

Highlights of 2018

In 2018 the Trinity Motor Neurone Disease (MND) research team under the leadership of Orla Hardiman, Professor of Academic Neurology, has continued the development of a multidisciplinary research programme. This spans from genetics and bioinformatics through new drug development in the laboratory, to studying people with the condition using detailed clinical evaluation and advanced bioengineering based technologies, and includes mapping the patient journey across the Irish and European health system. The work is tightly integrated with other research groups in Trinity College Dublin (genetics, bioengineering, imaging, neuropsychology, neural engineering and qualitative research) and with leading research groups across the world.

- Professor Hardiman's research team now comprises: two Research Associate Professors – Dr Bede, quantitative neuroimaging, and Dr Julie Kelly, drug

development; four Senior Research Fellows – Bahman, Miriam, Dara and Deidre; Research Manager Mr Mark Heverin; eight graduate students of whom four are clinicians, two are psychologists, one a neuroscientist and one a neural engineer; eight research assistants (four in psychology and four in engineering) and two research nurses. Two PhDs have been awarded in 2018 – to Dr James Rooney, epidemiology, and Dr Parames Iyer, signal analysis. The genetics group is led by Dr Russell McLaughlin, Ussher Assistant Professor, who is now supervising 4 PhD students within the School of Genetics, working on the Project MinE initiative.

- We are members of the SFI funded centre FutureNeuro, and have leveraged funding of €300,000 to support a large neural engineering project. We have also entered into a new collaboration

with the SFI funded ADAPT Centre, to provide electronic solutions to multidisciplinary clinics in the form of a customised Electronic Patient Record for Neurodegeneration with extension to Multiple Sclerosis in the coming year.

- Within the past 12 months, the group has raised over €1.5 million in research funding, including leveraging our membership with SFI Centres (FutureNeuro), and two grants from the Irish Health Research Board (HRB).
- Dr Russell McLaughlin was awarded the European Young Investigators Award in Oxford in June 2018, and Dr Marie Ryan (a PhD candidate within the Unit) won the Irish Institute of Neuroscience Registrars Award in November 2018.
- Dr Miriam Galvin, who leads the qualitative research group, was awarded a Global Brain Health Institute Fellowship, which commenced in August 2018.
- Professor Hardiman's group has published over 40 scholarly articles in peer reviewed journals in 2018 including ground-breaking work that provides novel neural engineering solutions that can provide new and more effective biomarkers in neurodegeneration.
- New collaborations include work with the ADAPT centre, and the formation of the European TRICALS Consortium, the purpose of which is to pool our resources across Europe to develop new and more effective strategies for clinical trials, including a multimodal platform that will collect and store patient data, and through which new investigator-led trials of new therapeutics will be administered.



Trinity MND team on the eve of the walk

Fr Tony Coote's Walk While You Can Raises €520k

In November 2017 Fr Tony Coote, then 53, had a fall which he thought nothing of at the time, but when it became a regular occurrence he went to the doctor and by spring 2018 he had a diagnosis of Motor Neurone Disease.

Fr Tony is a former College Chaplain of UCD and of Ballymun Comprehensive School, now based in the parishes of Mount Merrion and Kilmacud; a much-loved leader, he is well used to mobilising the community for a good cause. Once he had overcome the shock of his diagnosis he decided to take action to raise awareness of MND and funds for two key areas; as he explains: "One – there are only three nurses in the whole of Ireland working with people with MND, 400 people in total, and two, the medication that MND patients have is 24 years old, so unless there's research, there will be no hope for people in the future."

Fr Tony came up with a grand-scale plan for a 550km "Walk While You Can" walk, winding from Letterkenny, Co. Donegal to Ballydehob, Co. Cork, with the target of raising €250k to benefit the Irish Motor Neurone Disease Association and research into the condition conducted by Trinity MND research team. On 10 July 2018 Fr Tony and hundreds of supporters including Professor Hardiman and her team, along with volunteers from the Irish Motor Neurone Disease Association (IMNDA) and the SFI FutureNeuro Centre, set off on the first of 28 stages that would take four weeks to complete. People from all over the



On the walk



Fr Tony Coote presents a cheque for €520,000 to Róisín Duffy Chief Executive of IMNDA and Trinity Professor of Neurology Orla Hardiman, with Caroline Garrett (L) and Robert Brown (R)

country answered the call to join the walk and donations continued to flow in after it ended in Ballydehob on 6 August, helping Fr Coote to raise over €500k (€1,000 for each km of the walk), double his original target.

Sadly, Fr Tony's own condition is progressing rapidly, but he continues to help fundraising efforts for the pan-European TRICALS project, in which MND research centres across Europe are sharing expertise to develop more effective trials and personalised treatment for people with MND. At least 25 new drugs are in various early phases of testing, some by drug companies, and some by academic research centres such as Trinity's.

Professor Hardiman explains the importance of TRICALS: "Now is the time to move to a new precision-medicine-based approach towards treatment, but to achieve this we need a radical change in how we approach our research. We

now recognise that it is essential for MND researchers across Europe to join forces to capitalise on our individual strengths and to build on new and creative approaches that enhance our collective scientific expertise. It is also imperative that we include those, such as Fr Coote, who are experiencing the disease first-hand. By working together we have a better chance of succeeding in our shared goal to find a treatment for MND. We want to have the right drug in the right dose, for the right patient at the right time."

On 22 November the RTÉ TV documentary, aptly named *Walking the Walk* was screened in Trinity. A moving tribute to Tony Coote's efforts, the documentary aired on 6 December and is available on RTÉ Player.

To donate please visit https://www.idonate.ie/fundraiser/11368954_walk-while-you-can.html

The Andrew Lydon Scholarship in MND Research

On 21 September 2018 the Academic Unit of Neurology, Trinity College Dublin, held a ceremony to mark the establishment of a PhD Scholarship in memory of Galway man Andrew Lydon.

The four-year scholarship will support a PhD Scholarship in Motor Neurone Disease Research, and has been awarded to the Academic Unit of Neurology, TCD, by the Andrew Lydon Trust.

Andrew Lydon was a young Connemara-based computer programmer and father of two teenagers. He was diagnosed with motor neurone disease in 2010. By 2015 he had developed breathing problems that required invasive mechanical ventilation

requiring a lot of support to allow him to live at home. Andrew's community in An Cheathru Rua, Galway, set up a trust fund to raise money to make that happen.

Sadly, and after a long battle, Andrew passed away in December 2017 before it was possible for him to get home.

Andrew's family and community have now decided to establish a scholarship in his name to commemorate his life and his long and courageous battle with MND. Mary Lynch McDonagh and the members of the Andrew Lydon Trust, along with Andrew's wife Sally and his children Seosamh and Molly attended the ceremony in Trinity College on 21 September.

Dr Rangariroyashe Chipika, recipient of the scholarship, will pursue her PhD focusing on changes in Brain Imaging and Signal Analysis in MND. Professor Peter Bede, who is supervising Dr Chipika's work, was one of Andrew's doctors, along with Professor Orla Hardiman, Head of the Academic Unit of Neurology. "Andrew was a truly special person," said Professor Bede. "It is fitting that this scholarship will focus on computational analysis of imaging signals. Andrew was a brilliant computer programmer, and I had many long discussions with him about computers, coding and technology as he participated in our brain imaging studies."



Andrew Lydon's family with the Trinity research group

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 2018 SUPPORTERS:

- Fr Tony Coote and Walk While You Can
- The Andrew Lydon Trust
- The Iris O'Brien Foundation
- The Irish Motor Neurone Disease Association (IMNDA)
- Air Corps Charity Golf Outing in Grange Castle Golf Club, organised by Lt. Col. Retd John Hughes
- Maura McHugh and Friends, Donegal
- The Good Run, organised by Olivia Sexton
- Hähnel Industries in memory of Mr Walter Hähnel
- Rosemary McCarthy
- Ann McElwain
- May Langton
- Lisa Perkins



Cheque presentation for The Good Run 2018 by David Treacy and Olivia Sexton of The Good Run Organising Committee to Mark Heverin (Project MinE) and Gemma Watts (IMNDA) with Roy Barrett (MD of Goodbody Stockbrokers) pictured at centre