Irish Motor Neurone Disease Association
40 Years of Caring 2025

# CONNECT

ISSUE 28 | WINTER 2025

The latest news, views and information from IMNDA

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# IMNDA DIARY DATES

Irish
Motor
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Association

## DECEMBER

Light up a Star on our Christmas Memory Tree

## MARCH

Drink Tea for MND

DRINK TEA FOR MND
Helping others. It's everyone's cup of tea.

## APRIL

Memorial Service

## JUNE

Voice4MND

#Voice4MND

## JUNE

Global Awareness Day

## OCTOBER

AGM & Annual Conference

## OCTOBER

Walk While You Can

WALK WHILE YOU 5K CAN

**FOR MORE SEE IMNDA.IE**

# A NOTE FROM OUR CEO

Hi everyone,

As we close out 2025, I want to take a moment to reflect on what has been a truly landmark year for the Irish Motor Neurone Disease Association. This year marked our 40th anniversary—a milestone that gave us the opportunity not only to celebrate our legacy, but to build boldly on it. And build we did.

Thanks to our amazing fundraising team and the extraordinary generosity of our supporters, including a transformational legacy gift from the late Des Keely, IMNDA raised more funds in 2025 than in any previous year. That support has enabled us to invest €600,000 into a suite of strategic initiatives designed to deliver long-term impact for people living with MND. These include:

- A Cost-of-Living Fund to support families facing financial pressures
- Expansion of night nursing, ensuring care is available beyond end-of-life
- Increased access to communication technology through Safecare
- Enhanced home care and travel grants
- Investment in essential equipment
- And powerful new advocacy and awareness projects, including lived experience videos

Each of these investments is rooted in a simple but vital principle: that every person living with MND deserves the right support, at the right time, in the right way.

Our communications work this year has helped us connect more deeply with our community than ever before. Through campaigns, storytelling, and advocacy, we've amplified the voices of those affected by MND and brought their experiences to the forefront. One of the most powerful moments came on Global MND Awareness Day, attended by the An Taoiseach, Michèal Martin. Prior to this we had met with him to advocate for better services and support. That meeting has led to collective action taken by our community including the signing of petitions, sharing stories and working together calling for change.

Our Annual Conference in Cork was another highlight of the year. It was a vibrant, energising event that brought together families, caregivers, researchers, and international experts. The atmosphere was one of connection, learning, and solidarity. It was also a moment of transition, as we thanked Jonathan Healy for his years of dedicated service as Chair of the Board. Jonathan's leadership has been instrumental in shaping IMNDA's direction, and we are deeply grateful for his commitment. We were also delighted to welcome Norman Hughes as our new Chair, and I look forward to working closely with him as we continue to grow and evolve.

In our services, the demand for core supports has never been greater—and our team continues to rise to that challenge with compassion and excellence. A major milestone this year was the introduction of our seventh nurse, made possible by the Charlie Bird Development Fund. This expansion means more families across Ireland are receiving the care they need, delivered by a team of nurses whose professionalism and empathy are second to none.

Throughout the year, I've been continually inspired by the strength of the IMNDA community. Whether through fundraising, volunteering, advocacy, or simply offering a listening ear, you have shown what it means to stand together. Your support is not just appreciated—it is essential.

As we look ahead to 2026, we do so with clarity and purpose. We know the challenges are real, but so too is our determination. With your continued support, we will keep pushing forward—expanding services, strengthening advocacy, and ensuring that no one faces MND alone.

Thank you for being part of this journey. Here's to another year of impact, connection, and hope.

Warm regards,

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

# LATEST NEWS FROM THE ACADEMIC UNIT OF NEUROLOGY

## New Study Launches Investigating Neuroelectric Signaling - Dr Lara McManus

A new study investigating the neuroelectric signaling between the brain and motor neurons in ALS is now underway by researchers at Trinity College Dublin. A team led by Dr Lara McManus's will use non-invasive high-density surface electromyography (HDsEMG) to identify the firing patterns of individual motor units in the muscle. By analysing signals from both the brain and motor neurons, the team aims to understand how brain-muscle connectivity changes in motor neuron disease.

The team includes Dr Saroj Bista, a postdoctoral researcher whose PhD work found that in people with primary lateral sclerosis, parts of the brain that are not usually active during movement, step in to help perform certain tasks.

Two doctoral students, Giuseppina Del Duca and Zuyu Du, have also joined the project. Giuseppina's research will use HDsEMG to study the properties and behaviour of motor units in people living with ALS, and how these may change over time. A motor unit is a single motor neuron and the muscle fibres it controls, working together to produce movement. Giuseppina will also examine whether differences in motor unit function can help to identify different subtypes of ALS. Zuyu's work will focus on the relationship between brain and muscle, examining how brain activity influences motor neuron firing in people living with ALS. He will also develop new algorithms to improve the detection of motor unit firings, allowing researchers to more accurately track changes in motor neuron behaviour.

If you would like to find out more information about the study, or if you think you may like to take part, please see www.mcmanuslab.com or contact mcmanuslab@tcd.ie

## Exploring How Genetics, Family history and Brain activity influence MND - Dr. Ciara O'Donoghue

Dr. Ciara O'Donoghue is both a practicing doctor who works in the National ALS Service at Beaumont and a PhD researcher, working with Professor Orla Hardiman and Dr. Ross P. Byrne. Her work focuses on Motor Neuron Disease (MND/ALS), with a special interest in how genetics and brain activity might influence the illness. She combines her clinical work with research, aiming to deepen our understanding of ALS and, ultimately, improve care and outcomes for patients.

At a recent scientific meeting, Dr. O'Donoghue shared research on how genetic risk for other brain conditions such as mood or psychiatric disorders, and other neurologic disorders might also play a role in ALS. This is important because it suggests that ALS may share some underlying biological pathways with other brain-related conditions.

Dr. O'Donoghue is also exploring extended family trees in ALS. Sometimes, people who believe their ALS is "sporadic" (with no family history) may actually be connected to distant relatives in Ireland who also have ALS. This work could help uncover hidden genetic links or new risk factors, which may explain why some people develop ALS even if no obvious gene has been identified in their family.

Another part of her research, in collaboration with Professor Roisin McMackin, looks at brain activity exploring whether people with ALS who carry a higher genetic risk for psychiatric conditions might show unique brain wave patterns compared to others with ALS. If so, this could point to different "subtypes" of ALS, opening doors for more tailored approaches to treatment and care.

Together, these projects are helping to piece together the bigger picture of ALS. Understanding how genetics, family history, and brain activity fit into the puzzle could not only improve diagnosis but also move us closer to more personalized therapies.

## Study into the early signs of impaired neural activity in MND - Dr. Gabriel Costa

Dr. Gabriel Costa is a postdoctoral research fellow at Trinity College Dublin studying the early signs of impaired neural activity in MND. In 2023, he was awarded a Marie Sklodowska-Curie COFUND Fellowship to use advanced data analysis methods to further our understanding of neurodegeneration in MND.

Under supervision of Professor Orla Hardiman and Professor Bahman Nasseroleslami, his work at the Academic Unit of Neurology, TCD, has shown how distinct signals in the brain waves measured using Electroencephalography (EEG) are altered in MND, indicating the impairment of neural activity. These changes in brain cell activity may reflect ongoing degeneration, but they can also provide new insights into the mechanisms driving the disease.

To better understand the origin of these altered brain signals, Dr. Costa is combining EEG findings with detailed brain maps that chart the molecular and cellular characteristics of different regions of the human brain. This approach helps identify which neurons and brain areas are most likely responsible for the differences observed in EEG.

His recent work, presented at the ENCALS 2025 Conference in Turin, Italy, highlighted how particular neurotransmitters, the chemical messengers that neurons use to communicate, are linked to the EEG changes seen in MND. For this contribution, he was awarded a Best Poster prize at the conference.

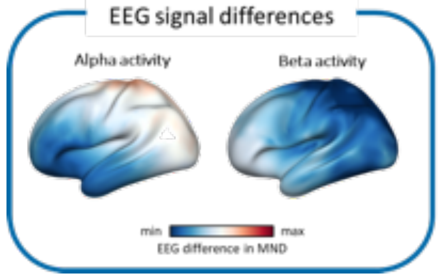

**Figure 1. Above:** Differences in EEG activity of distinct brain waves. Distribution of different neurotransmitters in the healthy brain.

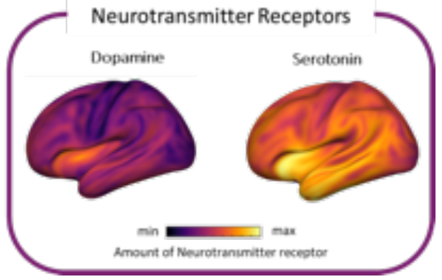

**Figure 2. Above:** The association of both types of brain maps, EEG activity and neurotransmitters, can help us understand the origins of impaired neural activity in MND.

### PRECISION ALS: An Irish-Led Innovative Collaboration across Research Active European Sites.

MND is a rare disease, it is vital that we have sufficient scale to allow us to make meaningful discoveries. Trinity College Dublin, along with the TRICALS (Treatment Initiative to Cure ALS) are working together to collect information from thousands of MND patients across Europe. The PRECISION ALS project is funded by Research Ireland, in collaboration with industry partners.

The TRICALS Consortium is co-chaired by Prof. Orla Hardiman (Trinity College and Beaumont Hospital Dublin) and Prof. Leonard van den Berg (University of Utrecht, Netherlands). 18 sites across 15 countries are now working closely together to collect prospective longitudinal data from as many people with MND as possible. The objective is to collect all aspects of the disease from the time of diagnosis through the entire patient journey, to understand all aspects of the condition. PRECISION ALS will also develop and utilise new technologies and devices to better understand differences in how the disease develops in different subgroups.

As data are collected and collated using a bespoke patient platform designed by data scientists in Trinity College Dublin, the large dataset will help to drive development of new AI and machine learning techniques, enhancing the potential for discovery of different subtypes of disease, and development of better therapies, so that we will eventually be able to provide the right drug for the right patient at the right time.

If you would like more information on PRECISION ALS you can visit www.precisionals.ie

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# MARKING GLOBAL AWARENESS DAY 2025

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. This year was a bit different as IMNDA marked 40 Years of Care, 1985-2025.

We once again held a reception in Salesforce Tower in Dublin's docklands area which was compered by Norman Hughes. We were very excited to be joined by An Taoiseach, Michèal Martin along with Professor Orla Hardiman, the Academic Unit of Neurology from Trinity College Dublin and our MND community.

This event highlighted the IMNDA's previous four decades of care as well as new developments within IMNDA, delivered by our CEO, Kevin Burn. We had presentations from Naomi Fitzgibbon, Director of Services and Nursing and Fiona Thornton, Head of Communications and Advocacy.

Our special guest, An Taoiseach, Michèal Martin arrived at the venue in time to hear Prof Orla Hardiman's talk, "MND in IRELAND", Reflections on a successful partnership over 30 years. Following this, An Taoiseach, Michèal Martin praised Prof Hardiman for her work into MND for many years and presented her with a Lifetime Achievement award for her dedication and commitment to Motor Neurone Disease.

This was followed by further awards to the founding CEO of IMNDA, Eithne Frost (who was unable to join us in person on the day) and Andy McGovern, MND Survivor, both were presented with MND Hero awards. We then had awards for our MND community, for people who have contributed and supported the association for many years. Finally, we presented awards to IMNDA staff members for their length of service. An Taoiseach Michèal Martin, presented awards to each person and congratulated them for their commitment.

Following the awards, attendees heard from Stefanie Havelka, who shared her own moving story of her MND experience. And finally, the IMNDA team made a presentation to the Late Lillian McGovern's family, the former CEO of IMNDA who sadly passed away in 2024. Lillian's daughter, Stephanie accepted the presentation on behalf of Lillian's family.

This year, we used the platform of Global Day to launch our annual Voice for MND campaign. In previous years, we asked people to lose their voice by doing a sponsored silence in order to give a voice to people with MND. But this year, we asked people to use their voice and speak up for the community. We launched a petition asking people to sign, share and speak out for people battling MND. The petition called on the Department of Health to increase funding and recognition for families living with MND in Ireland. We asked people to support our pre-budget submission and strengthen our case. This work continued in the months following the launch on Global Day. You can read more about this in our Advocacy section.

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.

# IMNDA AGM & ANNUAL CONFERENCE CORK

In October of this year, IMNDA's AGM and Annual Conference took place in The Talbot Hotel in Cork. 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 AGM took place early on Friday morning where the IMNDA's Board of Directors reviewed the operations and financial performance of the organisation in 2024.

This year's AGM also included the rotation of Directors meaning we had to say goodbye to Jonathan Healy who has been on the board since December 2012, where he served his time as a member of the board and then took up the position of Chairperson in 2022. The floor and the board voted in a new Chairperson, Norman Hughes. Two new board members were also coopted on to the board, Orlagh Reynolds and Aisling Moore. Orlagh is a seasoned recruitment leader with over 25 years' experience in her industry both at home and abroad. She sadly lost her husband Fraser to MND. Aisling Moore is a Senior Editor and Podcast Producer for Newstalk radio, with almost 20 years' experience in the media industry.

We would like to take this opportunity to congratulate Norman on his new position as Chairperson and we would also like welcome Orlagh and Aisling. Finally we would like to thank Jonathan Healy for his commitment to the IMNDA over the years. Jonathan was always a great help to the staff for his advice on communications and he has been a huge support to the IMNDA over the years, we thank him for all his help.

Following the formalities of the AGM, we were then treated to a very interesting conference with a variety of speakers MC'd by Jonathan and Norman. Jonathan welcomed people to his native city of Cork and spoke about how he was stepping down from the IMNDA board after serving 13 years.

Jonathan introduced the IMNDA's CEO, Kevin Burn who is in his second year with the IMNDA. Kevin, acknowledged Jonathan Healy's commitment to the association and thanked him for serving his time on the board for 13 years. He then spoke about how welcomed everyone has made him feel since he started with the association. He spoke about the IMNDA's 40th year anniversary and the importance of marking such an occasion. Kevin then went on to thank everyone serving on the board and the team at the IMNDA. He concluded by stressing the importance of having sustainable funding from the government to continue providing vital services to the IMNDA community.

Up next was the first of our international speakers, Prof Rebecca L. Gould. Rebecca is a Professor of Psychological Therapies at University College London (UCL) and Honorary Clinical Psychologist. She is the Chief Investigator of the COMMEND trial, which is a major randomized controlled trial of Acceptance and Commitment Therapy (ACT) for people living with MND, comparing adapted ACT + usual care versus usual care alone. Her work is helping to establish psychological therapies as evidence-based supports in MND care and she gave an overview of this work in her presentation.

Up next to the podium was the first of our MND Community speakers, Geraldine (aka Geri) & Martin Phillips. They shared their personal journey of living with MND. Geraldine was diagnosed with MND at just 57 and she talked about her everyday life with MND and how she copes with living with the disease. She told us that she found that the power of community really helped her to cope with her diagnosis. Following Geraldine's inspirational talk, we then heard from her husband Martin who gave up his job to become Geraldine's caregiver. He also spoke about his experiences of being a carer to Geraldine as they navigate the world of MND.

We then had Dr John Curtin. John is a graduate of UCC, completed higher specialist training in Palliative Medicine in the Oxford Deanery and obtained a mixed methods PhD through Oxford Brookes University. He took up his first consultant post at Mountbatten Isle of Wight Hospice in 2018 and returned to Cork with Marymount Hospice and Cork University Hospital in 2024. He discussed how multi-disciplinary and person-centred approaches can improve outcomes for families facing MND.

Attendees then heard from Orlaith Leo, a caregiver who has supported a loved one living with MND and spoke about her own experience of being in a caregiving role.

Following Orlaith's moving tribute, we had our second international speakers, Dr. Melinda S. Kavanaugh, PhD, LCSW. Melinda is a Clinical Social Worker and Professor of Social Work at University of Wisconsin–Milwaukee. She is a specialist in research on youth caregivers / young carers, particularly in families affected by neurological disorders such as ALS/MND. Her translational research focuses on giving a voice to children & teens who provide care, and developing tools and programmes that support them.

Next we heard from Dr Ciara O'Donoghue who attended our conference on behalf of Prof Orla Hardiman. Dr. Ciara O'Donoghue works at Beaumont and is a PhD student in the McMackin Lab at the FutureNeuro Ireland centre.

Finally, to the Podium, we had Clare Duffy. Clare is a Policy & Public Affairs Manager at Family Carers Ireland. She is also an advocate for the rights and wellbeing of family carers, Clare has led national campaigns and policy work to improve recognition, supports and entitlements for caregivers. She presented on benefits and finances for caregivers, outlining what practical supports are available and where gaps remain.

All our presentations from each of the speakers are available to view on our YouTube Channel @MNDireland.

We want to take this opportunity to thank both national and international speakers who took time out to come to our Annual Conference in Cork. We would like to thank all the organisations that took stands and spoke to our members. These organisations were: Dovida, Family Carers Ireland, Irish Wheelchair Association (IWA), The Academic Unit of Neurology in Trinity College Dublin (TCD), and RESMED PEI.

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 with Prof Rebecca Gould and the second with Prof Melinda S Kavanaugh.

# 36TH INTERNATIONAL SYMPOSIUM ON ALS/MND

The International Symposium on ALS/ MND took place in San Diego in the USA on 5th -7th December 2025, this event 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).

The 2025 Allied Professionals Forum took place from 1st -2nd December in Toronto, Canada. This event brought together 300+ healthcare professionals from around the world, including physiotherapists, respiratory therapists, nutritionists, speech & language pathologists, social workers and others working in the field of ALS/MND.

The Alliance Meeting is where member associations, including the Irish Motor Neurone Disease Association (IMNDA) met and shared experiences in growing, running and building an ALS/MND association to support people living with ALS/MND. The meeting was attended by 200+ delegates from over 40 countries around the globe, representing the Alliance's many member associations.

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.

This year Kevin Burn, CEO, Naomi Fitzgibbon, Director or Nursing & Services, Paula McNally-Krenn, Regional Services Coordinator and Fiona Thornton, Head of Advocacy & Communications represented IMNDA by attending the Allied Professionals Forum and the Alliance Meeting in Toronto.

For more information, please visit: https://symposium.mndassociation.org/

mnda motor neurone disease association
35th international symposium on ALS/MND

INTERNATIONAL ALLIANCE OF ALS/MND ASSOCIATIONS

# 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 Walk While You Can.  Sharing a personal story has helped us to raise awareness of MND and raised funds 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 Tony Ryan & Amanda Lillis who shared their story for the Drink Tea for MND Campaign and Paul McCormick who shared his story for the Walk While You Can event.

## LIVING WITH MND TONY RYAN, TOLD BY HIS PARTNER, AMANDA LILLIS.

"This is Tony's story. Known affectionately by most as Schillaci. He was born and raised in Nicker, Pallasgreen, County Limerick, the second youngest of 12 siblings. His parents, Mike and Eileen (Ninny) Ryan, built a home filled with faith, love and hard work, values that shaped him into the man he is today. Tony's Mother sadly passed away this January at the age of 84, but her strength continues to inspire him and live in him every single day.

He started working young and mainly in the construction industry. We met in the 90's and we built a life and had four incredible children: Corey (28), Tonieka (25), Zekeisha (17), and Zantianna (12). Life was good, busy, full of laughter, and focused on providing for our family. But in November 2020, everything changed.

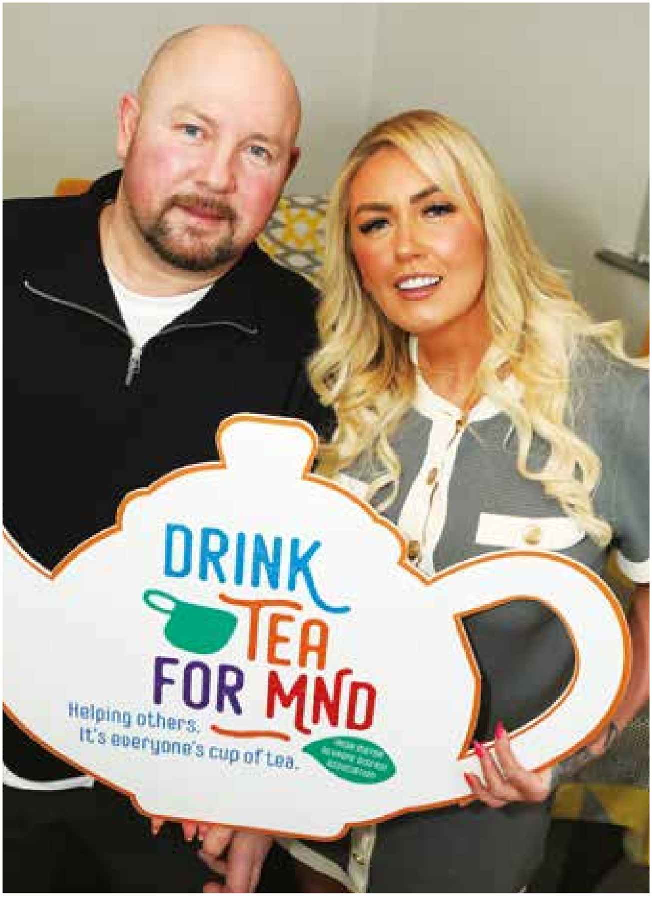
It started with something small, a twitch in his upper left arm. He brushed it off, blaming work strain and thinking it would go away. But it didn't. The twitch turned into persistent pins and needles, then a dead-arm sensation. When one of his arms started looking smaller, we knew something wasn't right. After weeks of my nagging and eventually dragging him to the doctor, the first referral from the doctor to the neurologist was August 2021 and then the journey of tests, referrals, and waiting began.

In April 2022, Tony received his official diagnosis: Motor Neurone Disease from Professor Orla Hardiman in Beaumont Hospital.

MND is a cruel and relentless illness. It attacks the nerves that control your muscles, slowly taking away movement, speech, swallowing, and eventually breathing. The worst part is your your mind stays sharp the entire time. There's no cure, no set timeline, no way to predict which muscles will fail next. It's living with uncertainty, knowing that every day could be the last day you do something on your own.

The muscles slowly waste away, making even the simplest tasks impossible. Tony can no longer dress or feed himself without help which I have stepped into this role. It's not easy, for either of us. In the beginning, Tony struggled with embarrassment, the idea of needing help, of losing his independence, of not being the man he once was. But what Tony has learned is that strength isn't just about doing everything yourself. It's about facing the battle head-on, finding new ways to adapt, and accepting the love and support around you.

Since Tonys diagnosis, we've made it our mission to create as many memories as possible. We've travelled, laughed, and lived with urgency because we don't know what tomorrow will bring. But we also face daily struggles that many don't understand.



Because Tonys disability isn't always visible, we often run into challenges that shouldn't exist. A recent trip to buy clothes turned into a humiliating experience when we were told he couldn't bring someone into the fitting room to help him. We had to explain that he couldn't dress himself and even then, it took time for them to allow it. If he had a cast on his arm, nobody would question it. But MND is invisible to those who don't know – and that's why awareness is so important.

We are beyond grateful for the incredible team supporting us – from his Doctor from Abbey River House, Dr Maurice Rowsome,  Palliative Day Care in Milford Hospice, Cappamore Health Centre to Beaumont Hospital and the IMND Association. The IMNDA relies on fundraising for over 85% of its income, providing crucial support for families like ours. At first, he wasn't ready to sign up, maybe because doing so felt like admitting to himself what was happening but they have been incredible in helping and funding services and equipment that is vitally needed for Tony to have somewhat a feeling of independence."

## LIVING WITH MND, PAUL MCCORMICK

“My name is Paul Mc Cormick. I am 59 years old. I am originally from Monaghan town but have lived most of my life outside Monaghan. I came to Dublin in 1983 aged 17 years to study medicine and graduated from the Royal College of Surgeons in 1989. I eventually trained to be a General Practitioner in 1997. I have been a GP Principal in a practice in Dublin since 2001 until late 2024 when I stopped working. I have worked in the Mayo Clinic in Rochester Minnesota and also in Sligo and Mayo. I met my wife Blaithin while doing my internship in Beaumont Hospital. We got married in 1991. She was my practice Nurse when I was working as a GP. We have 4 adult children aged 31, 29, 25 and 22 years, 3 boys and a girl. Two of the boys are Doctors. One is a Senior Registrar in Emergency Medicine. The other has just qualified and is doing his internship in Beaumont Hospital, as I did in 1989. The other boy works in administration in Trinity College. My daughter, the youngest, has just completed a degree in social science and has been offered a place to study medicine in the Royal College of Surgeons ( just like me).

My hobbies are sports, especially team sport. I have played soccer and Gaelic football since I was young. I have played tag rugby when older. I enjoy watching soccer, rugby and Gaelic football. My teams are Leeds Utd, Monaghan, Leinster and of course Ireland in any sport. I have been lucky enough to attend games at each of the last 3 Rugby World Cups. I also enjoy watching old film classics.

I experienced some weakness in my left hand in October 2023. I noticed that I could not snap the necks of small Vitamin B12 vials, use a nail clipper with my left hand or unbutton my trousers when going to the toilet. I was feeling exhausted and overwhelmed at work. I attended my GP who sent me for a nerve conduction study/electromyogram. I was then admitted to hospital and had some MRI scans of my head and neck, I also had blood tests and a neurological exam while in hospital.

We had big decisions to make as I was a GP running my own practice with my wife who was the practice Nurse. We needed to really think about it. It became obvious to us that it would be impossible to run a busy practice with a progressive neurological illness such as ALS. Running a busy practice means you are responsible for staff and patients alike. I also was in my 18th year of working as a GP trainer and was responsible for training and supervising a GP Registrar. You need to be in full health to do this.

We made a trip to Melbourne where my oldest was based at the time. Australia had been on my bucket list. We visited Sydney and the great barrier reef and I have the photos to prove it. Ultimately we decided to try and find a Doctor or Doctors to take over our practice and stop working as soon as possible to avoid leaving patients without a GP and so staff could continue working and getting paid without interruption. I could use my free time doing trials to help find a cure for this debilitating and life limiting condition. We managed this with some expert help. It took about 7 months from start to finish. My wife and I stopped working in October 2024.Fortunately I had some income protection to fall back on.

We have renovated our home to make it wheelchair accessible. I don’t need a wheelchair at the moment. I am involved in a phase 1 drug study for ALS in St. James’s Hospital. There are no results yet.I am also involved in another study with the Beaumont Dietetics Department regarding increased calorie intake as a treatment for Motor Neurone Disease. I attend Professor Hardiman in Beaumont. She and her multidisciplinary team are very supportive. My GP has also been great. I have received fantastic psychology assistance from Annette Lloyd through the clinic. The IMNDA have also been supportive through their Nurse, Louise and their financial support for things like counselling and acupuncture which we have availed of. It’s great to know that they are there to provide assistance during my MND journey. My daughter Aoibhinnn organised a Walk While You Can event on New Year’s Day 2025. It was a great success. She raised awareness and about €12,000. I still have a ‘clumsy’left hand and there is some weakness in my left arm. I need to take a nap every day. At the moment we are enjoying our time off and have done some travelling.

Motor Neurone Disease affects the whole family. My children are still trying to forge their careers and I am trying to be as supportive as possible for as long as possible. My eldest has moved back from Australia with his girlfriend to spend time with me. My wife Blaithin provides unwavering support. At the time of diagnosis, my thoughts were 90% occupied by Motor Neurone Disease. At the moment I am only giving it 10% of my thinking time. I am very lucky to have a supportive family and friends as well as the help of the Health Professionals and the IMNDA.” Paul Mc Cormick.

# CARING FOR CAREGIVERS ONLINE PROGRAMME

We are once again delighted to announce the return of the online programme for caregivers which is being funded by the Charlie Bird Development Fund (CBDF). This online programme entitled Caring for Caregivers, Coping Techniques is designed for family caregivers who are looking after a person living with MND and who is also a registered client of the IMNDA.

This online programme is 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 into the future. We are grateful to Mary for her support in developing this programme.

**"Great course and the opportunity to talk with others who are on a similar journey is hugely important".**

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.

# HEALTH INFORMATION PASSPORT

The **Irish Motor Neurone Disease Association** has put together a Health Information Passport with help from the MND Association, England, Wales & N. Ireland as well as members of the Irish MND community.

The aim of the Health Information Passport is to assist Health Care Professionals (HCP's) to understand the needs of the person living with MND during their health care visits. More information can be found on our website, please visit **www.imnda.ie**

# NEW FAMILY SUPPORTS ANNOUNCED AT IMNDA ANNUAL CONFERENCE

At our annual conference in Cork this October, the IMNDA team was delighted to share news of a new range of supports for families living with MND.

Thanks to a once-off funding surplus this year, we've been able to invest directly in areas that families tell us make the biggest difference day to day. These new measures aim to provide timely, practical relief and include:

- **Cost of Living Fund:** Flexible financial support to help with essential expenses such as energy bills, transport, respite care, or home adaptations.
- **Expanded Night Nurse Support:** Night nursing care available at any stage of MND, giving carers vital rest and reassurance.
- **Communication Supports Programme:** Funding for communication aids such as speech-generating tablets and eye-gaze systems, helping people maintain their voice and independence.
- **Essential Equipment Fund:** A rapid-response fund to meet urgent equipment needs like wheelchairs or specialist mattresses.
- **Travel Grant:** More funding available to assist with getting to and from appointments.
- **HSE Homecare Top-up:** IMNDA will top up homecare hours.

These new supports are about listening to families and responding to what matters most.

As we look to 2026, IMNDA remains focused on ensuring no family faces MND alone — and that every euro raised continues to go where it's needed most.

# IMNDA COMMUNITY HUB

Did you know that the IMNDA has set up a Community Hub for people affected by Motor Neurone Disease (MND), their caregivers and families?

The IMNDA Community Hub is an online support community for people affected by Motor Neurone Disease (MND). It is a safe and supportive online discussion site for the MND community.

- Looking to discuss your experiences with other people?
- Interested in finding, receiving and providing support?
- Want to connect with others at a time convenient for you?

Our community page allows you to post questions, share tips or advice, and interact with people with MND and their loved ones from around the country.

Registration is free and your contact details are kept confidential. You can submit your own questions and use the answers provided by the community to help support you with MND. You will find our online community hub here at **community.imnda.ie**.

Once registered, you will have access to the following services:

**Forums**
Our forums can be read by anyone, but in order to interact with others and post messages of your own, you will need to register with this site.

**Blogs**
A blog is a shared online journal where people can post diary entries about their personal experiences. We will also share entries by health professionals and those involved with research.

**Connect**
Reach out to people living with MND. Registered members can connect to freely discuss topics in a private and safe area.

The online community is open to people affected by Motor Neurone Disease and provides a place to connect, and find support in a safe space. For more see: http://community.imnda.ie/

# VOICE4MND 2025: WHAT YOU TOLD US ABOUT THE POWER OF VOICE

As part of our Voice4MND campaign, IMNDA asked the public what it means to lose your voice. Almost 200 people took part in the Voice4MND Public Awareness Survey, offering powerful insights into how voice loss affects people living with Motor Neurone Disease (MND).

Over 94% of respondents already knew that voice deterioration can be a symptom of MND, yet one in eight had never truly considered its impact. When asked what they would miss most if they lost their voice, two thirds said "talking to family," followed by "laughing with friends" and "saying I love you."

An overwhelming 95% said their voice is central to their sense of identity, and 92% believe it is extremely important to raise awareness about voice deterioration in MND. Encouragingly, 78% had heard a recorded or computer-generated voice used by someone with MND, and most said it made them think differently.

More than three quarters said they would support future awareness campaigns, with 69% likely to donate.

Through Voice4MND, IMNDA will continue to amplify the voices of those affected by MND and ensure that no one faces silence alone.

#Voice4MND

# PETITION & TD OUTREACH UPDATE

2025 has been a landmark year for advocacy at IMNDA. Our Communications team has been working tirelessly to amplify the voices of people living with MND and to ensure that their needs remain firmly on the public and political agenda.

A major highlight of our work this year has been our national petition which we launched at Global Day, which has now gathered **almost 6,000 signatures**. This powerful show of support calls for increased government investment in MND to sustain the services that people with MND depend on every day.

To build on the momentum of the petition, we also reached out directly to our community to encourage people to contact their local TDs. The response was inspiring as many messages were sent to representatives across the country, helping to ensure that the voices of people with MND and their families are heard where it matters most.

Throughout the year, we've worked closely with partners, supporters, and the MND community to share real stories that humanise the challenges behind the statistics. From national media features to awareness campaigns, our goal remains to drive positive change for the MND community.

We are so grateful to everyone who has signed the petition, contacted their TDs, shared their story, or supported our campaigns in any way. Your voices really do make a difference and together, we're building the momentum needed to secure better care, more funding, and stronger recognition for those living with MND.

# IRELAND AM & DRINK TEA FOR MND EVENT

The IMNDA celebrated 40 years of care on the 1st May this year, we marked this occasion in so many ways. We were very excited to hold a Drink Tea event in the exquisite Hilton Hotel in Charlemont Street in Dubin. Ireland's favourite early man, Deric Ó h'Artagáin from Ireland AM, was there with us to film a segment of the show and we were live on the telly!! Deric interviewed Professor Orla Hardiman, IMNDA's CEO, Kevin Burn, and Andres Estevez Guersanik who is living with MND and his wife Jennifer Estevez. The show highlighted the Drink Tea event and the work of the association, research into MND and living with MND.

# THE IMNDA MARKED 40 YEARS CARING FOR PEOPLE LIVING WITH MND AND THEIR FAMILIES THIS YEAR - 2025

The IMNDA was set up on the 1st May 1985 by a small group of people who had never heard of Motor Neurone Disease (MND) but had friends and family members who were struggling with the condition. They came together to set up on the IMNDA, and the support continues today… here is a look back over the history of the association.

**1985:** The very first meeting of the Association was held on Wednesday 1st May 1985 in the Friends' Meeting House, Lower Churchtown Road, Dublin. The founding members of our association were Carmel Ross, Mary Callinan and Cathy Feeney who were the initiators and organisers of this meeting. At the time over 60 people were affected by MND each person had a strong belief that there was need for a support organisation. The primary goal of the association in 1985 was to break the isolation experienced by MND people, their carers and families. With this goal in mind and a strong determined group, the Irish Motor Neurone Disease Association was formed, and the rest is history.

**1986:** The association was slowly becoming established; the first major fundraiser was the premier of 'Eat the Peach' in the Savoy Cinema, this fundraiser raised £14,000 that year.

**1987:** The first information leaflet was launched – MND – What is it?

**1988:** The Association moved to a new office run by the Community Services Project at Christchurch Place and is managed by Chairperson Eithne Frost, one of the founding members of the association. Also in this year the British Director of the MND Association makes a visit to Dublin and offers advice and assistance. Both associations developed a good rapport with each other. The larger and somewhat older UK Group assisted Irish beginnings with practical support.

**1989:** Eithne Frost resigned as chairperson to take up the first post as administrator in the Association. Eithne's work involved making contact with existing and new patients. The association's service expands and active networking is in place with healthcare professionals.

**1990:** The Association is on the move again. We move to more permanent and bigger offices in Carmichael Centre. During this year the John Harty Race Ride takes place, this gives the association a great boost and helped to improve the equipment bank.

70 PATIENTS NOW

**1991:** Motor Neurone Disease linked to gene… Researchers in the US find certain probes link to the gene causing familial MND.

**1992:** IMNDA plays an important role in the new international worldwide alliance of Associations working to help people with MND.

**1993:** The Freefone no is launched 1800 403 403, this was funded by the then Eircom and today this continues to provide a very important link between the Association and people with MND and their families.

**1994:** The first patient & carer weekend takes place in the heart of the country – The Hodson Bay Hotel in Athlone. The Duchess of York, Sarah Ferguson pays a surprise visit to a Cork man who has MND; she spends the afternoon with him before flying back to England. That year the committee and staff of the IMNDA also meet the Duchess of York, Sarah Ferguson, at the International Alliance.

MND features on the television; Check Up programme is screened on RTE. Professor Stephen Hawking visits Dublin to give lecture on 'The Beginning of Time'. Patients and members of the organisation get to meet him.

**1995:** The tenth anniversary of the Association, one of the highlights for the association is the Gala Concert that is held in the national concert hall. Mary Robinson opens the 6th annual ALS/MND Symposium which takes place in the Burlington Hotel in Dublin, with 370 delegates representing 21 countries.

**1996:** MND Liaison Nurse Bernie Corr is assigned to care for MND patients on a full-time basis. Also during this year The Film Premiere of 'The Last of the High Kings' in association with Dublin Film Distribution Co Ltd and First Independent Films Ltd. The event raises a staggering £11,500 IR for the association.

**1998:** The launch of Andy McGovern's first book, 'They Laughed At This Man's Funeral', this launch is held in Eason's Book Shop in Dublin City and is attended and supported by the great actor Mick Lally. Andy is one of the Ireland's longest survivors of MND.

**1999:** By the end of the 1990's the Association is in touch with over 200 people with MND. A broad network of supporters is established throughout the country and credibility with the Department of Health and other statutory bodies is built.

**2000:** 15 years of caring and the Association is on the move again, but only across the road this time, Coleraine House, Coleraine Street.

**2001:** Launches the new email address for the association info@imnda.ie

**2004:** The launch of the National Radio Advertising Campaign, "My legs won't walk, My Mouth won't talk, I'm losing control of my body, but my mind works perfectly" this 30-second radio advert runs for three weeks on RTE's radio and receives a massive response from the general public.

**2005:** Motor Neurone Disease goes live, the Association's Website is launched during this year, and the domain name is www.imnda.ie – the home of where we are today! This year also sees the '16th International Symposium' return to Dublin and is held in the Burlington Hotel.

**2006:** The Film Premier – The Tigers Tail takes place in the Savoy Cinema with an after party in Croke Park. The film is about Ireland's Celtic Tiger years and features English Canadian Actor Kim Cattrall, Irish Actors father & son: Brendan & Briain Gleeson. This year also sees Olympic Gold Medallist, Michael Carruth take to the stage to perform some Irish dancing in the Celebrity Jigs n 'Reels TV dance show.

**2007:** The Association employs two specialist MND nurses to provide people with practical advice and emotional supports on how to manage the disease. Fidelma Rutledge is one of these nurses that joins the IMNDA team and is still working with us today.

**2008:** The Association appoints a new patron – RTE's sport broadcaster Jimmy Magee. Jimmy's son Paul was diagnosed with MND a few years earlier, but he sadly passes away in 2008.

**2009:** An awareness video is made in 2009 about the work of the Irish Motor Neurone Disease Association featuring actresses Sinead Cusack and Mary McEvoy, IMNDA Patron and RTE Broadcaster Jimmy Magee, Fair City Actor Thomas Jordan and IMNDA supporters, Patrick Kelly, Amanda McCormack and Nora O'Leary.

**2010:** The Association visits Áras an Uachtaráin where we meet President Mary McAleese in April of this year, we are joined by many of our people with MND, their families and many of the associations supporters who have been with us down through the years.

That year also sees the Celebrity Soccer Classic organised by World Title Boxer Bernard Dunne. With big names like Liverpool's Ian Rush, Ireland's Packie Bonner and Ronnie Whelan to name but a few! This celebrity team was managed by the IMNDA's very own and much-loved Patron Jimmy Magee.

**2011:** Sports commentator Jacqui Hurley gives up her time for IMNDA to help with the promotion of the Women's Mini Marathon. The first ever Tag Rugby Cup is brought to Blackrock RFC and is organised by the association.

**2012:** In January of this year, we see the most thought provoking and inspirational documentary entitled 'MND-The Inside Track' the famous sports broadcaster Colm Murray's documentary on his journey with MND. Colm passed away the following year in 2013.

**2013:** The longest person living with MND in Ireland Mr Andy McGovern takes to the books again!! Andy dictated his book "Against the Odds" using voice recognition technology. This inspirational book is about his life and his diagnosis of MND and was launched on Andy's 80th Birthday on the 10th February. This year the Association also welcomes a new CEO, Aisling Farrell, who joins in May of this year.

**2014:** August of this year will not be forgotten for a long time! The Ice Bucket Challenge which originated in America– this absolute phenomenon that raised incredible awareness and funds for the IMNDA by someone simply recording a video of another person pouring a bucket of ice over themselves and uploading it to social media, nominating another 3 individuals to do it and donating €2 to the association! And it spread…like wildfire!

**2015:** 30th Anniversary… In light of the special anniversary the IMNDA is marking this year, President Micheal D. Higgins and his wife Sabina invited 50 people involved with the association including our members, staff and board members, active fundraisers and dedicated volunteers who could make the journey to come along to the Áras an Uachtaráin

**2016:** The 27th Annual International Symposium for ALS/MND comes to Dublin and is held in the Dublin Convention Centre, December 2016.

**2018:** Eurovision's Roy Taylor launches Drink Tea for MND this year and with his band Jump the Gun, they create a catching 'Drink Tea for MND' melody. This is also the year that Fr Tony Coote organised and took part in 'Walk While You Can', a fundraising walk from Letterkenny, Co. Donegal to Ballydehob, Co. Cork. The walk of over 550 kilometres received national attention with Tony completing the journey in his wheelchair in 4 weeks in every weather condition imaginable. Over 260K is raised.

**2019:** This year sees 'The Riverdance Danceathon for IMNDA' take place outside the Gaiety Theatre in Dublin and the IMNDA Nurses help launch this event.

RTE's presenter, Claire Byrne, supports Walk While You Can in the Phoenix Park, this is because of her close friendship with Fr Tony Coote.

**2020:** Drink Tea for MND is forced to go online due to Covid but raises the most ever - €250k!!!

**2021:** The association employs a new CEO, Lillian McGovern, she comes with a wealth of experience from the Charity sector. Also this year, The Book 'Living with Motor Neurone Disease A Complete Guide' by Dr Marie Murray is launched in UCD along with RTE's presenter, Claire Byrne.

**2022:** This is another monumental year for fundraising & awareness of MND. Climb with Charlie takes place this year and raises a staggering €3,376,000 for IMNDA & Pieta House.

**2023:** From the proceeds raised by the Climb with Charlie event, 'The Charlie Bird Development Fund' is set up to help people living with MND & their families –this also allows the Association to employ an additional MND Nurse this year, we now have 7 nurses in total, including a Director of Nursing. Also this year, Kevin Sinfield comes to Ireland in December for his 7in7in7 Ultramarathon Challenge raising awareness & funds for MND, he meets Charlie Bird in Croke Park at the start of his challenge.

**2024:** The Association employs a new CEO, Kevin Burn, Kevin comes with a wealth of experience from the community & voluntary sector. This year Irish Life chooses IMNDA as their charity partner for a record 3rd time.

**2025:** IMNDA marks 40 years of care on the 1st May 2025, founding CEO, Eithne Frost, meets current CEO, Kevin Burn, together they plant a tree of hope for the future. This year, IMNDA makes a video with CB media, to mark the Association's 40 years of Care, 1985-2025. This video featured images and commentary from down through the years. To watch this video, you can visit our YouTube channel @MNDireland and search for: IMNDA Over the Years.

Let's hope there will be only one story in the next era and that is…'A World Free of MND'

# IMNDA PLANTS TREE TO MARK 40 YEARS OF CARE

On the 1st of May this year, the Association marked 40 Years of Care. To commemorate this, we visited Irish Trees in the Naul in Co Dublin where we planted the 'Tree of Hope' and scattered Cornflower seeds for our MND Community.

We were delighted to be joined by the founding CEO of the IMNDA, Eithne Frost. We were also joined by a small group of supporters of IMNDA. We gathered at the tree planting site where refreshments were had, and we listened to Eithne Frost talk about the humble beginnings of the association and how it all came about. We also listened to Kevin Burn, current CEO of IMNDA who spoke about the association now and our hope for the future.

We then made our way to where we would plant the Tree of Hope and scattered cornflower seeds for our MND Community. Eithne & Kevin together planted the tree to reflect the past and the present… what we have been through and what we hope for the future, **A world Free of MND.**

A special thanks to Bob Hamilton & John Doran from irishtrees.ie & IrishUrns for allowing us to hold the event in the peaceful & beautiful surroundings in the Naul in Co Dublin, a place well worth visiting. Both Bob & John from Irish Trees welcome the public to visit the site and plant a Tree as a lasting legacy in memory of a loved one. More information can be found in the fundraising section of this magazine.

# 40K YOUR WAY IN MAY

Over 100 people joined our 40K Your Way in May challenge and helped us mark 40 years of care to the MND Community. An amazing €74,000 was raised from your efforts! A huge thanks to all who took part, we can't wait to bring back this challenge next May. We think this lovely poem perfectly sums up an incredible month…

**40k Your way in May**
**From the Irish Motor Disease Association**

We walked and we swam, some limped through the day
To all who joined in-thank you for doing 40k Your way in May
With runners aacnd smiles, we gave it our best
Even if some of us needed a Rest

Naomi was swimming with power and grace
Making big splashes all over the place!
Aine, Fidelma and Maire took flight
Walking in the sunshine and even at night

Louise got creative and gave us a giggle, her dog wore the hat
And started to wiggle
Charlene made headlines (or so we suppose)
By spraining her foot - on purpose? Who knows?

Kathryn kept dancing, she twirled with such flair
Spinning and grooving somewhere in Kenmare
Gemma and Jackie in fundraising bliss
Cheering each euro- nothing was missed

Derbhla told stories, she nailed every line
While Fiona in PR made our message shine
Lisa & Paula, equipment queens supreme,
Sorting gadgets and gear like a well-oiled team

Audrey and Declan- accounts royalty,
Keeping things balanced financially
Johanna took charge of each call with grace
No question too tricky, she handled the case

And leading the charge with a CEO glow
The captain of calm-our Kevin you know!

But none of this magic would ever be real,
Without all of YOU, and your spirit and support we feel
You donated, walked, swam, and shared with such care
Your kindness and heart were felt everywhere

Together we laughed, we limped, and we ran,
Each with our own slightly odd plan.
But one thing is clear, through effort and fun
We're grateful to YOU, each and every one!

So, from all of us here, in our own special way,
A heartfelt thank you for doing 40k Your way in May

# DRINK TEA FOR MND FUNDRAISER 25

As the association marked 40 years of care, this was a special year for all our events. The Drink Tea fundraiser once again was a wonderful success; we asked people to organise tea parties around the country and this they did. Another epic year as the campaign raised over €150K which included funds raised from the Exclusive Drink Tea event which took place in Powerscourt.

We would like to thank everyone who supported us in 2025. We wish you all a Merry Christmas & Happy New Year.
If you would like to support the association this Christmas, please scan the QR code to donate.

Thank you

# AFTERNOON TEA AT POWERSCOURT HOUSE

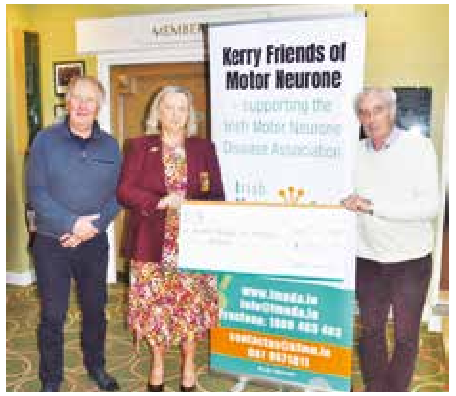
Our exclusive Afternoon Tea event at the stunning Powerscourt Estate took place on Saturday 29th March of this year. This event was to highlight our 40th anniversary and mark our annual Drink Tea for MND campaign, and we invited the MND community to join us for a truly special occasion in a wonderful setting.

Our community joined us for an afternoon of seasonal delights, music, special guests and prizes on the Mother's Day Weekend. As well as having the opportunity to walk round the stunning 47 acres of the Powerscourt Gardens which was open on the day.

We were very excited to have the legendary artist Don Conroy (who many will remember graced our screens with Zig and Zag on the Den 40 years ago!) who offered a special art class in the house prior to the afternoon tea. We are also delighted to to be joined by Terence Taylor, son of the late Roy Taylor ('Jump the Gun' fame) who lived with MND and was instrumental in raising awareness of the condition. Terence performed songs from his late father's wonderful catalogue of music along with members of the band 'Jump the Gun'. We are also joined by the renowned guitarist, Pat Coldrick, a sellout artist, who too played at the event.

It was a wonderful day spent with all these wonderful artists and over €10K was raised from the event.

# THANK YOU TO ALL OUR COMMUNITY FUNDRAISERS WHO HELPED MAKE OUR '40 YEARS OF CARE' SPECIAL. HERE ARE SOME OF THE EVENTS THAT TOOK PLACE OVER THE YEAR.



# THANK YOU TO OUR COMMUNITY FUNDRAISERS

# WE EXTEND A HUGE HEARTFELT 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.

We have nearly reached the end of Year 2 of 3 as one of William Fry's chosen charities. As ever it is always a pleasure to work closely with such a caring and passionate team. The William Fry gang attended our Powerscourt Estate Drink Tea for MND in March as well as Global Day in June. Between step challenges, treasure hunts and kind donations they are always keen to get involved. Thank you and we look forward to a super 2026!

A massive thanks to the staff at Irish Life who raised €530K during 2024 and donated €280K of this to the Irish Motor Neurone Disease Association at the end of the partnership.

Cormac Donnelly from Irish Life presents the cheque to (left -right) Gemma Watts, Head of Fundraising, Tracy Hutchin, Community Engagement Manager, & Kevin Burn, CEO from IMNDA.

In December 2024; Cormac Donnelly wrote "The Irish Motor Neurone Disease Association is a charity that holds a special place in my heart. Last week, I presented them with a cheque for €280,000, on behalf of staff at Irish Life and Canada Life. This is the third time in the last 12 years IMNDA was elected by staff, and a total of €530,000 has been donated. The generosity of staff never fails to amaze me."

To every company who donates, volunteers, organises Christmas jumper days, bake sales, takes on active challenges or simply helps to raise awareness of MND; thank you from the bottom of our hearts. We are so grateful!

# PLANT A TREE FOR MND

## SOMETIMES, WHEN WORDS ARE NOT ENOUGH….

This is a beautiful way to create a lasting 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. We were delighted to be joined by the IMNDA's founding CEO, Eithne Frost where we visited the site on the 1st May to mark the Association's 40th anniversary. We planted a tree for those we have lost to MND and as a symbol of hope for the future.

If you would like to consider planting a tree dedicated to your loved one, you can visit https://irishurns.com/product/imnda-memorial-tree/ or contact bob@irishurns.ie"bob@irishurns.ie. You then choose your preferred species, and Irish Trees will plant your tree at their beautiful 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. Thank you to Irish Tree for this initiative

# KEVIN SINFIELD 7 IN 7 TOGETHER 2025 CHALLENGE

We were thrilled to welcome Kevin to Cork on 2nd December as he continues to raise monumental funds and awareness for Motor Neurone Disease in Ireland, the UK and beyond!

This years epic challenge started on 1st December in East Anglia, running from Bury St Edmunds to Ipswich then across the Irish sea to Cork where Kevin received a fantastically warm Irish welcome as he started out from Cork's Red FM, visiting Virgin Media Park, running with invited guests at MTU for the Extra Mile and contiuning on via Cork City Hall finally finishing up at SuperValu Páirc Uí Chaoimh. Thanks to everyone who came along and supported Kev and to all who donated.It was another wonderful day and the IMNDA were proud to be involved.

From Cork, Kevin headed to Swansea, then Cumbria, and on day 6 up to Dundee in Scotland.

The end of the challenge saw Kevin and the team emotionally return to Leeds for the first time since 2023 and the passing of Rob Burrow last year.

Thank you Kevin for all you do!!!

The donation page is still open, if you would like to support Kevin's event, please check out this link:

**https://donate.giveasyoulive.com/fundraising/kevin-sinfield-7-in-7-together-challenge**

# IMNDA OFFICE UPDATES

## Baby Oisín

A huge congratulations to Johanna McGrath who gave birth to her baby boy, Oisín McGrath. Oisín was born on Monday 14th July 2025. Sending love to all of her family on this joyous occasion.

## Lorraine Carroll

We would like to welcome Lorraine who joined us this year to cover Johanna McGrath's maternity leave. Lorraine is working in the services department and is helping people living with MND and their families. She will be with us into 2026.

## Rhian Sayers

A huge welcome to Rhian who joined the IMNDA this year. She is working closely with the Fundraising, Accounts, Services, and PR and Communications teams to ensure a coordinated and impactful approach.

## Delcan Fenlon

We would like to welcome Declan Fenlon to the Association who joined at the end of 2024. Declan is the Head of the Finance Department.

## Eleanor Burke

We would also like to welcome Eleanor aka Ellie to our finance department too, Ellie has just joined us recently.

## Elizabeth Doyle

And a warm welcome to Elizabeth who too has joined the IMNDA's Nursing team recently, she is covering Dublin South and North Wicklow area.

# IMNDA OFFICE MOVE

The IMNDA have moved office, and this time to a permanent home. We are located here:

IMNDA, Ground Floor,
Merchants House,
27-30 Merchant's Quay,
Dublin 8, D08 K3KD.

Please phone in advance on 01 670 5942 if you wish to visit us.

# CALL FOR CREATIVITY

We know a lot of our MND community are very creative, so we are on the lookout for any inspired pieces, be it, artwork, poetry, or a story that you would like to share. If you would like to contribute a piece, we will happily share it on our Community Hub.

To send in a piece for review, please email pr@imnda.ie

# JOHN DALY'S POETRY LEGACY

John Daly was living with MND, but he sadly passed away in 2024. He very kindly got involved in our campaigns and was interviewed on RTE News in 2023 about Voice Banking. John had a love of writing and wrote so eloquently, he wrote several poems. We would like to share with you a second poem of his, enjoy. Once again, a very special thanks to his wife Deirdre for sending them to us.

**The Marine Hotel, Dun Laoghaire**
March 2023, John Daly

Deep in leather armchair, contemplations grow,
Tall casement windows frame a striking view.
Myriad miniscule people, on the eastern bight,
Slowing, as they now approach,
Our imposing harbour-entrance light.

Trailing above, tiny hidden souls descend,
Wishing for, hoping for, a gentle journey's end.
Suppressing worry, in that silver tube,
'No right to flight', 'No right to flight',
Whispers each inner 'rube'.

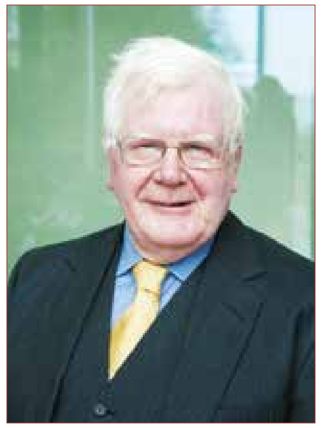
Gentle clouds and laden ships, float by,
Soft music counterpoints, a growing caffeine high.
Business talk murmurs, quietly through the room,
While Nature with a care-worn pride,
Works softly on her loom.

For this imposing, ne, impasto sight,
Jack Yeats, he should be here by right,
Creating yet another perfect morning scene,
And insisting once again "There Is No Night

## Lillian McGovern

It was with incredible sadness that we at the Irish Motor Neurone Disease Association (IMNDA) had to bid farewell to our beloved former CEO and dear friend, Lillian McGovern, as she passed away in December last year.

Lillian led the IMNDA with a steadfast commitment to improving the lives of individuals and families affected by Motor Neurone Disease (MND). Her vision and direction played a pivotal role in advancing our mission, ensuring that those living with MND had access to vital resources, support, and care. Under her leadership, the IMNDA grew, both in the services it offered and in the hearts of the community it served. Her legacy is one of kindness and compassion.



## Declan Mac Daid

The IMNDA was also deeply saddened to learn of the passing of our former Chairperson, Dr. Declan Mac Daid as he passed away in August of this year.

Declan joined our Board in 2012, at a time of great challenge for charities, and went on to serve with commitment and vision for a decade. He became Chairperson in 2014, guiding the Association through important changes in governance, compliance, and succession planning—work that strengthened the foundations of the IMNDA as it stands today.

Declan stepped down in 2022, leaving behind a legacy of leadership, professionalism, and dedication to people living with MND and their families.

# Christmas Memory Tree

### Remembering our MND Community

Irish
Motor
Neurone
Disease
Association

**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**

**To Contact Us**
Irish Motor Neurone Disease Association
Ground Floor, Merchants House,
27-30 Merchant's Quay, Dublin 8D08 K3K0

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

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