen Barrett Bursary Launches

In 2024, we were proud to announce the establishment of "The Aileen Barrett Memorial Bursary" in honour of Ms. Aileen Barrett.

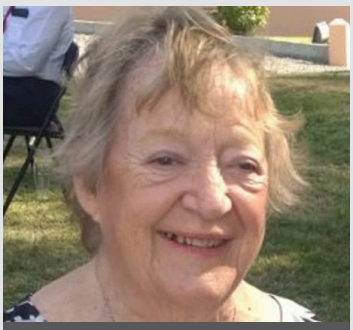
Aileen was a respected colleague, mentor, and leader within the Irish Society of Chartered Physiotherapists (ISCP). She made significant contributions to the physiotherapy profession throughout her distinguished career, notably serving as Head of Physiotherapy at Beaumont Hospital. Even after retirement, she remained a dedicated mentor, generously sharing her wisdom with generations of physiotherapists and healthcare professionals.

Aileen also played a pivotal role in MND research and advocacy, serving as the founding Chair of the Board of Research Motor Neurone, where she remained an active board member until her passing in January 2023.

Founded by her son Richard, this bursary was created to support allied healthcare professionals in the field of Motor Neurone Disease (MND) who reflect Aileen's values, dedication, and spirit. It ensures her legacy lives on through those who share her commitment to excellence in patient care and research.

This year, we were delighted to award the bursary to Mr. Simon Gilligan, Clinical Specialist Physiotherapist in Motor Neurone Disease. Mr. Gilligan is an integral member of the MND multidisciplinary team at Beaumont Hospital, where he plays a key role in physiotherapy management for people with MND.

By empowering future generations, this bursary preserves Aileen's lasting impact, vision, and dedication to healthcare, inspiring others for years to come.



Aileen Barrett

Precision ALS Update

Precision ALS (www.precisionals.ie), the €10 million research programme uniting researchers from SFI Research Centres ADAPT and FutureNeuro, alongside TRICALS, Europe's largest ALS research initiative, has continued to accelerate its groundbreaking work throughout 2024.

Since its launch in March of 2022 at Trinity College Dublin (TCD), the project has made significant strides toward its primary goal: creating a pan-European Patient Data Platform that enables research sites across Europe to collaborate in the search of effective ALS treatments. The ultimate objective of Precision ALS is to develop innovative, personalised treatments for MND patients through precision medicine, using artificial Intelligence, data science, and clinical expertise to shape the future of ALS research.

A key highlight of 2024 was the Precision ALS Amsterdam Masterclass, held in February at Novotel Amsterdam. This two-day workshop focused on real-world data collection and collaboration, bringing together leading academics, clinicians, and industry experts to drive discussions on data harmonisation, patient monitoring, and biomarker development.During this intensive workshop , Professor Orla Hardiman, Director of Precision ALS and Professor of Neurology at Trinity College Dublin, alongside Assoc. Professor Miriam Galvin, highlighted the critical need for real - world data to ensure research translates into meaningful clinical advancements.

CTO Dr. Anthony Bolger and Senior Software Developer Matthew Nicholson presented the latest developments in the patient data collection tool and WebApp interface. Dr. Dara Meldrum and Dr. Deirdre Murray led a session on remote patient monitoring, showcasing an innovative approach to capturing critical health measurements in-home. Prof. Jochen Prehn presented cutting-edge transcriptomic research, while biomarker discovery projects in partnership with Novartis and SomaLogic were also reviewed.

Dr. Florentine Barbey (Cumulus) also introduced exciting results from a 16-sensor headset, designed to detect speech changes —a promising biomarker for disease progression that has drawn significant interest from pharmaceutical companies.

Looking Ahead, 2025 promises to be another year of important developments for this important project. We take great pride in our involvement in this groundbreaking research and will continue to provide updates on its advancements as we move closer to our goal of transforming ALS research and patient care.

Study Launches Exploring How Digital Technology Can be Used to Measure Changes in MND Symptoms Over Time

In Autumn of 2024, Professor Orla Hardiman, Dr. Dara Meldrum, and Dr. Deirdre Murray launched an innovative study examining how digital technology can be used to track changes in MND symptoms over time. This collaborative research is being conducted through the SFI-funded PrecisionALS programme ([www.precisionals.ie], the HRB-funded MIRANDA doctoral award programme, and with support from the NeuroInsight programme.

The study is included as part of work package four of the PrecisionALS research programme which addresses the need to provide a flexible, agile and modular solution to address challenges around treatments for ALS and other diseases. One of the measurements traditionally used in research is the ALS Functional Rating Scale-revised (ALSFRS-r) questionnaire. This measurement has been criticised for being unable to detect small but important changes that occur in MND progression.

In an era of advanced digital technology, there is a growing need for more precise and sensitive ways to measure disease progression. The study asks people with MND to use different technologies to see if they are acceptable to use, and if the technologies are able to pick up changes that occur with MND over time.

This study will assess various digital tools to determine their effectiveness in tracking physical changes such as walking, speech, swallowing, hand strength, breathing, and dexterity. Whether people with MND find these technologies easy to use, and how these tools can improve monitoring of disease progression, care planning, and evaluation of new treatments. The study aims to improve the ability to measure changes in MND in a more precise way. This information can then be used for better measurements of how the condition progresses in clinic, planning care needs and evaluating the impact of new treatments.

Index-eTap: Advancing Hand Dexterity Measurement in MND Research

Index-eTap, a groundbreaking device designed to objectively measure hand dexterity, continues to make significant progress in its development. Featured in last years edition of this newsletter, the device was created at Trinity College Dublin's Unit of Neurology and School of Engineering. It was developed by Dr. Conor Hayden, a biomedical engineer and Precision ALS postdoctoral researcher, as part of his PhD research, under the supervision of Dr. Deirdre Murray and Prof. Bruce Murphy.

The Index-eTap device digitises the widely used Finger Tapping Test, which assesses neurological function. By having participants rapidly tap their index finger against their thumb, it generates a dexterity score ranging from 0 (minimal function) to 1 (optimal function). This precise and objective scoring system sets Index-eTap apart from traditional manual dexterity assessments.

The development of Index-eTap has advanced steadily throughout 2024. A patent application is in place, and Enterprise Ireland has provided funding to assess its commercial potential. While the commercialisation process takes time, the device is now integrated into Precision ALS (www.precisionals.ie) —research programme.

Within Precision ALS, Index-eTap is part of Work Package 4, a study launched in Autumn 2024. This study is exploring how digital technology can track changes in MND symptoms over time, with Index-eTap specifically assessing progressive changes in hand dexterity. The first data collection study confirmed that Index-eTap effectively differentiates between individuals with varying levels of dexterity. The next step is to determine whether it can track changes over time. This requires repeated testing on the same individuals over 12 months—for example, assessing dexterity every three months—to evaluate how accurately the device records progressive changes or stability in hand function. This marks an important milestone for Index-eTap.

We look forward to sharing further updates in next year's edition as the study progresses.

Study on How the Presence or Absence of Genes Associated with MND Affects the Brain

Dr. Narin Suleyman, a researcher in the Discipline of Physiology at Trinity College Dublin recently embarked on her PhD to study how the presence or absence of genes associated with MND affects the brain. Under the supervision of Dr Roisin McMackin, Dr Suleyman is currently testing how brain cells communicate with each other by looking at brainwaves recorded during a variety of thinking and language tasks. She is also exploring the way these brain cells communicate with the muscles, by stimulating the part of the brain responsible for movement and monitoring the response from the muscles.

The results from these non-invasive and painless tests will be analysed to determine if there is any relationship between brain function and genes associated with MND. Through this research, Dr. Suleyman and other researchers at Trinity hope to identify markers that will detect MND earlier.

Dr. Suleyman's study recruited volunteers over the age of 18 who do not have MND but have two or more family members affected by the disease. For her research volunteers are asked to: Sit comfortably for 2–3 hours while their brainwaves are recorded and/or their brain is stimulated, and to provide a small - blood sample for genetic testing results for research purposes.
We are looking forward on keeping you updated you on this groundbreaking research as it progresses.


Dr. Narin Suleyman

MND Public and Patient Information panel update


2024 annual MND PPI information event

Last year we updated our newsletter readers that under the leadership of Prof. Orla Hardiman, the MND research team in the School of Medicine, Trinity College Dublin, had established the first Irish PPI advisory panel for MND research. This panel now provides an opportunity for people diagnosed with MND, their family, friends, or caregivers, to help shape the MND research carried out in the School of Medicine.

Public and Patient Involvement (PPI) aims to give a voice to people who are directly impacted by a medical condition, so they can have a say in how research about that condition is carried out. The opinions and perspectives of PPI panel members help researchers to design studies that are not overly burdensome for participants. In this way, PPI expands the partnership between researchers and people impacted by MND.

To launch the panel in November 2023, an information event was held for panel members and researchers to meet each other through in-person or online attendance, learn about TCD active research studies and discuss how the panel would operate. Following positive feedback from those who attended, TCD researchers hosted a similar annual event in November 2024 for all active panel members as well as those considering joining in the future.

As of January 2025, the panel now has 27 active members; 17 people who have been diagnosed with MND and 10 family members Since its inception panel members have participated in a number of activities such as ; Discussion of research study protocols , Reviews of information leaflets, Trial runs of research methods and Presentation of information about the panel.

If you have been diagnosed with MND or are a family member, friend, or caregiver of someone who has been, then you are eligible to join the panel. New members can join at any time. Participants are not required to have any specific skillset, and do not need to have experience in research or medical/scientific knowledge to take part.

If you would like to join the panel or receive an information leaflet, you can email **Aisling at researchmnd@tcd.ie.**

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 2024 SUPPORTERS.

- Hähnel Industries – In memory of Mr Walter Hähnel
- Mr Andrew O'Connel – Caragen
- Mr Gerry O'Connor – GOC estate agents/ Stewartstown SkiAssociation
- Ms Lisa Kelly – VHI Women's Mini Marathon
- Fingal County Council
- Mr Michael Walsh - Fundraising evening and Coffee Morning
- Mr Jim O Leary - Fundraiser in memory of Cathy
- Mrs Mary Buckley, (bequest) facilitated by Mr Paddy Buckley
- Mrs Maeve Kilgannon and family - Maeve's Coffee Morning
- Ann and Roger Barnes' Xmas Lights display
- Irish Motor Neurone Disease Association (IMNDA)
- Fr. Noel Keogh and Terence Taylor – The Roy Taylor Organisation
- Ms Patrica McCarthy
- GAA Club JK Brackens in Templemore, Co Tipperary.
- Cavan Equestrian Centre
- Ms Denise Conlon - VHI women's Mini Marathon
- St Joseph's Primary School Templemore - Bake Sale
- Donation in memory of Mr Fraser Holden by wife Mrs Orlagh Reynolds
- Mrs Noreen Leahy
- Ms Lisa Kelly - VHI women's mini marathon
- Ms Rachel Stanley - Dublin Marathon
- Mr John Deane

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