

2020 was for all of us a year like no other. It was particularly challenging for those with MND and their families. With COVID-19 restrictions in place, appointments had to be moved online and services limited. However, while clinical work was somewhat disrupted, the clinical team rapidly adapted to the new restrictions,

and teamed up with nurses from the IMNDA to provide a national service that delivered very high-quality care across the country. In the main, the research efforts by the MND Research Group at Trinity also proceeded as planned. We are also delighted that the activities of Research Motor Neurone (RMN), our charity, continued

under the leadership of the RMN board headed by Dr Rozanne Barrow. We would like to use this opportunity to thank all members of our community for the ongoing support for MND research despite difficulties. Your loyalty and dedication inspire us, researchers, to try harder. Below are some 2020 highlights.

OUR SINCERE SYMPATHIES TO THE FAMILIES OF THOSE WHO LOST THEIR LOVED ONES.

TRICALS Update

In November 2019 European MND/ALS Centres have joined forces to build new and creative approaches that enhance the collective scientific expertise to make MND a manageable disease through TRICALS (www.TRICALS.org), a large-scale European research consortium of 42 top research centres in 16 countries aimed at development of effective treatments for MND.

TRICALS centres are working together to conduct clinical trials of drugs for which there is scientific basis for exploring MND, but which are of limited commercial interest to drug companies. While separate countries might not have enough patients to test drugs' efficacy, pan-European trials will provide the required scientific evidence based on the adequate numbers of patients enrolled across centres.

TRICALS is about to begin two investigator-initiated trials. The first is of the compound TRIUMEQ, which is used in the treatment of HIV. There is evidence from studies in Australia that this drug may slow progression in ALS. Designing a clinical trial is expensive and time consuming, and each study needs to be approved by the regulatory agencies in Europe and in local countries.

The TRIUMEQ study (entitled Lighthouse 2) was scheduled to commence in Q3 2020,

but the restrictions imposed by COVID have precluded this, and the revised scheduled start date is at the end of Q2 2021. Additional TRICALS sponsored clinical trials scheduled for 2021 include the use of Lithium in those with ALS who have a specific genetic profile, and later in the year, studies using other repurposed compounds including combinations of antibiotics.

The cost for each Irish person who participates in TRICALS trial is €18,000. This covers doctors, nurses, drug management, safety monitoring, insurance costs and follow up for the duration of the study.

Over the coming two years, we aim to raise €500,000 to support

the clinical trials participation of Ireland-based patients with MND.

Apart from the clinical trials, the Irish research group is leading the TRICALS effort to create an ICT platform for the clinical trials to be applied across all sites. It is being done in conjunction with the ADAPT Centre at Trinity College Dublin, along with industry partners, and will cost €9.8million.

For more on the TRICALS Lighthouse trial see: www.tricals.org/trials/the-lighthouse-2-trial/

TRICALS Towards a cure



TRICALS Consortium Executive

Pat Fogarty & Friends Golf Classic

In the face of adversity brought about by the MND diagnosis, Pat Fogarty of Herbertstown, Co. Limerick, who died on 21 January 2021, decided to do everything in his power to help expedite MND research into this so far incurable disease. Realising that clinical trials is the most effective way to find treatments, during his last months Pat generously put his energy in raising much needed funds.

A committee of determined volunteers led by Pat persevered with the organisation of a golf classic in support of RMN and the MND Research Group at Trinity College. It was held over two lovely days in September of 2020 in Dromoland Castle. Even though the restrictions meant no socialising away from the golf course,

90 teams came out in force, supported by many celebrities from the world of sport.

As an avid sportsman and a sports fan, Pat believed in sports as a vehicle that brings people together to share the moments of competitiveness and joy. Pat attracted a number of beloved personalities and sports legends to participate in the golf classic to make it an outing to remember.

€90,000 raised will go directly to research and will benefit the participation of the Irish patients in pan-European clinical trials (TRICALS) in an effort to expedite the research to make MND a manageable disease. Pat's legacy is tremendous and motivates us to continue our search for solutions.

Our deepest sympathies to Pat's wife Deirdre and daughter Marsha and the whole family on their loss. May he rest in peace.



Deirdre & Pat Fogarty are presenting Orla Hardiman with the cheque

Healey Centre International Prize for Innovation in ALS to Professor Orla Hardiman

Professor Orla Hardiman was honoured, as part of an international collaboration, with the second annual Healey Centre International Prize for Innovation in amyotrophic lateral sclerosis (ALS/motor neurone disease). Professor Hardiman is part of an international team, the Project MinE Consortium, developing the largest single disease whole genome sequencing project in the world. The team have sequenced the genomes of 22,500 people to increase our understanding of the genetic variations that alter the risk of ALS/MND as well as other

clinical aspects of the disease. The impact of this sequencing is tremendous as the genes identified from this collaborative effort are currently and actively used in diagnostic tests, gene therapy and drug discovery efforts in the field. The award was presented virtually at the 31st International Symposium on ALS/MND. On receiving the prize, Professor Orla Hardiman said, "As an early participant of the Project MinE Consortium, and on behalf of my colleagues in Genomics led by Dr Russell McLaughlin, I am truly honoured that we have been

awarded the prestigious Healey Foundation Award for Innovation in ALS Research. Understanding the genetic factors that contribute to this devastating disease will be pivotal to finding new treatments. And by combining genetics with clinical information, we are definitely making progress. We will continue to work hard with our European colleagues to make ALS a treatable disease." For more information about Project MinE please visit www.projectmine.com



Peter Bede

Peter Bede Appointed Professor in Computational Neuroimaging

We are delighted to announce a new appointment in the Unit of Academic Neurology – Professor Peter Bede, whose ground-breaking research using brain imaging has been contributing to the understanding of MND. Professor Bede has an international reputation as a world-class research clinician scientist, and his work focuses on new ways to make earlier

diagnoses, and to identify patterns of changes in the brain that might be used to test the effects of new treatments. Professor Bede's work complements that of Dr Bahman Nasserroleslami, Fr Tony Coote Assistant Professor of Signal Analysis, whose research focuses on change in brain wave patterns in MND.



Roy Taylor

Watch Your Back MND

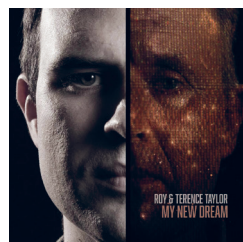
After being diagnosed with MND in April 2018, Roy Taylor decided to roll up his sleeves and campaign for RMN. Together with his son Terence, he set up an initiative called Watch Your Back MND with the sole aim of raising funds for RMN. In February 2020, Watch Your Back MND put on a fantastic sold-out concert with RTE Radio One's Ronan Collins and The Sugar Cubes band in Erin's Isle GAA Club, Dublin raising over €7,000.

Watch Your Back MND joined Pat Fogarty and his incredible family and friends in September to support the Research Motor Neurone Golf Classic in Dromoland Castle.

Roy and Terence, being musicians by trade, decided to use their musical talents to campaign for MND research. In October 2020, they released an original song called "My New Dream". A hard-hitting emotional anthem

telling the story of a father and son dreaming of the day that MND is finally defeated. Hence, the initials of the song – MND. The song and music video exploded online taking the song to No.1 in the Irish iTunes Charts!

Towards the end of 2020, Roy and his band of musician friends recorded a song in honour of Scottish rugby hero and avid MND campaigner, Doodie Weir. The track is



Cover of the song by Roy & Terence Taylor

called "Doin' It For Doodie" and will be released early 2021.

To date Watch Your Back MND has been involved in fundraising over €140,000 for RMN.

hähnel industries support in memory of Mr Walter Hähnel

Mr Chris Hähnel of hähnel industries has been generously supporting Project MinE since the MND Research Group at Trinity partnered with the Netherlands colleagues in 2014 to launch it. The donations are in honour of his father, Mr Walter Hähnel, who died of MND.

hähnel Industries are one of the leading manufacturers of award-winning, high quality, photographic accessories. Their experience in the photographic market dates back to the early 1950s when hähnel was first founded.

From humble beginnings as a distributor of professional movie equipment in Köln, Germany, hähnel progressively developed over time and has had many achievements including being the first to develop the world's only Motorised Splicer for editing 8mm film and a slide viewer with a built-in screen. Hähnel also designed the first and only optical zoom light and then progressed shortly afterwards into the charger market with the Pro 9000 high tech charging technology and thereafter developed the world's first plug-in charger for Lithium-Ion batteries, the Digital PowerStation DCL.

In 1958 hähnel started trading under the hähnel logo in Germany and in 1975,

they opened up a production company in Bandon, Co. Cork, Ireland, which has progressively grown over the years. In June 2007 hähnel industries ltd. opened their new offices in Bandon. The hähnel headquarters remains in Co. Cork with shipping to Ireland, UK and Europe.

hähnel industries have well-established distributors throughout Europe with over 20 countries now representing the hähnel brand.



Mr Walter Hähnel



Maura McHugh

Maura McHugh, RIP

We would like to extend our deepest sympathies to the family of our long-term supporter and a good friend Maura McHugh (1960-2020). Maura will be missed by all who had the privilege of meeting or knowing her.

An angel taken before her time

She only ever saw the best in everyone and

Gave her best to everybody – friend or stranger.

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

activities and motivates its staff to volunteer. It also nominates three charity to support each year. Its trucks carry logos of charities supported by the Careys Foundation.

The lorry with RMN colourful branding was going around its business all over the UK. The £26,000 that has been generously donated by the Careys Foundation will be used to support enrolment of the first Irish patient into TRICALS.



The colourful RMN branded lorry

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 2020 SUPPORTERS:

- Analog Devices
- Blanchardstown Centre
- Careys Foundation
- Fr Tony Coote and Walk While You Can
- CUBE Design. Print. Package
- Dell Technologies
- Duggan Systems
- Mary Doran's Estate
- Una Duffy
- Pat Fogarty & Friends Golf Classic
- FOXCONN
- hähnel industries in memory of Mr Walter Hähnel
- The Hayes Family
- Anne Heffernan's Estate
- Irish Motor Neurone Disease Association (IMNDA)
- Interchem Ireland Limited
- Lyons of Limerick
- My Name's Doddie Foundation
- Rosemary McCarthy
- Maura McHugh and Friends, Donegal
- Louise O'Connor
- Partners at Law
- Lisa Perkins
- PROTECTiT
- Sanofi
- Roy and Terence Taylor (Watch Your Back MND Initiative)
- The Andrew Lydon Trust
- The Good Run, organised as a virtual event in 2020 by TRICALS Céad Míle Fáilte
- The Iris O'Brien Foundation
- TRICALS Céad Míle Fáilte
- Upperchurch - Drombane Development and District Association Tractor Run 2020