Irish
Motor
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Disease
Association

# CONNECT

ISSUE 27 | WINTER 2024

The latest news, views and
information from IMNDA

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# IMNDA DIARY DATES

## FOR OUR 40 YEARS OF CARING 1985 -2025

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40 Years of Caring 2025

### DECEMBER:

Light up a Star on our Christmas Memory Tree

Light up a Star
on our
Christmas Memory Tree
fundraise.imnda.ie/event/christmas/home

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### MARCH:

Drink Tea for MND, Exclusive Afternoon Tea

**Powerscourt Hotel:**
**29th March**
**2025**

### APRIL:

Memorial Service 26th April 2025

*IMNDA*
*Annual Memorial Service*
**26th April 2025**

### MAY:

Our 40th anniversary - 40k Your Way in May Challenege

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40 Years of Caring 2025

1st May 2025 is the 40th anniversary of the IMNDA.
Will you take on the '40k Your Way in May' challenge?

### JUNE:

Voice4MND

#Voice
4MND
40 Years of Caring
1985-2025

### JUNE:

Global Awareness Day

### OCTOBER:

AGM & Annual Conference 3rd October 2025

Irish
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Neurone
Disease
Association
40 Years of Caring 2025

40th IMNDA Annual
Conference & AGM
Friday 3rd October 2025

**FOR MORE SEE IMNDA.IE**

# A NOTE FROM OUR CEO

Hi everyone,

As the new CEO of the Irish Motor Neurone Disease Association (IMNDA), having joined this incredible organisation in June 2024, I wanted to take a moment to share how delighted I am to be in this role. Over the past few months, I've had the privilege of meeting many remarkable people within the MND community, and I have been constantly inspired by your bravery and resilience. It's truly humbling to witness the strength and determination that exists in every corner of this community.

A huge thank you to everyone who attended our 39th Annual Conference on October 4th. I hope the event provided useful information and insights while also offering moments of connection and support. We aimed to ensure the day was both informative and enjoyable, and I trust many of you walked away with valuable takeaways (and perhaps a smile or two).

### Awareness and Challenges

One of the key areas IMNDA continues to focus on is early diagnosis. While there is still no cure for MND, early diagnosis can help manage symptoms and improve quality of life. Raising public awareness is crucial to ensuring more people understand the disease and seek help earlier.

We're also continuing our advocacy efforts, pushing for increased funding from the government and HSE to support MND research. Research offers hope for the future, but it requires sustained investment if we are to get closer to finding effective treatments or, one day, a cure.

### Walk While You Can (WWYC) Initiative

Another initiative close to our hearts is the "Walk While You Can" campaign. Started by the late Fr. Tony Coote in 2018, this campaign has raised over €500,000 for MND research and care, with €150,000 coming from last year alone. Fr. Coote's vision continues to inspire us, and we are proud to carry on his legacy through this impactful event. This year, we are grateful to have Kevin and Margaret Carroll as our ambassadors, bravely sharing their journey with MND to raise further awareness.

### Key Findings from the 2023 IMNDA Annual Report

Our 2023 Annual Report highlighted some important figures: over 600 families were supported by IMNDA last year alone, with our nurses making 1,070 home visits and nearly €875,000 spent on specialised equipment. We are proud that 89 cents of every euro we raise goes directly toward services for people with MND. We also raised over €2.7 million in total, which will help us continue providing much-needed support and services to the growing number of families affected by MND.

### IMNDA Conference Highlights

The recent Annual Conference was a powerful reminder of the importance of collaboration. We heard from experts like Prof. Peter Bede on brain imaging and Prof. Orla Hardiman on clinical trials, both offering critical insights into the latest research. But it wasn't just the experts who left a mark—the stories shared by families living with MND reminded us all of the deep sense of community that helps carry us forward in this fight.

### Government Policy and Support

We are continuously advocating for stronger support systems, particularly in areas like disability care, home adaptations, and access to specialised services. Many families face significant challenges, including financial strain and long wait times for necessary home adaptations. Our work with policymakers will continue to prioritise these issues, ensuring that the needs of people living with MND are not overlooked.

### Looking Ahead

As I look to the future, my vision for IMNDA is to keep growing our services, advocating for more research funding, and ensuring we remain a sustainable organisation. We will do everything we can to support people with MND and their families while continuing to push for advances in care and treatment. I encourage everyone to stay involved, whether by donating, volunteering, or simply spreading awareness.

While we know there are still tough questions ahead, especially as there is currently no cure for MND, we will never stop pushing for progress. Our guiding principle is simple: "Until there is a cure, there is care." Every day, we strive to improve the lives of those living with MND through practical and compassionate support.

Warm regards,

**Kevin Burn**
**CEO, Irish Motor Neurone Disease Association (IMNDA)**

# IMNDA AGM & ANNUAL CONFERENCE DUNDALK

In October of this year, IMNDA's AGM and Annual Conference event took place in The Fairways Hotel in Dundalk. We had a wide range of speakers and exhibitors at the event. It was well attended with over 200 delegates in person as well as members joining us on Zoom. The business part took place early on Friday morning where the IMNDA's Board of Directors reviewed the operations and financial performance of the organisation in 2023.

This year's AGM also included the rotation of Directors and sadly we had to say goodbye to Katie Hallissey who has been a board member since she joined in December 2012, where she served her time as Company Secretary. Also, Bernie Conolly served as a board member since she joined in November 2013, as well as a clinical specialist on the advisory panel to IMNDA.

We would like to take this opportunity to thank Katie Hallissey and Bernie Conolly for their commitment to the IMNDA over the years. There was never a task too big or small for either of these ladies, they have been a huge support to the staff over the years and we thank them for all their help.

Following the formalities of the AGM, we were then treated to a very interesting conference with a variety of speakers MC'd by IMNDA's board member Jonathan Healy. Jonathan introduced the IMNDA's new CEO, Kevin Burn. Kevin talked about how moved he was when he entered the organisation as the new CEO. He spoke about the knowledge and skills of the staff and how he was met with a wave of passion when he walked through the IMNDA door. He then talked about the MND community itself, the people that are living with the disease and the strength and resilience within this community which he finds truly inspiring. He also spoke about the importance of the caring for caregiver's programme and the volunteers and ambassadors who bravely share their powerful stories. He then went on to talk about the Irish Life charity partnership and the importance of networks like this to help with fundraising. He concluded on the sad passing of Charlie Bird earlier this year.

Up next was Shaun McCormack from Safecare Technology who spoke about Technology and what it can do for you. How it can keep you working and keep you connected. It can also keep you in control which in turn ensures you can participate in what's going on around you. He also spoke about voice banking and message banking availability, for more on this topic, you can get in touch with services department in the IMNDA.

Up next to the podium was Prof Peter Bede, from Trinity College & St James's Hospital in Dublin. Peter is also the IMNDA's Medical Patron. He presented a very visual talk on Brain Imaging & EEG (brain connectivity) Research. He talked about the collaborative approach that is now used as Brain imaging in ALS/MND which used to be very academic with limited clinical relevance. In the last 2-3 years this has changed and has helped to become a meaningful tool to aid the diagnosis of MND and predict the outcome when it comes to therapy.

We then had Catriona Dixon to the podium who gave us a very moving account of her MND story. She was diagnosed with MND in 2023, and she shared her experience of life with it so far. From Gorey in Co Wexford, Catriona talked about how 'MND lives with me.' She talked about her early symptoms and how she got whiplash after a fall at work. She couldn't understand how this had happened, so she went to her GP who referred her on to see Prof Orla Hardiman. Christmas week was the most difficult week for her, as she had to tell her children. She then told her family, her friends, and her work colleagues. She still felt however that it was getting out of control until she 'announced to the world that she had MND.' She then decided to open up her house and have a coffee morning, people came and talked and shared stories, there were hugs and tears, but from that point onwards, she decided that MND was living with her and not the other way around.

We then had Dr. Annette Lloyd, who is a Senior Clinical Psychologist specialising in MND, from Beaumont Hospital in Dublin. She talked about 'The Psychological Impact of MND.' She told us how everything she has learned about MND is through the collective experience of those who are living with the condition. She spoke about how psychology is one of the most hidden aspects of MND in her experience. She talked about the MND journey and that there is no right or wrong way to cope with the disease and that individual impact is different for everyone. Some people have experienced loss in their lives before and some people have not.

We were then treated to findings from the Ice Bucket Challenge: 10 Years Later which was presented by Fiona Thornton who is Head of Advocacy and Communications in the IMNDA. Fiona talked about how IMNDA partnered with iReach and conducted a survey which delivered some interesting results; 50% of people remember the Ice Bucket Challenge and feel it led to increased awareness of MND. 50% of the people that responded took part in the Ice Bucket Challenge. 1 in 5 know someone with MND and 41% are more familiar with the services that the IMNDA provides.

We then had the experience of listening to Catherine Jennings who delivered a talk on The Caregiver Experience. Catherine is wife and caregiver to her husband Barry Jennings. Catherine talked about their story and how every journey is individual and painfully unique. She spoke about how being a caregiver had been one of the hardest things she has done but that it also has its rewards too. She then went on to talk about The Caring for Caregivers course that is run by the IMNDA and how useful she has found this. She talked about being open to help, but that it should be help that helps you, and not hinders you and not to be afraid to put boundaries in place when people offer help. She said to continue to do things that you both enjoy and focus on what the person with MND can do. She concluded that the Caregiver matters just as much as the MND warrior.

Next up to the podium was Prof Orla Hardiman, she is the Professor of Neurology at Trinity College Dublin, and a Consultant Neurologist at Beaumont Hospital. Prof Hardiman delivered the most interesting talk on the Latest News on Precision ALS & Genetics. She spoke about 'What are we trying to do to move forward in MND?' We can cure MND in mice, worms and flies, but why can't we cure it in people? Where should we be going – Precision ALS is about getting the right drug to the right person, with the right dose at the right time. TRICALS was set up to which Prof Hardiman is the chair of and this involves working with 62 centres across Ireland and the rest of Europe. The reason this was set up was because: even though we have a register of

2,500 people over the last 30 years, it still isn't enough people or data to work with, but by combining data from all these centres, this provides more information to the clinicians so that they use a more precision based approach to treat MND just like they have done with Cancer.

Finally, to the Podium was Tara Agnew from Irish Life, she talked about financials and the importance of planning for your future. She advised finding the right person with the right qualifications, someone you can trust, someone you get on with.

All our presentations, including the panel discussion which took place after all the talks, are available to view on our YouTube Channel @MNDireland.

We want to take this opportunity to thank all the speakers who took time out of their day to come to our Annual Conference in Dundalk. We would like to thank all the organisations that took stands and spoke to our members. These organisations were: Family Carers Ireland,

Irish Wheelchair Association (IWA), Motability Ireland, The Academic Unit of Neurology in Trinity College Dublin (TCD), Task Community Care, Safecare Technologies & Irish Life.

And finally, thanks to audience in the room and all of you who joined us online. Together we created a conference full of knowledge, working to provide care & support to those living with MND in Ireland. Once again, the conference is now available on our YouTube channel @MNDireland.

Following on from the Conference that morning, two workshops took place in the afternoon, one for caregiver's and one for people living with MND.

Mary Scarff facilitated this caregiver's workshop following the successful Caring for Caregiver Online Programme this year. This was the second time we held an in-person workshop for caregivers and family members at our annual conference. A packed room of people attended the workshop and Mary discussed anticipatory grief, trauma and anxiety, self-talk, relationships, conflict, sleep and the process of change. The interactive workshop was a special opportunity for everyone to learn from each other and share their unique experiences. We look forward to hosting more in person events in the future. The next Caring for Caregivers Online Programme facilitated by Mary Scarff will take place in Spring 2025.

The IMNDA held a workshop for People with MND because of the survey What Matters to You. This highlighted the need for a peer support group for those living with MND. The purpose of the workshop was to create connection, social engagement and belonging amongst those living with MND. We chose five topics from the survey which included Equipment, Coping with MND and Emotional Support, House Modification, Living with MND- getting out in the community and complimentary therapies.

Naomi Fitzgibbon, Director of Nursing & Service, along with Dr Annette Lloyd, Clinical Psychologist from Beaumont Hospital introduced the workshop. The IMNDA nurses facilitated each table of participants where the conversations were open and honest with a mix of tears, laughter, and incredible insights into living with MND.

Please complete the evaluation form coming your way. We will review your feedback for the next workshop in 2025.

# MARKING GLOBAL AWARENESS DAY 2024

In June, as with other countries across the globe, we marked ALS/MND Global Awareness Day with an event for our members, including people living with MND in Ireland and their families.

We held a reception in Salesforce office which is in Dublin's docklands area. We were joined by the then Lord Mayor, Daithi DeRoiste along with the Academic of Neurology from Trinity College Dublin and our MND community.

This event highlighted new developments within IMNDA such as the announcement of our new CEO Kevin Burn. It also included insights into MND Research, which was led by Dr Miriam Galvin. After that Lesley Doyle, Speech and Language Therapist spoke about Patient Public Involvement (PPI) and was also joined by client Michael Clancy. Catriona Dixon delivered a very moving story of her MND experience. Irish Life staff charity committee member Cormac Donnelly gave us an insight into the current partnership between our organisations. There were updates from the Charlie Bird Development Fund (CBDF) by Director of Nursing, Naomi Fitzgibbon and finally results of the Voice Banking Survey by Fiona Thornton, Head of Advocacy & Communications.

During this event, we presented Appreciation Awards to our fantastic community for their incredible efforts in raising awareness of MND and funds for IMNDA. The then Lord Mayor Daithi DeRoiste presented each of them with a small plaque as a token of the IMNDA's appreciation.

We also used the platform of Global Day to launch our annual Voice for MND campaign. Alongside the fundraising element of the campaign this year, where we encourage people to lose their voice for a period of time to give people with MND a voice, we also wanted to highlight the personal impact of this symptom. We wanted to focus on how a deterioration in voice for people with MND can affect their confidence and social interactions, and how more awareness among the general public can lead to wider recognition of a deterioration in voice as a symptom of MND.

We put together a survey to gain an insight into what people with MND and their family's thoughts and experiences were on voice deterioration for people living with MND. We received a very high response rate with hard-hitting results including the fact that three quarters of people with MND have their confidence affected and a worrying 42% saying they avoid social situations because of it.

At the Global Awareness Event in Salesforce Offices, we delivered a presentation on the findings. This survey helped to inform us for our Voice for MND campaign this year and we would like to express our sincere thanks to all who contributed to it. The full results of the survey can be found on our website; www.imnda.ie













We would like to take the opportunity to thank Salesforce for inviting us into their offices and allowing us to use the space to host our Global Day Event. We would also like to acknowledge all the Salesforce volunteers that helped us on the day. Our MND Global Day Event was recorded and is available on our YouTube Channel, @MNDireland.

# TCD PUBLIC AND PATIENT INVOLVEMENT ADVISORY PANEL FOR MND RESEARCH

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. Under the leadership of Prof. Orla Hardiman, the MND research team in the School of Medicine, Trinity College Dublin, have established the first Irish PPI advisory panel for MND research. This panel 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.

Research involves many stages from planning how a study will run, to gathering and analysing data (information), and sharing the results. PPI is different to being recruited as a research participant; it does not involve providing data for a study. PPI contributors are frequently involved in the planning stage. 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.

As of September 2024, the panel has 19 active members; 14 people who have been diagnosed with MND and 5 family members. When a researcher wishes to consult the panel, they prepare a meeting or task description. This is circulated to panel members who can then express interest in that activity. PPI contributions take several formats with a variety of ways for panel members to communicate opinions. So far, the types of activities panel members have participated in are:

- Discussion of research study protocols: Researchers prepare protocols when planning a study to describe exactly how, when and where participants' data would be collected. Feedback was gathered separately for two upcoming MND studies, one which will involve at-home use of technologies for self-assessment of physical function and one involving focus groups to gather opinions to aid the design of a telerehabilitation platform. During online group meetings, aspects of the study designs were discussed. Study protocols were then amended based on panel input.
- Reviews of information leaflets: Before joining any research study, potential participants must be provided with an information leaflet that clearly explains exactly what participating would involve. Panel members reviewed draft versions of participant information leaflets in their own time and provided individual comments via email or video calls with a researcher. PPI comments were used as the basis to reword phrases that seemed too technical, remove unnecessary repetition or add clarifying information.
- Trial runs of research methods: Prior to collecting participant data when a new study launches, it is useful to do a live run through of planned processes to test them out. Panel members acted as faux-participants and helped rehearse a variety of data collection protocols. These included piloting a survey; trialing a procedure to speak thoughts aloud while using an MND symptom-tracking platform; and participating in practice assessments of physical functions using questionnaires and technologies. These trial runs helped researchers to clarify participant instructions, adjust data collection forms and amend assessments if any of these aspects were reported as uncomfortable or hard to follow.
- Presentation of information about the panel: Due to the collaborative nature of engagement between researchers and PPI contributors, panel members have an important role in promoting the panel and have co-presented with a researcher at MND community events.

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.

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 aim to host similar annual events for all active panel members as well as those considering joining in the future.

If you would like to join the panel, receive an information leaflet or receive details about the annual information event, you can email Aisling at researchmnd@tcd.ie. The MND research team look forward to hearing from you.

## Study on how the presence or absence of genes associated with MND affects the brain - Dr Narin Suleyman

Dr Narin Suleyman of the Discipline of Physiology at Trinity College Dublin has 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, she will test how brain cells communicate with each other by looking at brainwaves recorded during a variety of thinking and language tasks. She will also explore 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 is currently looking for volunteers over the age of 18, who do not have MND themselves but have two or more family members affected by MND. Volunteers would be asked to relax in a chair for 2-3 hours at a time while their brainwaves are being recorded and/or while their brain is being stimulated. They would additionally be asked to provide a small amount of blood for genetic testing. Results from genetic tests will not be shared as they are collected for research purposes only. If you are interested in volunteering, email Dr. Narin Suleyman at info@mcmackinlab.com for more information.

## Index-eTap: improving measurement of hand dexterity in MND. - Dr. Conor Hayden

Index-eTap is a novel device to objectively measure hand dexterity. It was featured in the Autumn 2023 edition of this newsletter. The device was developed in the Unit of Neurology along with the School of Engineering in TCD. It was developed by Dr. Conor Hayden, a biomedical engineer and postdoctoral researcher, employed by PrecisionALS, as part of his PhD research under the supervision of Dr. Deirdre Murray and Prof. Bruce Murphy.

The device digitises the conventional Finger Tapping Test—a widely used neurological evaluation. Participants place their index finger on their thumb and perform rapid, upward movements, generating a series of taps. What sets this innovation apart is its capacity to produce a dexterity score ranging from 0 (indicating minimal hand function) to 1 (representing flawless hand function).

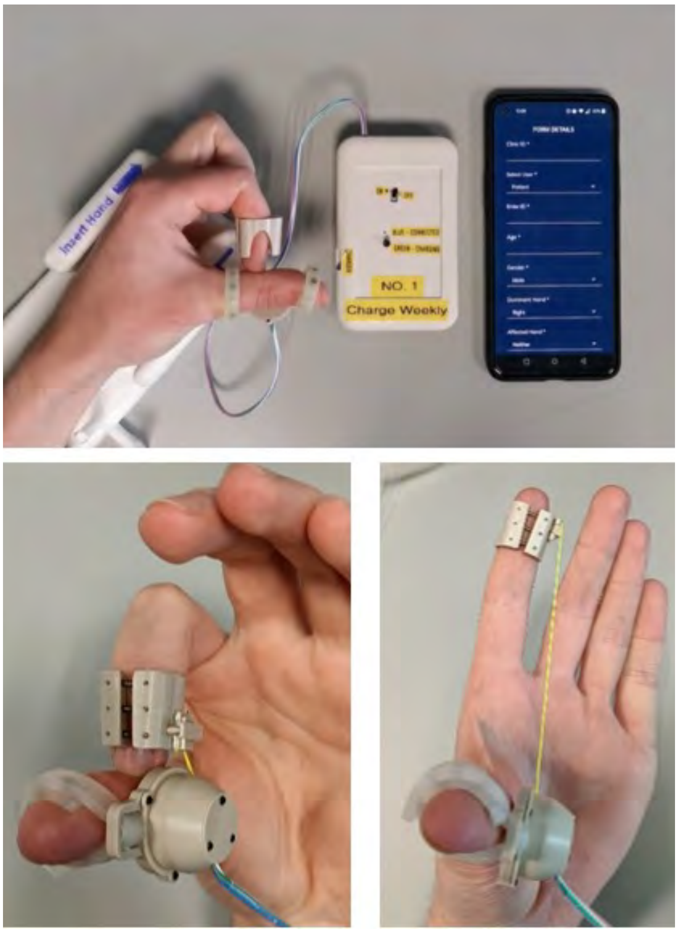
The device's development has continued during 2024. There is a patent application in place and the project received funding from Enterprise Ireland to assess the commercial viability of the device. Commercialisation is a slow process and Index-eTap is now involved with PrecisionALS (www.precisionals.ie) a €10 million euro research programme involving researchers at the SFI Research Centres ADAPT and FutureNeuro along with the TRICALS Consortium, Europe's largest ALS research initiative. Its goal is to create a pan-European Patient Data Platform, allowing research sites across Europe to work together towards a common goal of finding a treatment for ALS.

Precision ALS is divided into seven work packages, each led by a leading researcher in their respective field. Altogether, the work packages combine to make up the structure and to carry out the objectives of the overall programme.

The Index-eTap device is included in a study in work package four of the research programme. The study will begin in Autumn 2024 and focus on how digital technology can be used to measure changes in MND symptoms. This device will be utilised to see how well it can distinguish changes in hand dexterity over time.

This is an important next milestone for Index-eTap. The results from the first data collection study showed that Index-eTap, with its 0-1 score, can distinguish between people with different levels of hand dexterity. It next needs to show that it can detect changes over time, i.e., it needs to be tested on the same people over a period of time, for example every 3 months for 12 months, and see if it accurately records a person's hand dexterity, i.e., if it changes or if it stays the same. We hope to have another promising update in next year's edition.

**Figure 1:** Different images of Index-eTap showing the entire device, its mobile app and how it attaches onto a person's hand. A paper on this device has been published since the last update (https://doi.org/10.1115/1.4064583), while a final paper with all the results from the 250 individuals, including more than 50 living with MND collected during Conor's PhD, is under review and will be published before the end of 2024.



## Study launching exploring how digital technology can be used to measure changes in MND symptoms over time

Professor Orla Hardiman, Dr Dara Meldrum and Dr Deirdre Murray are launching a new study exploring how digital technology can be used to measure changes in MND symptoms over time. The study is being done as a collaborative project between the SFI funded PrecisionALS programme (www.precisionals.ie) and the HRB funded MIRANDA collaborative doctoral award programme, as well as with the support of the NeuroInsight programme.

The study will be 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 pick up small changes that can occur, and in the digital age is outdated.

The study will ask 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.

These technologies will measure physical function including walking, speech, swallow, hand strength, breathing and hand dexterity. There will also be some questionnaires about health, symptoms of MND, and the participants' experience of using the different technologies.

Researchers need to make sure that these technologies work effectively, that people want to use them, and that they find them easy to use. 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.

This study will begin recruiting 60 participants starting in Autumn 2024. If you are interested in hearing more about this project, and potentially participating, then please contact the research team at technologystudy@tcd.ie

This study will be run by a team of researchers in Professor Hardiman's group.

Lesley Doyle is a clinical specialist Speech and Language Therapist who previously worked in the national MND service in Beaumont Hospital. Her research is focused on how digital technologies can be used to measure speech and swallow in accurate but low burden ways for people living with MND. These technologies could potentially be used in the future for home monitoring between clinic visits and as precise ways to track symptoms during clinical drug trials.

Emily Beswick recently joined the team as a NeuroInsight postdoctoral fellow, jointly funded by the European Commission's MSCA program and the SFI Research Centres (FutureNeuro and Insight). Her work focuses on how we can assess cognition using digitally collected speech data.

Dr. Conor Hayden is a biomedical engineer and postdoctoral researcher, employed by PrecisionALS. His involvement in this study (noted in the Index-e Tap update in this publication) is centred on hand dexterity.

David Murphy is a physiotherapist. His research aims to optimise the design of a remote monitoring system which collects patient-reported questionnaires and metrics used to plan clinical care.

David Fletcher, an engineer and systems developer, whose work focuses on the design and development of a Patient Home Health Hub, a system designed to monitor and track longitudinal changes in physiological measurements, such as hand and tongue strength, over time.

Lesley Doyle, David Murphy and David Fletcher are currently undertaking PhDs within Professor Hardiman's research team in Trinity College Dublin.

# 35TH INTERNATIONAL SYMPOSIUM ON ALS/MND

The International Symposium on ALS/ MND is taking place this December, this is the biggest annual conference dedicated to ALS and MND research. Each year the MND Association supported by the International Alliance bring together researchers from around the world to share new understanding of amyotrophic lateral sclerosis (ALS) and motor neurone disease (MND). This year's event will take place in Montreal, Canada on 6th - 8th December 2024.

The key to defeating MND lies in fostering strong collaboration between leading researchers around the world and sharing new understanding of the disease as rapidly as possible. Each year, the Symposium attracts over 1,000 delegates, representing the energy and dynamism of the global MND research community. It is the largest medical and scientific conference specific to MND/ALS and is the premier event in the MND research calendar for discussion on the latest advances in research and clinical management.

The IMNDA's CEO, Kevin Burn, along with MND Nurse, Louise Hennessy, will be representing IMNDA by attending this conference in Montreal in December.

For more information on the International Symposium and to receive updates about what's going on, please visit: https://symposium.mndassociation.org/

# LIVING WITH MND STORIES

We would like to thank all the people living with MND who have bravely contributed their stories of MND. They have helped us with our ongoing campaigns such as Drink Tea for MND and Voice4MND. Drink Tea for MND took place in March this year and it was an enormous success with over 100 tea parties organised around the country, raising a staggering €158K. Voice4MND took place in June this year raising the wonderful sum of €38K with over 60 families staying silent to highlight how MND can affect the speech.

Walk While You Can took place in October and raised a massive €100K and again over 100 families organised walks in their local areas. Thank you everyone!! Sharing a personal story has helped us to raise awareness of MND and in turn helped us to raised funds which helps us to provide the services needed by people living with MND and their families. If you would like to share your personal story, please get in touch by emailing pr@imnda.ie or telephoning the office on 01 670 5942. Read on for the personal stories from Catriona Dixon, Eileen Butler, Howard Grice and Kevin Carroll.

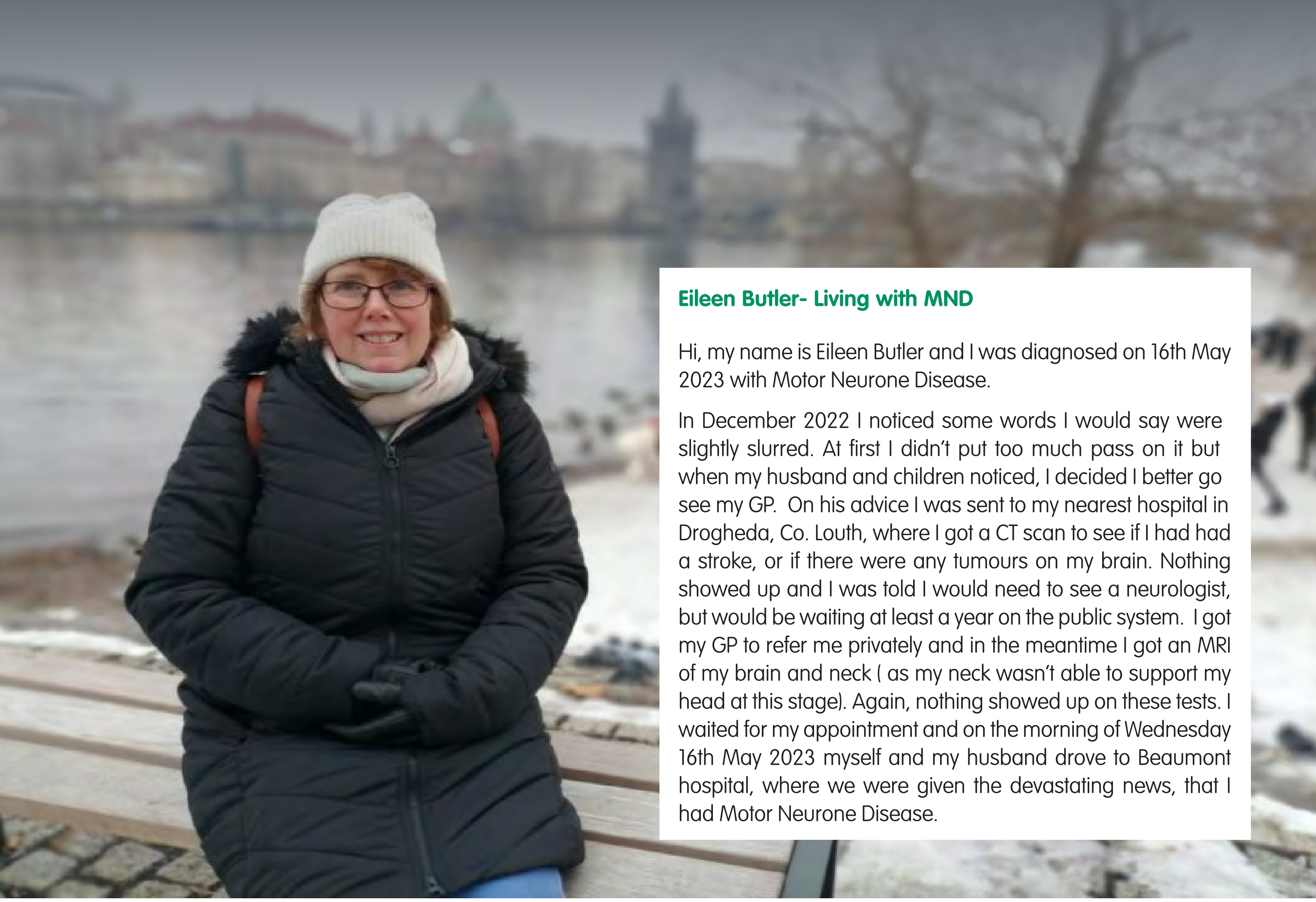
## Living with MND Catriona Dixon

Hi,"My name is Catriona Dixon; I am 58 yrs old from Gorey in County Wexford. I was diagnosed with Motor Neurone in December of 2023. Joe and I have two beautiful daughters and a great extended family. We were all devastated by my diagnosis.

I used to work full time as a Clinical Nurse Manager in a service for those with an intellectual disability. I was a coach for Special Olympics for many years and was lucky enough to attend the Special Olympics world Summer games in 2003. I always encouraged those with additional needs to be as independent as possible and to be an active part of their community. My family and I have supported positive mental health in our community and nationally for years. Though I've had to reduce some of my activities, I still remain active.

The support of the IMNDA is helping me come to terms with my diagnosis. It's an ongoing loss but I am making the best of it. I no longer work, but I intend to live fully with my condition for as long as I can. This year, I fulfilled a dream and went inter-railing across Europe, saw the Alps in Switzerland and searched for the Loch Ness Monster in Scotland.

More importantly, I have been connecting with my family, my friends, and my community. We regularly walk, talk, drink tea and connect. It really helps to stay active. I couldn't have done that without the support and expertise of the IMNDA Nurses. Their services, here in the community and in the clinics have been invaluable to me and my family. They support me to maintain my independence and live my life fully regardless of my condition.



## Eileen Butler- Living with MND

Hi, my name is Eileen Butler and I was diagnosed on 16th May 2023 with Motor Neurone Disease.

In December 2022 I noticed some words I would say were slightly slurred. At first I didn't put too much pass on it but when my husband and children noticed, I decided I better go see my GP. On his advice I was sent to my nearest hospital in Drogheda, Co. Louth, where I got a CT scan to see if I had had a stroke, or if there were any tumours on my brain. Nothing showed up and I was told I would need to see a neurologist, but would be waiting at least a year on the public system. I got my GP to refer me privately and in the meantime I got an MRI of my brain and neck ( as my neck wasn't able to support my head at this stage). Again, nothing showed up on these tests. I waited for my appointment and on the morning of Wednesday 16th May 2023 myself and my husband drove to Beaumont hospital, where we were given the devastating news, that I had Motor Neurone Disease.

We came home in a haze. Our whole future just seemed to have been wiped away in a matter of a few minutes. It just didn't seem real. I looked fine, I was able to do all my usual things but only my speech and neck muscles were affected. We cried and hugged and hugged and cried, trying to accept it. We then had the difficult task of telling our children. We have four but they are all young adults or teens. And the ironic thing is, in January 2022 I took our two youngest ones to Glendalough for a hike. One of them got a camera for Christmas and he busy taking photographs of the lovely views. We had only commented that we hadn't met anyone when a few minutes later we passed the late Charlie Bird, his wife Claire and their dog. I explained to our two boys the awful disease that Charlie had and how sad it was that his life was being cut short, little did I know a year later I would have to tell them that I had that same disease.

My parents, sisters and closest friend were all then told. Lots of tears, teas, coffees followed but the saddest thing was I realised that this disease is not just affecting me, but my whole family, my friends and I knew then we were all in this together. And a year on the support from them all and also my neighbours and the community is amazing. My house was like a florist shop at one stage with so many beautiful bouquets people had dropped in. The mantle- piece was filled with lovely cards from everyone. Everyone was and still is very considerate and caring, and I'm always been told if there's anything they can do for me, I'm to call.

And then started the different appointments and therapies and tests. So at the moment I attend Speech and Language therapy and Physiotherapy. I have a nurse from the clinic in Beaumont call out to me every month to my house and I also have a nurse call out to me from the IMNDA. These two ladies have now become friends. The kettle goes on and we have a cuppa and a chat. Their visits are so important to me as sometimes there are things that may not be mentioned in a clinic setting but in your own familiar surroundings you will be more comfortable to talk about something that is bothering you or upsetting you.

And now I am a whole year into my MND journey and thankfully I'm still mobile. I'm still able to drive which is so important to me. Yes, my speech is really bad but before it got too bad I voice banked my voice. I am now waiting to get a tablet with my own voice on it, so I will be able to still give orders around the house and keep everyone on their toes. My swallow has certainly been affected too and in March I got a feeding tube fitted. It has been a bit of a game changer. I can take fluids through it to keep hydrated, I take extra nutrition through it and also I can take all my mediation through it.

Since my diagnosis last year, my whole outlook on life has changed. The next 24 hours is not guaranteed for any of us. Yes I have a terminal illness but I'm still alive and I am living my life as best I can. I'm grateful every morning I wake up and can get out of bed myself. It mightn't always be like this I know, but for now it is.

## Howard Grice – Living with MND

My diagnosis of Motor Neuron Disease took a bit of a circular route. I'd noticed my speech was deteriorating in 2022 but I'd had Covid and then a tooth extraction and was applying the old "lets wait and see if it gets better" approach. It didn't, instead, it continued to get worse. A few years earlier I'd been diagnosed with an acoustic neuroma, a type of brain tumour, for which I'd received a course of radiotherapy. The tumour had affected my hearing and I am profoundly deaf in one ear, and severely deaf in the other. When I spoke to my GP about my deteriorating speech in 2023, we both wondered if it was in anyway caused by my tumour but to be safe he referred me to Cork University Hospital where I was admitted for a few days to undertake various tests.

When I was discharged from hospital in May 2023, the thinking at the time was that my speech may have been compromised by nerve damage following the radiotherapy for the tumour. It was agreed that I'd meet the neurologist again in a few months' time to review the test results and see if anything changed in the meantime.

Unfortunately, whilst waiting for my follow up appointment, my speech continued to deteriorate, and I started to experience a "pins and needles" type sensation in my left arm. At my follow up appointment in October 2023 the neurologist concluded that it was likely that I had Motor Neuron Disease. I was referred to Professor Hardiman's MND clinic in Beaumont Hospital, Dublin in December 2023 where the MND diagnosis was confirmed.

Those first few weeks following diagnosis were tough. A lot of emotional hurt, anger, fear, sadness, worry…the type of stuff that messes with your head and keeps you awake in the small hours with dark thoughts. I resisted the temptation to scour the internet and decided to take my information from health professionals who worked with MND.

When I had first experienced my deafness, I received a lot of support from the Cork Deaf Association, and they gave me the confidence to embrace the change in my situation and not to hide myself away but to go out and continue living life and learn how to deal with challenging situations in such a way that I could cope with them. This stood me in good stead with the MND diagnosis and I was determined to adopt a similar approach.

Telling family and friends of the diagnosis was difficult; both because of my speech issues and also the emotion that would rise to the surface during the discussion. And such conversations were exhausting, both physically and mentally. I've been actively involved with a local rugby club for over twenty years, Muskerry RFC, and know a lot of people through the club. I couldn't possible tell everyone individually of my situation so asked two people to speak with players and committee members to update them on my situation. The compassion and support I have received from the folks involved with the club has been fantastic and a major boost to my confidence to remain actively involved. My thanks to everyone there and a special mention to the club President and the Head Coach who agreed to help in speaking to everyone on my behalf.

Personal contacts aside, I have also received tremendous support from a spectrum of health professionals; the multi-disciplinary teams at the MND clinics in both Beaumont and Cork University hospitals, the community health care team at St Marys Health Campus in Cork and the Irish Motor Neuron Disease Association. This pool of neurologists, speech and language therapists, dieticians, physiotherapists, nurses, occupational therapists, social workers and others offer not only professional advice but help you realise you're not alone on your journey. Knowing there are people you can call on for assistance is a great help, metaphorically you're holding someone's hand whilst walking down a sometimes dark and difficult path, and that is very reassuring when you're feeling vulnerable.

My speech continues to deteriorate, my swallow function is getting worse, and my breathing isn't as good as it used to be. But I continue to work and remain active. I enjoy being outdoors and spend most of my recreational time hill-walking, helping out at the rugby club and in the garden.

A few friends from overseas visited me a couple of weeks ago and took me out. We went into a well-known bar in Cork city and I ordered drinks. The barmaid declined to serve me and stated I'd had enough to drink. A friend of mine stepped in and explained that I have MND and my speech was affected. The poor barmaid was mortified, very apologetic and insisted the first round was on the house as a gesture of goodwill. It was a light, humorous moment (although not for her) but brought home to me the reality of my situation.

I still try and use my speech as much as I can, but I know I can be very difficult to understand sometimes. I use the SpeakUnique and Deaf Note apps on my phone to assist with communication and have found people to be very supportive and attentive when they realise your speech is challenged.

MND support has received some high-profile coverage recently with the likes of Charlie Bird in Ireland and Kevin Sinfield in the UK doing fantastic work to highlight the condition and raise much needed funding for support organisations. They have been the "public face" of an extensive network of individuals, often unseen by the public, who support people like me, my family and others with MND.

Life goes on, it's a constant process of adaptation and some days are better than others, but I'm determined to enjoy the moment and am forever grateful to everyone who helps me along the way to achieving that.

### Kevin Carroll – Living with MND

Four years ago, I was enjoying a very active retirement. I had always been an outdoor person. I played sport in my early years, was involved in youth and community groups, did hill walking and played music - both guitar and piano. I loved travel and exploring different cultures. Indeed travel was to become a big feature of my life and the family's life, particularly with my work in the Department of Foreign Affairs and before that in Trocaire. I visited many parts of the world, especially Africa which I came to love. I was privileged to live in five different countries, four of them in Africa, the other being India. It wasn't always easy but I think living in challenging environments can make us more resilient. And that helps in later life. More importantly, I have been blessed with many happy memories of my time overseas, especially the extraordinary people I met during my career who were and are trying to make the world a better place.

I retired in 2014 but continued to work part-time as a consultant for a number of years. In addition to playing music in my local church, I joined a choral society, a hobby I would recommend to anyone who likes music. I learnt to become a better cook. I became a board member with a number of charities. My wife Margaret and I continued to travel and we walked a lot. A highlight was the Portuguese route of the Camino de Santiago, one of the nicest experiences of my life.

In 2022, I began to notice a problem when playing the piano. Some of the fingers in my left hand were losing power. I had a number of MRI scans which revealed nothing unusual. I attended a physiotherapist but the fingers continued to weaken and my left arm also became affected. Eventually, I went for nerve conduction studies at Beaumont hospital and Professor Orla Hardiman subsequently confirmed I had Motor Neuron Disease.

It was an emotional time for Margaret and I and the family. Motor Neuron Disease wasn't on my radar but Margaret had been worried as she had also worked in neurology during her nursing career. I had always considered myself healthy. I kept very fit. I ate wholesome food and apart from picking up occasional tropical bugs overseas I was rarely sick.

My experience of living with MND is just that - my own experience. The disease affects people in different ways. It can impact different parts of the body. For some, it might be upper body, for others lower body or for others it can be both. The progression can be slow for some while for others it is more rapid. The reason I say this is because I think we need to be careful about how we talk about or label MND, especially in using emotive language about its impact or putting a time on one's life expectancy. For some people, that can be frightening. We are all different and how we react to it can be different.

As MND progresses, you have to let go of things that you can no longer do. In my case, I have had, over time, to give up driving, playing my piano, cooking, writing in longhand, and taking long walks. I am unable to carry out many of the normal activities of everyday life such as dressing myself, preparing meals, making a cup of tea and more recently shaving. With my particular form of MND, I have no choice. For this reason I'm not a fan of the idea that you 'fight' a serious illness like this - that makes me uncomfortable because it implies that you devote all your precious energy into trying to be cured of a disease that is not yet curable. It is a perfectly natural response, especially when you first get a diagnosis, but I don't think it's good for you in the longer term.

I think there has to be a period of adaptation and over time, an acceptance, a letting go and, dare I say, a surrender to something over which you have limited control. And like it or not I have become more dependent on others for the daily things that we can all take for granted. If that all sounds terribly defeatist it is not meant to be. It is of course possible and appropriate to slow the progression and to maintain a quality of life. And for some, life expectancy prospects can remain good. At this stage in my experience, I don't think of timelines or plan too far ahead, apart from ensuring that my financial, legal and other affairs are in order. It is more important for me now to focus on the present. I want my life to remain as purposeful as possible, contributing as best as I can within my limitations.

So now for the positive part. My gratitude list is quite long. In spite of my limitations, I can still manage to walk, read, sing, laugh, travel, socialise and take an active role in my board meetings. I can still type (with one finger!). But here is the important thing - it is not just about me. A serious illness impacts on family and friends, yet at the same time it brings out the best in us. Margaret has been my rock and because of her love and constant support my quality of life is good. She really is a special person, as those who know her will testify. We have three lovely, caring children, a beautiful grandchild and another one on the way. My brothers and sisters and my in-laws have been a great support. And we have valued friends.

We often hear complaints about our health service. No institution or health care system is perfect. My experience has been positive. Professor Hardiman is the leading expert on MND in Ireland and internationally respected. The multidisciplinary approach at the Beaumont MND clinic gives me access to a range of supports from health professionals, all of whom have been helped to make life easier. My local health centre has been equally supportive. The Irish Motor Neurone Disease Association has, along with Beaumont and the health centre, visited my home on a number of occasions. All have provided really practical advice and tangible assistance. I know this is more than a job for them - they really do care and I am very grateful for this.

So what else can I say that I have found helpful, bearing in mind again that this is based on my experience I think attitude is important. That may sound simplistic. After all, I am 72 years old, my family is reared and I have great support. Others are not so fortunate. I believe however that we can maintain or cultivate a positive attitude when we are ill. Does that mean I can always be content and not experience moments of sadness or loss? Of course not. I am human and like everyone else I have to expect some suffering in life. But in my encounters down the years with people coping with major life challenges far worse than mine, I am inspired by their resilience and their positive attitude. They are everywhere and their positivity creates a ripple effect which benefits us all.

This brings me to an area in my life that has been very important for my own personal growth. Almost thirty years ago, I started to practise meditation. I read many books on the topic, tried different techniques and eventually settled on an approach that suits me. Now, I prefer to call it contemplation. I believe we are all spiritual beings and that meditation or contemplation can bring us to a quiet place where our soul resides. To me this is a form of prayer. But no matter what we believe in, meditation is very good for you. When I let go, my body relaxes, the clutter, the distractions and the random thoughts in my mind begin to fall away. In that space there is no MND. I find this really helpful.

I go for acupuncture regularly. My acupuncturist is also a physiotherapist so I get a double benefit from my visits. She has years of experience in neurology and firsthand experience of MND. Acupuncture does not make any claims about curing MND but importantly it strengthens the immune system and, along with physiotherapy, can help maintain quality of life.

I make sure to get out every day, preferably surrounded by nature and I walk as much as I can. My challenge as a stubborn man is not to overextend myself, not just in walking but in other activities also and my body lets me know that!

Finally, I want to mention social connection. Even though I consider myself a private person it is very important to me. I lived alone a number of times in my life and am quite content in my own company. Indeed, I value private space in my life. But no person is an island. We are all interdependent and need each other. That means receiving as well as giving. I love good company, especially those who can be themselves, irrespective of who they are or their social standing. Everyone has a story to tell as I find out regularly when I meet strangers on the bus! And for those of us living with a disability, just treat us as normal. Even if you feel awkward, let us not be secretive because that creates barriers. We have to embrace reality. I think that is healthier for us all.

# A CAREGIVER'S PERSPECTIVE BY CATHERINE JENNINGS

"My name is Catherine Jennings, and my husband Barry has MND for over 6 years now. I suppose I'll start with telling our story from the beginning, but this is our journey and every single MND diagnosis & journey is **different**, **individual** and **painfully unique**. At the moment Barry is still doing ok and is still walking and talking but with great difficulty, but I am grateful for that every single day and long may it last.

Barry was diagnosed in 2018 & at that time, he had slightly slurred speech especially when he had a couple of drinks, we were noticing some drool stains down the front of t-shirts and shirts. Barry was an amazing singer and guitar player and he had noticed he couldn't hit some high notes singing. We also had to take a close up passport picture of him for a new job and noticed a slight droop in the left side of his face and then one day he said to me that his tongue felt different in his mouth....and I thought to myself "Something isn't right here!"

So off to his GP he went, and she referred him to Neurology in Galway and that's where we got the news "**It's a form of MND**" and our little lives changed forever in that room.

The beginning of the MND journey is strange because you are absolutely catapulted into this whole new world. As I said earlier, we are 6 years into this journey now and have picked up a few things along the way.

For us with Barry we are very lucky because Barry's progression has been quite slow, so we have had more time to try and adapt to things as we have gone along.

This disease takes everything from your loved one and you. Of all the things MND has taken I miss Barry's voice, I miss the craic we used to have laughing and joking and I miss the flow of conversation we used to have that would keep us talking for hours.

Being a carer is the hardest thing I've ever done in my whole life; it has come with every emotion under the sun but it is also the most rewarding thing I've ever done and I've learned a lot about myself since taking on this role. It's putting someone else's needs before your own on a daily basis, but believe me when I say that your needs still matter.....and I cannot stress that enough.

The care I provide means that Barry will stay in our home for all of his illness and with the support from the IMNDA and the amazing MND nurses, you are not on your own. Reach out to them and ask for the help you need, that's what they are there for and they are so happy to help.

You are not superwoman or superman; you are human and as cheesy as it sounds you need to pour into your own cup as much as possible because you cannot pour from an empty cup! I learned that the hard way unfortunately and absolutely ran myself into the ground a few times and just burnt out! Of all the emotions that being a carer has brought, guilt has been the most prevalent, but I work really hard on trying to ease that, because I cannot cure Barry, I cannot take away all his struggles that MND has given him, even though I want to, but that's just not possible.

Carers stress is real so take your breaks & respite when you can because it really does recharge your battery and research shows that carers are at particular risk of experiencing poor health, both emotionally & physically and sometimes the risk of emotional distress is higher for carers than for those whom they are caring for because they now have multiple responsibilities that previously would have been shared. Your self-care has to be top tier, and you need to do this daily because unfortunately nobody is going to look after that only you.

Don't let MND define you, don't let MND break you or turn you bitter against the world, because for all the cruel in the world (and there is plenty) there is such beauty and kindness, and the kindness of people never ever ceases to amaze me and I hold that very very close.

I am grateful to everyone who has helped and will continue to help us on the rest of this journey.

Be open to help, but don't feel pressurised into accepting it all because it has to suit you as a couple or family. Some people think they are helping but unless the help is tailored for you don't be afraid to put your boundaries in place and don't feel one bit bad about it! What help looks like for one might be a hindrance to someone else and that is absolutely ok.

Make the most of the time you do have, as best you can, do things that you both enjoy and make all the memories and take the bloody pictures!

**We do our best to focus on what Barry can do, and not on what he can't do.**

But please please remember that you matter just as much as the MND warrior you care for.

My therapist told me on one of my very first sessions years ago....

"MND is going to take one person, don't let it take two"

# CARING FOR CAREGIVERS ONLINE PROGRAMME

This year the association was delighted to announce a new online programme for caregivers which is being funded by the Charlie Bird Development Fund (CBDF). The online programme entitled Caring for Caregivers, Coping Techniques has been run on three occasions so far this year. It is designed for family caregivers who are looking after a person living with MND and also a registered client of the IMNDA.

These online programmes are skilfully facilitated by Mary Scarff who is a trained psychotherapist with over 25 years' experience in private practice. She provides clinical supervision to therapists, trainee therapists, nurses and teams. She facilitates psychoeducational courses and talks in many well-established charities nationwide.

During the online programme, Mary focuses on the following topics: Anticipatory grief, trauma and anxiety, self-talk, relationships, conflict, sleep, process of change and self-care programme.

Throughout the programme, the participants can connect with others who are experiencing difficulties such as supporting themselves and their family as they navigate the challenges of MND.

The feedback from the online programme has been very positive so far and has ensured that it is now an established programme of support for 2025 and beyond. We are grateful to Mary for her support in developing this programme.

"The course was amazing. Mary was fantastic and so open and kind. Johanna was a fountain of information to have for any questions that needed answering. The breakout rooms were so good, it really gave us all a chance to chat and share our experiences. I would recommend any carer to do this course as it helped me so much. Thank you."

The programmes usually run on a Tuesday and require a commitment of 7 weeks with a two-hour slot for each one. Places are limited so if you are interested, you can contact the services department by emailing services@imnda.ie or by telephone 01 670 5942.

## Caring for Caregivers

### Online Weekly Programme

### Funded by Charlie Bird Development Fund (CBDF)

Coping Techniques with Mary Scarff, Psychotherapist.

**Time:** 3- 5pm
**Duration:** 7 weeks

***ROI based. Places limited, must be a caregiver of IMNDA registered clients & must be able to commit to all 7 sessions.**

**Email: services@imnda.ie**

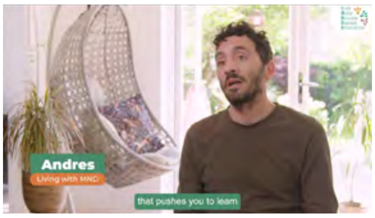
# IMNDA LAUNCHES NEW VIDEO CAMPAIGN TO HIGHLIGHT THE CHALLENGES FACED BY PEOPLE LIVING WITH MOTOR NEURONE DISEASE IN IRELAND

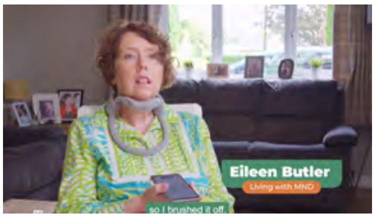
75% of people with MND who experience voice deterioration say that their confidence is affected. 96% believe there needs to be more awareness among the general public about voice deterioration being a symptom.

The Irish Motor Neurone Disease Association (IMNDA) has announced the launch of a new awareness video campaign in collaboration with CB Media. The series of four powerful and personal videos sheds light on the everyday challenges faced by people living with Motor Neurone Disease (MND) in Ireland. The project aims to raise awareness about the struggles people with MND endure and how society can offer more support and understanding.

The first video in the series depicts a fictionalised scene that many with MND experience all too often—misunderstanding and prejudice. The video features a man with MND entering a pub. As he contemplates his order internally, his thoughts are clear, and his inner voice is strong. However, when he tries to order a pint, his speech is slurred due to the effects of the disease. His movement is also slow and unsteady, which can be a further symptom. The barman, assuming the man is intoxicated, refuses to serve him. It's only after a bystander steps in to explain that the man is living with MND, not intoxicated, that the barman realises his mistake and apologises.

The remaining three videos focus on the real-life personal stories of individuals living with MND; Andres Estevez Guersanik from Dublin, Eileen Butler from Co Meath, and John Daly from Dublin, who has since sadly passed away. Filmed in their own homes, these videos offer an intimate view into their lives, featuring conversations with their families and their MND nurse from the IMNDA. Each story brings to light the emotional and practical challenges the family faces daily and outlines how we can do more to support those with MND while at the same time, shows an appreciation as to how far society has already come and the support offered by many.





The video project comes in the wake of a survey conducted earlier this year by the IMNDA, which revealed the significant impact of voice deterioration—a common symptom of MND—on social interactions and quality of life. According to the survey, 75% of participants reported that losing the ability to speak clearly has affected their confidence, with almost half (47%) stating social situations can be uncomfortable and a further 42% saying they avoid social interactions altogether as a result. These findings highlight the urgent need for greater awareness and sensitivity toward people with MND.

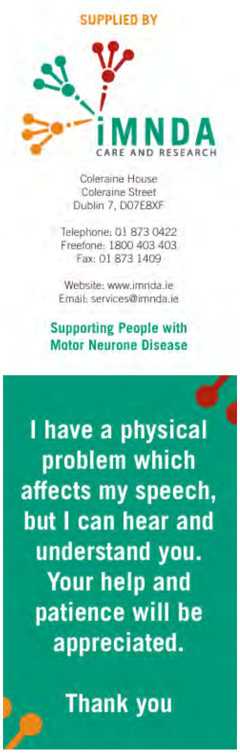
The IMNDA hopes that this project will prompt viewers to reflect on how they can make a difference in the lives of people living with MND, from offering practical support to simply being more understanding in everyday situations.

The videos are on the IMNDA's social media platforms as well as the IMNDA website www.imnda.ie

If you or your family member has MND and you are out in public, the Association has cards available to explain that 'your speech is affected and to please be patient.'

You can contact the IMNDA office by telephone 01 670 5942 or by email: info@imnda.ie to avail of these cards.

There are also JAM cards available from Transport for Ireland, JAM stands for Just A Minute, these cards can serve a similar purpose in informing members of the public to be patient. More information can be found on their website here: https://www.transportforireland.ie/accessibility/jam-card/



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iMNDA
CARE AND RESEARCH

Coleraine House
Coleraine Street
Dublin 7, D07E8XF

Telephone: 01 873 0422
Freefone: 1800 403 403
Fax: 01 873 1409

Website: www.imnda.ie
Email: services@imnda.ie

Supporting People with
Motor Neurone Disease

I have a physical problem which affects my speech, but I can hear and understand you. Your help and patience will be appreciated.

Thank you

# THE WORK OF THE IRISH NURSING NEUROLOGY FORUM

IMNDA Nurse, Maire Hayes has worked as a Neurology Clinical Nurse Specialist (CNS) for over 10 years. As well as working in this field, Maire is also the Co-Founder and Education Officer of the Irish Neurology Nursing Forum (INNF). This is a non-profit organisation established in 2022 by a group of volunteer specialist Neurology nurses, whose vision is to collaborate and support neurology nurses nationally. They provide a platform to share best practice, educational activities and networking opportunities, Maire and her colleagues within INNF believe that they can promote their vital role and treat patients with neurological conditions in a timely and holistic manner.

The aims within INNF are to increase the number of neurology posts nationally; to build a sustainable mixed level workforce and introduce a postgraduate Level 9 course for neurology nurses to gain the academic criteria to hold a Clinical Nurse Specialist (CNS) and Advanced Nurse Practice (ANP).

A national audit of neurology services, carried out in 2020 by the Neurological Alliance of Ireland (NAI) along with the National Clinical Programme in Neurology, found that staffing levels for clinical nurse specialists were significantly below minimum recommended levels across neurology services. Maire worked with the Neurological Alliance Ireland (NAI) at awareness raising events for the Southeast of the country between 2021-2022. She engaged with patients in six regions across Ireland, as a specialist nurse helping patients to live well with their neurological condition. The NAI highlighted the need for an additional 100 Neurology nurses and based on a submission through the HSE Clinical Leads Programme, the Department of Health provided funding allocation for 21 new nursing posts in 2022 with more to come incrementally.

Since its inception, the INNF has been working to attain a Level 9 Neurology post graduate course to be made available in Ireland. There is currently no neurology focused post graduate specialist course for those nurses wanting to specialise in medical neurology e.g. epilepsy, multiple sclerosis and headache disorders. This is a minimum requirement to attract new candidates to the specialism and allow experienced Neurology nurses receive the academic criteria to gain entry on the specialist register on Nursing and Midwifery Board of Ireland (NMBI). This dedicated and experienced workforce will ensure the highest quality of care navigating through primary, secondary, and tertiary care for optimal patient outcomes. A key focus is on building capacity within Neurology clinics and Nurse-led outpatient and outreach clinics for neurological conditions, with clinical governance through the Neurological Hubs across the country. Investment in Neurology Clinical Nurse Specialists and Advanced Nurse Practitioners will focus primarily on new patient review or complex review patients, which in turn will create a downward shift on the growing waiting lists, which in January 2022 reached over 23,000 patients.

The INNF held its annual Conference and AGM on November 22/23rd 2024 where an update was discussed with members. This is available on their website www.innf.ie or email: info@innf.ie

# IMNDA OFFICE UPDATES

## A fond farewell to Lillian McGovern

We would like to wish Lillian McGovern who has stepped down as CEO the very best as she starts her retired life. We would like to thank her for all she has done for the Association and the MND Community over the last few years.

## Welcome to Kevin Burn

We would like to welcome Kevin Burn to the Irish Motor Neurone Disease Association as he takes up his position as CEO. Kevin joins the association with a wealth of experience having served as CEO of Exchange House Ireland: National Travellers Service for over six years. He has also undertaken a Transformative Leadership Course, CEO/Chair Training by Boardmatch and the Navigator Leadership Programme by Common Purpose. Kevin is committed to excellence in governance and compliance and his passion for promoting the mission, vision, and values of his previous organisation aligns perfectly with the goals of the Irish Motor Neurone Disease Association.

## Thank you to Maeve Leahy

We would like to wish Maeve Leahy all the best for her future as she stepped down as Head of Advocacy & Communications after several years. Maeve started out as intern in 2009 and worked her way up to become Head of Communications. We would like to thank her for all she has done for the Association and the MND Community over the last 15 years.

## Welcome to Fiona Thornton

We would like to welcome Fiona Thornton to the role of Head of Advocacy and Communications. Fiona is responsible for the management and implementation of the IMNDA's Advocacy, PR & Communications strategy. With over a decade of experience in public relations and communications, she works to ensure the voices of families affected by MND are heard, building strong relationships with stakeholders and the media. Fiona oversees PR and advocacy campaigns, media relations, and social media outreach at IMNDA, playing a key role in enhancing the organisation's visibility and impact.

## Thank you to Eithne Cawley

We would like to wish Eithne Cawley who stepped down as IMNDA Nurse after many years of service. We would like to thank her for all she has done for the Association and the MND Community over the last few years and wish her success in her onward journey.

## Welcome to to Charlene Crawford

We would like to welcome Charlene to the nursing Team as she joins the team of six dedicated IMNDA nurses. She qualified as a general nurse in 2010 from Letterkenny Institute of Technology. Charlene worked in the Stroke and Medical Rehabilitation unit for 13 years and from there she went on to become a CNM2 of a busy Respiratory ward. Charlene gained a vast amount of knowledge of neurological conditions within the rehabilitation unit. Within the respiratory unit she gained experience in the use of Bipap, CPAP and Airvo machines. She has always had an interest in neurology, and she hopes to widen her knowledge in due course. Charlene also has a keen interest in palliative care.

We would like to send a huge welcome to Michelle Fanning & Catherine Corbett who have recently joined the board of the IMNDA. Both of these ladies have a wealth of experience, and we look forward to working with them in the future.

# TEN YEARS SINCE THE ICE BUCKET CHALLENGE: NEW RESEARCH REVEALS LASTING IMPACT ON MND AWARENESS IN IRELAND: 1 IN 5 PEOPLE IN IRELAND HAVE A CONNECTION TO MND

This year marked the ten-year anniversary of the Ice Bucket Challenge, the viral phenomenon that swept the globe in the latter half of 2014, raising unprecedented awareness and funds for Motor Neurone Disease (MND). To commemorate this milestone, the Irish Motor Neurone Disease Association (IMNDA) partnered with iReach to conduct new research* exploring the lasting impact of the Ice Bucket Challenge on public awareness of MND in Ireland.

The findings showed high levels of recollection as well as increased awareness of the disease, but also that a significant number of people have a connection to MND:

- **1 in 5 people in Ireland know someone or knew someone with MND**, underscoring the widespread impact of this debilitating disease within our communities.
- **94% of people remember the Ice Bucket Challenge**, illustrating the profound effect it had, even ten years later.
- **More than half of respondents either participated in the challenge or donated** to the cause, reflecting the broad engagement and support the campaign garnered.
- **Almost half (48%) say their awareness of MND increased** as a direct result of the Ice Bucket Challenge.
- **41% of respondents are now more aware of the IMNDA** than they were a decade ago.

Commenting on the research, IMNDA CEO Kevin Burn said:

"The Ice Bucket Challenge was a watershed moment in our efforts to raise awareness of Motor Neurone Disease. The fact that 94% of people still remember it a decade later shows the profound impact it had. This challenge not only increased awareness but also connected communities across the globe in support of those living with MND. We are incredibly grateful to everyone who participated, donated, and helped spread the word. The awareness and funds generated supported the vital services we provide to individuals and families affected by this devastating disease. Lots done but still much more to do in the fight against MND."

The IMNDA continues to provide vital services to individuals and families affected by MND. These services include specialised equipment loans, home visits by MND nurses, and access to support groups and counselling, all aimed at improving the quality of life for those living with the disease and their caregivers and families.

*Research conducted by iReach among 1,000 participants across Ireland in August 2024.

## JOHN DALY'S POETRY LEGACY

John Daly was living with MND, but he sadly passed away earlier this year. He very kindly got involved in our campaigns and was interviewed on RTE News last year about Voice Banking. John had a love of writing and wrote so eloquently. He wrote several poems, and this is one of them that we have selected for this newsletter. We will be posting his poems on our social media channels over the next couple of months. A very special thanks to his wife Deirdre for sending them to us.

### *Sometimes sculptures, speak to me*

*June 8th , 2024*

*Sometimes sculptures, speak to me*
*A masterclass, making shapes you see*
*A message, conjured for each of us alone,*
*Silently emerging, from bronze or wood or stone.*

*In Paris once with Rodin's Thinker on his rock,*
*Not trapped like I am now, behind those special locks*
*He pensively held his head upon his hand,*
*He could act, when once he knew, where he should stand.*

*Sometimes, I seem carved by Henry Moore,*
*Spaces and abstract lines speaking to the viewer.*
*My neural signals though, mere messages to a cul-de-sac*
*Echoes of what I think, they just bounce right back.*

*Above Carrara, saw once, a solid cube of white*
*Awaiting a modern Michelangelo, to be brought into the light.*
*I was once so carved by nature and let go,*
*Each ruffled surface and humble contour made, just so.*

*But Cú Chulainn, in our GPO, he says it crystal clear,*
*Each held up, nearing our final step, that end of years*
*The crow on both our shoulders has bitten clean through,*
*We must stand at our silent posts, while fading fast from view.*

*Oh yes, I have filled a certain space for just a while,*
*I have etched my message sharply, but with a smile,*
*Words, sculptures, character, which one of these will out-last,*
*Carved, as we all are, from our recent and ancient pasts.*

## IMNDA OFFICE MOVE

The IMNDA are in the process of moving offices to nearby Unit 6 Bond House, 9-10 Bridge Street Lower, Dublin 8 D08TH76.

This is a temporary relocation while we are waiting for a more permanent office to be ready in Spring 2025. Keep an eye on our website and social media channels for updates.

During the relocation process we are still more than happy to receive visitors to the office. We would ask that you phone us on 01 6705942 or email us in advance to ensure you have our correct location. All contact numbers and email addresses will remain active during the move and there will be no changes to these contact details. Post sent to the Marshalsea Court address will be redirected to Bond House.

## A TRIBUTE TO CHARLIE BIRD

At the IMNDA, we were deeply saddened this year by the passing of the remarkable and truly inspiring Charlie Bird. Charlie's impact on the MND community in Ireland and beyond is profound. His gift for extending what he called "the hand of friendship" brought people together from every corner of the country through the Climb with Charlie initiative, raising millions and igniting a widespread commitment to fight MND, support those living with the disease and their families, and drive meaningful change.

We are forever grateful for Charlie's contributions to the IMNDA. Not only did his efforts provide critical funding that has significantly strengthened our support for families, but his presence also raised vital awareness, helping many to recognise the reality of this devastating disease. In many ways, Charlie sparked an important conversation, one which we must all now carry forward in his honour.

# SHOUT OUT TO YOU, OUR INCREDIBLE COMMUNITY FUNDRAISERS!!

The IMNDA wouldn't be here without you — our incredible community. The hundreds of wonderful fundraising events that take place across Ireland throughout the year are truly at the heart of this organisation. While we can't name every single one of you, please know how much we appreciate everything you do to support people with Motor Neurone Disease. Your dedication means the world to us and to those we serve.

Thank you from the bottom of our hearts!

Denise Mulcahy's mini concert wasn't so mini last October. This Johnny Cash Tribute night in Mallow in memory of Denise's husband John raised an incredible €25,000. Wow!

Simon Besanson ran several fundraisers as part of his Racing for a Reason initiative which finished with a Cheltenham Preview Night in February of this year. We were blown away by the €34k raised!

Following on from the O'Connor family's immense fundraising in 2023, their Monster Raffle took place in May with the most wonderful prizes on offer! Congrats to all the winners and thank you Stephen and Brian for organising.

Our wonderful John Considine rallied the people of Ennis once again in June – it was well worth the effort as these fundraising events raised over €25,000. John, we don't know how you do it, but we are so glad you do!

## Active Community Events

We have been truly blessed in 2024 to have been inspired by some remarkable and unique challenges!

We couldn't have kicked off 2024 any better than how Paddy Conaghan did with his ducking and diving campaign. Paddy is a true inspiration, he is in his 80s and from Arranmore Island, Donegal. He took on a lake or sea swim in every county in Ireland during January and some of February whatever the weather and raised over €10k. Well done Paddy!

Springtime brought out the walkers in their droves… particularly in Cork where the students of Coachfield College took part in a disability awareness week in January and as part of that organised a walk. To say the support was monumental for this would be an understatement! These amazing pupils raised over €50,000! This was all in honour of their much-loved teacher Diarmuid Hickey. Sadly, Diarmuid passed away from MND in March. May he RIP.

Throughout the whole of March, Sligo's Joe and Carmel Mahon took on '100k on Knocknarea' and got such wonderful community support. Many joined the Knocknarea Trail throughout the month and raised a phenomenal €52,500!!

Adrian Harkin had the wonderful idea of a paddling and climbing fundraiser around Ireland in April with his Summit2Sea for MND challenge. The support for this initiative was monumental with €105k raised. Adrian, a keen Kayaker, was diagnosed with MND in 2022 took part in the event. He sadly passed away in June, RIP Adrian. You have left an amazing legacy.

Alan Gilmartin decided he would participate in Sligo's famous Warriors Run but he wouldn't just complete it once…. Alan did this gruelling course twice over in quick succession!!! We are blown away by what Alan has achieved both through this physical challenge but also the funds that have been raised - an enormous €37,330!!!

## Every pedal counts

There are too many cycling fundraisers to mention but we must give major Kudos to Adam Brennan and his Ignite Fitness gym who for the 3rd year running organised a Spinathon in Greystones. This year was the biggest one yet with an enormous €60k handed to the IMNDA! We must also thank Adam's brother Cian Brennan for his run the dart line fundraiser. What a family!

September brought the incredible United for Dave cycling event organised by Irish Nurses and Midwives Organisation (INMO) in honour of Dave Hughes who is living with MND. A few friends and colleagues from the trade union movement came together and cycled 100km from Dublin 7 to Co Meath and back, raising €53K in the process!

## Every step makes a difference

So many of you sign up and take part in runs across Ireland and beyond and we are so grateful! Be it a 5k or a mini, half or full marathon – you are superstars!

The VHI Women's Mini Marathon in June was another wonderful day with so many amazing ladies taking part wearing IMNDA green. Together you raised a massive €45,000!!

Our Cork ladies also did us proud in the Echo Women's Mini Marathon in September with over €12,220 raised so far and with more funds to follow!

The 2023 Dublin City Marathon was a huge success for the IMNDA with over €70,000 raised and 2024 has seen a surge of support with over 30 runners on Team IMNDA. Well done and thank you everyone who participated this year and last.

A special mention must be given to James Gillivan who took on not just the Dublin City Marathon but 4 marathons in 4 days!! James ran from Athlone to Dublin then completed the Dublin City Marathon in memory of his dad who passed away from MND in March this year. James, you are a true inspiration, and we know your dad was right behind you for all those 100 plus miles. James raised a phenomenal €47,701!

## Tee Time is the Best Time

There have been so many amazing golf events over the last year, thanks to all!

Brian Ormond teed off in style back in April at the stunning Luttrellstown Golf Event raising a whopping €27,750.

Thank you to Kathy McGreal, Sean O'Donohue and all involved in the Castlebar Golf Club fundraiser which raised nearly €29k in June!

O'Mahony Insurance's Golf Classic in Castletroy raised a wonderful €9,700 (special thanks to Eimhin Wallace) and Rathfarnham Golf Club Captains Charity Day hit a hole in one raising €11k! Well done Loreto Meagher.

Phil and Seamus Hayden organised a hugely successful Golf Event in Roscommon Golf Club handing over a huge €20k to the IMNDA, amazing!!

## Goodbye to an old friend

We were deeply saddened to hear the news of Eileen Boland's passing in August.

Eileen had a long-standing relationship with the IMNDA after her husband Charlie was diagnosed with MND and sadly lost his battle. Eileen selflessly dedicated so much of her time to giving something back to the IMNDA. She was an intrepid fundraiser and would turn her hand to any challenge.

She organised several fundraising events including table quizzes, coffee mornings and raffles and even took on a sponsored silence for 24 hours as part of our #Voice4MND campaign! Not to mention getting 'married' all in the name of charity.

In March of this year, Eileen shaved her hair off in what was to be her last fundraising initiative. On Global MND day in June, we were honoured to present Eileen with a lifetime achievement award for all her efforts, which she was delighted to accept.

As well as raising hundreds and thousands of euros over the years and raising awareness of MND – she was a huge inspiration and support to the team here at IMNDA and we will never forget all she has done. She was such a part of the IMNDA family since her husband Charlie's journey with MND and we were always proud to have her in our corner.

You will be so sorely missed Eileen

# A MASSIVE THANK YOU TO ALL THE WONDERFUL COMPANIES WHO SUPPORT US!

*Whether it's an official charity partnership, a donation, volunteering or organising an event we are so grateful to our corporate supporters who get behind us. Here are just a few…*

In 2023 we were honoured to partner with Network Ireland who undertook a number of events throughout the year. President Emma Early Murphy proudly presented a cheque to our now retired CEO Lillian McGovern for a wonderful €14,768.

A massive thank you to all the staff PTSB Ireland who raised an incredible €50,000 for the IMNDA. In total the staff raised a phenomenal €150,000 throughout 2023, which was generously matched by the company totalling €300,000 and shared between six charities. We are so grateful to have been selected.

We were also beyond thrilled to be chosen by Lord Mayor Daithí de Róiste as one of the three chosen charities for the 2024 Lord Mayor's Ball in April at the stunning Round Room of the Mansion House. What a truly wonderful night it was raising more than ever before with the IMNDA receiving €50,000!

We have nearly reached the end of Year 1 of 3 as one of William Fry's chosen charities. It has been wonderful to work alongside William Fry who, amongst other initiatives, supported the Lord Mayor's Ball and took on an abseil at the Generator Tower in Smithfield. They also hosted a Drink Tea for MND event and a Step Challenge. We look forward to the next 2 years.

Well done to all who took part in the Garda Tour De Force Cycle in September for which the IMNDA is a beneficiary. As well as all the Spinathons and collections that have taken place over the last few months the main event took the intrepid cyclists on a journey throughout Spain for more than 21 hours of cycling. They climbed over 4,600m during their 433km journey. Wow!!! Total funds raised to be announced. Thanks all!

The IMNDA is honoured to have once again been chosen as one of Irish Life's charity partners for 2024. It's an absolute pleasure to work alongside the team in Irish Life who are nothing but supportive of our events and the work we do. As well as all the fundraising the company undertake throughout the year they also attended and volunteered at 2 of our key events, Global Awareness Day in June and our annual conference in October. Special mention to Irish Life Dundalk for all their efforts this year. Thanks for all you do; we look forward to the cheque handover day in December!

## WE MISS OUR LOVED ONES ALL YEAR ROUND BUT AT CHRISTMAS WE MISS THEM THAT LITTLE BIT MORE. IT'S A TIME TO KEEP THEIR MEMORIES SHINING BRIGHTLY EVEN THOUGH THEY ARE NO LONGER WITH US.

Lighting up a star on our online Memory Tree is a small way of remembering someone special during the festive period.

The stars that light up the darkest night are the lights that guide us.

**To light up a star please visit** https://fundraise.imnda.ie/event/christmas/home or scan the QR code above

# CHRISTMAS SHOP

## Decorations

Our beautiful Christmas decoration will look lovely sparkling in your home over the festive season or even all year long. This durable ornament can be personalised with a favourite photo of family or special friends and would be a perfect Christmas gift for someone special. The decorations have a green ribbon for hanging up and come safely packaged in a white box with the IMNDA logo on the lid.

Each decoration is €15 excluding postage and packaging.

**Christmas Tree decorations are available to purchase at imnda.ie/shop/or by calling the Fundraising Team on 01 670 5942.**

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## FraEye Shop Collections

IMNDA is honoured to announce that the amazing fashion website, FraEye, created by the late Fraser Holden has been gifted to the IMNDA by his wife Orlagh on what would be Fraser's 54th Birthday in October of this year.

This site is Fraser's parting gift, designed with the same creativity and determination that defined him. Despite his own battle with MND, Fraser remained dedicated to helping others and raising awareness about MND. He used eye-gaze technology to design the collections on FraEye, producing unique artwork and beautiful products.

From now on, 100% of the profits from FraEye will support the IMNDA, directly assisting clients and families affected by MND. As Christmas and the holiday season approaches, we invite you to explore the FraEye shop when considering gifts.

We extend our heartfelt thanks to Orlagh for her generosity and to Fraser for leaving behind such an inspiring legacy.

Please visit the site here:

fraeye.org/collections
or Scan the QR code below

**#IMNDA #FraEye #MND #Support**

## Irish Singer to Release Charity Single 'You'll Never Walk Alone' in Support of MND Community

Professional Irish singer Catrina Scullion is set to release a heartfelt rendition of "You'll Never Walk Alone" as a charity single, with all profits dedicated to the Irish Motor Neurone Disease Association (IMNDA) in Dublin and MNDA in Northern Ireland. The release is part of her "Sparkle for Sinead" campaign, a personal initiative inspired by Catrina's cousin, Sinead, who was diagnosed with an aggressive form of Motor Neurone Disease shortly after the birth of her third child in 2021.

The diagnosis has profoundly affected Catrina and her close-knit family. "Sinead's courage, positivity, and strength inspire me every day. I promised her that I would use my voice to raise awareness and support for MND charities, and this song is my way of honouring that commitment," shared Catrina.

The "Sparkle for Sinead" campaign will launch this Christmas and includes two charity concerts featuring special musical guests. Both events will support the single release and raise awareness of MND, with all profits from ticket sales going to IMNDA and MNDA Northern Ireland.

Concert details are as follows:

- **Ballymena Concert:** December 1, 7 PM, Ballymena North Event Centre, featuring the Sanctuary Singers under the direction of conductor Loreto McAuley.
- **Dublin Concert:** December 6, 7 PM, St. Mary's Church, Haddington Road, Dublin 4 featuring St. Andrews College Junior Choir led by conductor Karen Armitage.

Both concerts will include piano accompaniment by Catriona McElhinney-Grimes, Catrina's long-time friend and collaborator.

Alongside the concerts, a GoFundMe link will allow the public to purchase the single, make donations, and buy concert tickets through Eventbrite.

"The power of music to unite people in solidarity and compassion is undeniable," says Catrina. "With 'You'll Never Walk Alone,' I hope to bring people together to support families affected by this challenging disease and honour Sinead's spirit and positivity. This campaign is for her and for every person touched by MND."

For more information on the "Sparkle for Sinead" campaign, visit Catrina's fundraising page
https://gofund.me/d2fe20e6
or the IMNDA's website www.imnda.ie.

# KEVIN SINFIELD'S 7 IN 7 IN 7 CHALLENGE: A MARATHON EFFORT FOR MND, AND HE'S COMING TO BELFAST THIS DECEMBER!

In December 2023, the IMNDA was honoured to be part of an incredible feat of endurance, commitment, and unity in the MND community: Kevin Sinfield's "7 in 7 in 7" marathon challenge. Kevin Sinfield, celebrated England rugby star, undertook this epic journey to complete seven ultra-marathons in seven cities over seven days across the UK and Ireland, all in support of those affected by Motor Neurone Disease. This remarkable effort was dedicated to his former teammate Rob Burrow, who was diagnosed with MND in 2019.

For the first time, Ireland had the privilege of hosting one of these ultra-marathons, with Kevin and his team bringing their inspiring journey to Dublin on Day 5. The IMNDA was involved in the preparation and planning for this special day. Special guests included Charlie Bird and Irish rugby icons who joined Kevin in his "Extra Mile," where a select group were invited to run alongside him. Our ambassador Andres Estevez Guersanik was interviewed that morning on BBC Breakfast alongside our then CEO Lillian McGovern at the Aviva Stadium. It was a memorable occasion, where MND advocates and sports heroes were united for a common cause.

With significant media coverage, the story of Kevin's journey, the IMNDA, and the MND community was seen by many and from this one day in Dublin, a substantial six-figure amount was raised, contributing to the overall sum of more than £1 million raised throughout the challenge. The IMNDA alone received nearly €77,000, which will go directly toward supporting individuals and families affected by MND in Ireland. Beyond the funds, the event fostered new international connections and friendships between MND charities and the rugby community.

Sadly, we have since lost both Charlie Bird and Rob Burrow to MND this year. Their courage, friendship, and unbreakable spirits touched the hearts of many, and their legacies continue to inspire us to carry on the fight against MND.

Looking ahead, we are honoured to share that Kevin Sinfield will be returning to Ireland in December 2024 for yet another challenge, this time in Belfast on the 3rd. We look forward to cheering him on again.

Thank you, Kevin, for all you do.

# PLANT A TREE FOR MND & CREATE A LEGACY FOR THE ONE YOU LOVE.

This is a beautiful way to create a legacy, planting a tree dedicated to the one you love is an act that will enhance the natural world for generations to come. The IMNDA have partnered with Irish Tree to create this legacy of planting a tree for the one you love. If you would like to get involved in this initiative, you can visit this link https://irishurns.com/product/imnda-memorial-tree/

You then choose your preferred species, and Irish Trees will plant your tree at their lakeside woodland which is located in the Naul in Co Dublin. Each tree arranged has an embedded donation of €40 which goes to support the work of IMNDA. Once arranged, a tree planting certificate will be posted to your chosen delivery address along with a handwritten card, or blank card if being sent to yourself. Irish Tree can arrange visits to the site that your tree is being planted in. Thanks to Irish Tree for this initiative and thank you for your support

THE LEGACY TREE

Irish
Motor
Neurone
Disease
Association

# MARKING 40 YEARS OF IMNDA: A LANDMARK YEAR AHEAD!

Irish
Motor
Neurone
Disease
Association

**40 Years of Caring 2025**

As we wrap up another year of vital work, we're excited to announce that 2025 marks the 40th anniversary of the Irish Motor Neurone Disease Association (IMNDA)! Since our founding on May 1, 1985, we have been dedicated to our mission to support people living with motor neurone disease (MND) and to fund critical research. Forty years later, we are still standing strong, thanks to the incredible community of supporters who have walked, volunteered, and contributed in countless ways.

This milestone year is shaping up to be a great one, filled with events and opportunities for everyone to get involved. We invite you to help us celebrate the journey so far, raise even more awareness, and, most importantly, build support for the future.

Here's a snapshot of some of the exciting happenings planned for 2025 and ways you can join in the celebration!

### Save the Date: Exclusive Afternoon Tea at Powerscourt Hotel: 29th March 2025

Join us for a luxurious Afternoon Tea at the stunning Powerscourt Estate, House & Gardens this coming March. With special guests, speakers and surprises, this event is a chance for us to come together as a community, connect, and mark the start of what promises to be an incredible year. Mark your calendars, as this will be a day to remember! Keep an eye on our website and social media as we'll be announcing tickets very shortly.

### Celebrating 40 Years in 40 Ways: How You Can Make a Difference

With "40" as our theme, we're inviting supporters to make 2025 a year of impact. Whether it's through personal challenges, community events, or workplace initiatives, there are countless ways you can join in and help us spread the word about MND.

### Ideas to Get You Started:

- 40k your way in May: In honour of our official anniversary month, take on an activity challenge your way and aim to cover 40 kilometres throughout May. It could be cycling, running, walking, swimming, whatever you choose. Invite friends, family, or your local club to join in.
- Host a "Drink Tea for MND" Tea Party: Gather 40 friends, family members, or colleagues for a tea party to raise funds. Whether it's a cozy get-together at home, a local café, or an office event, it's a simple and enjoyable way to raise awareness.
- Share the Message with 40 Friends: Spread the word on social media or in person by reaching out to 40 people about the IMNDA's work. Every share, conversation, or post helps us reach a larger audience and raise awareness about MND.
- Voice4MND – 40 minutes or 40 hours, you decide. Can you stay silent for 40 minutes for the IMNDA's Voice4MND campaign and raise funds to support our work? Or if you really want to challenge yourself, could you stay silent for 40 hours and come up with other ways to communicate with friends, family, coworkers? Talk to us for more ideas!

### Ideas for Corporate and Business Involvement

The 40th anniversary is also an excellent opportunity for businesses to make a positive impact. If you own or work for a business, here are some ways you can show your support:

- 40 Days of Corporate Giving: Sponsor a specific initiative, where your business donates a percentage of profits over a 40-day period. It's a meaningful way to support the IMNDA while showcasing your company's commitment to social responsibility.
- Match Employee Donations: Motivate your employees to participate in our anniversary fundraising by offering to match any donations they make to the IMNDA.
- "Round Up" for IMNDA Campaign: Retail businesses can invite customers to "round up" their purchase amounts, with the extra funds going directly to the IMNDA.
- Create a unique Challenge: Challenge your staff or customers to come up with unique ways to contribute 40 hours, 40 tasks, or even €40 donations that benefit the IMNDA.

### Join Us in Celebrating 40 Years

As we prepare to step into our 40th year, we know that this journey would not have been possible without each and every supporter. Whether you're a long-time contributor or new to our community, your involvement makes all the difference. Join us in 2025 to celebrate our history and to help us write the next chapter of hope and support for people living with MND in Ireland.

Let's make this a year to remember! We look forward to celebrating with you and thank you for all your support.

## Registering your Fundraising Event

Please register all fundraising events with the IMNDA before they take place and ensure all your details (name/address & event) are on the lodgement slip when lodging proceeds into the bank.

To register and receive promo items / lodgement slip etc:

**Email:** fundraising@imnda.ie
**Freefone:** 1800 403 403

Thank you for your support and co-operation.

**IMNDA Bank Account details:**
'Motor Neurone Disease Association'
AIB, Capel Street
**Sort Code:** 93-13-14 **Acc No.** 07725002
**IBAN:** IE32 AIBK 9313 1407 7250 02
**BIC/SWIFT:** AIBKIE2D

Irish
Motor
Neurone
Disease
Association

**To Contact Us:**
Unit 6 Bond House,
9-10 Bridge Street Lower, Dublin 8
D08TH76

Tel: 01 670 5942 Freefone: 1800 403 403
Email: info@imnda.ie

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### Contributions to the next edition of Connect:

If you would like to submit a story, photo, or something you would like to share then please contact the office.

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### Disclaimer

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**MEDICAL PATRON:** Prof Peter Bede MD. PhD. MRCP Associate Professor Trinity College Dublin.
**DIRECTORS:** Jonathan Healy (Chairperson), Catherine Corbett (Hon Treasurer), Michelle Fanning, Norman Hughes, Lisa Doherty, Joseph Ritchie, Gillian Lynch.

CHY 8510 R.C.N: 20021009