Irish
Motor
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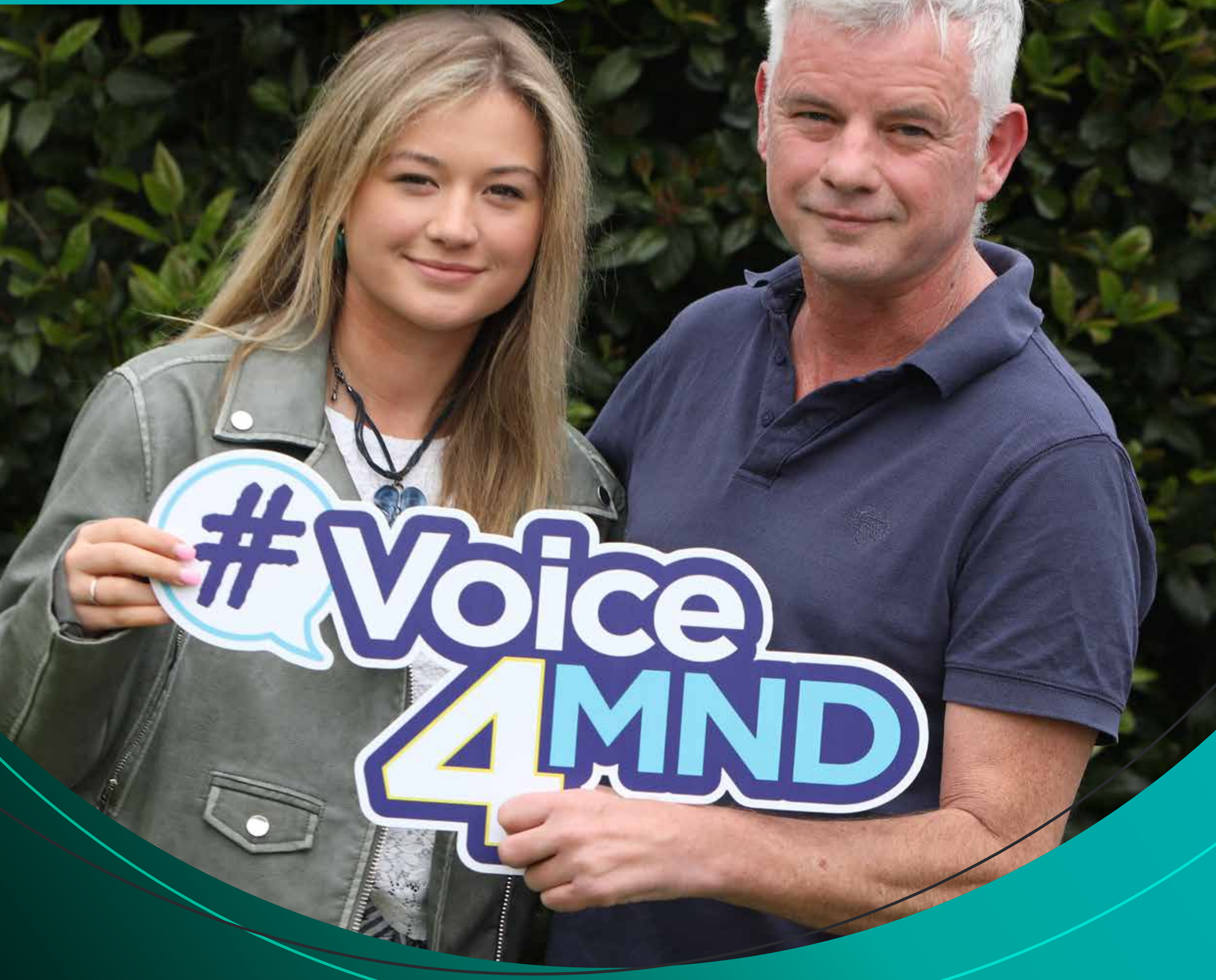
Association

CONNECT

ISSUE 26 | AUTUMN 2023



The latest news, views and
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Voice Banking for People Living with MND

by Lesley Doyle SLT

Irish Motor Neurone Disease Association

Webinar 8th November 2023

NOVEMBER – DECEMBER:

Light up a Star

on our

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fundraise.imnda.ie/event/christmas/home

Irish Motor Neurone Disease Association

CHRISTMAS:

- IMNDA Christmas Decorations for sale!
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Drink Tea for MND

DRINK TEA FOR MND

Helping others. It's everyone's cup of tea.

IRISH MOTOR NEURONE DISEASE ASSOCIATION

JUNE:

Voice4MND

#Voice4MND

JUNE:

Global Awareness Day

FOR MORE SEE IMNDA.IE

A NOTE FROM OUR CEO

Welcome to our 2023 Autumn Newsletter. We have had an extremely busy year with several new initiatives being developed for our MND community.

"Climb with Charlie" was a wonderful initiative as you know, and with monies raised from this fantastic fundraiser we now have a development fund in place. This has allowed us to fund new transport grants and provide financial assistance for respite breaks for families. It has also allowed us to deliver the latest technology in voice-banking with "I will always be me" which was developed and shared by MND Association in England, Wales & Northern Ireland.

We also welcomed our sixth MND nurse, Aine McFadden who now supports our clients in the midlands and eastern region of the country.

In keeping with our aim of supporting research we made €250k available to Trinity College Dublin, to support a three-year European research programme looking at targeted therapies.

Much done………more to go. We are now turning our attention to other priorities for the year. We want to do more for our carers and with that in mind, we are looking to develop a programme that meets their needs in ensuring that they receive the necessary support they so badly need. In addition, we want to focus on longer-term respite care for our clients as they navigate this disease. We hope to develop a pilot programme in conjunction with other organisations that are experienced and equipped to provide this service.

Our national campaigns were again a success this year. We moved our "Drink Tea for MND" campaign to March for the first time and thanks to our loyal supporters we had over 100 tea parties taking place in homes, workplaces and community centres around the country. A staggering €150k was raised from the Drink Tea event. A very special thanks to Lily Chen for fronting this campaign and to her husband Dom McGroddy who took part in several media interviews to raise awareness. The month of June marks Global Awareness Day which takes place on the 21st. To mark this, we had our annual joint event with the Academic Unit of Neurology in Trinity College Dublin. We also held our "Voice for MND" campaign which highlights the importance of speech, which is sadly lost because of MND. Always a very successful campaign, this year raised over €58k and more importantly, raised the awareness of the huge challenges faced by those who lose their voice – which is so closely aligned with our identity. This year a special thanks to Caleb Sheehan and John Daly who fronted the campaign and took part in several media interviews.

Walk While You Can" took place in October this year, honouring the late Father Tony Coote. This year Andres Estevez Guersanik, his wife Jennifer and our MND nurse Louise Hennessy were all ambassadors for the campaign. A huge thanks to them all for doing media interviews to highlight the campaign and a huge thank you to everyone who took part this year.

During the year we carried out a national survey along with MND Scotland among people living with MND and their carers. We talked to our clients, their carers and those who have lost someone to this illness. We are happy to share the findings here with you in our magazine and we hope that you might give us your feedback on any aspects of the study or indeed, offer some suggestions as to how we might improve our services in line with the findings.

We held our 38th Annual Conference in the Hodson Bay Hotel, Athlone. This event was hugely successful, and we hope that the conference provided information, advice and support to our clients and their families. We were also very excited to welcome RTE News to the conference to highlight MND and the new voice bank technologies that have come to Ireland.

Without a doubt, everyone seemed to enjoy the day and we concluded with a dinner and entertainment that saw many take to the floor to the beat of some wonderful music. The team here at IMNDA are already in planning mode for next year's event and again, we would love to hear your feedback and suggestions for an even better conference.

Everything we do at IMNDA would simply not be possible without the support of our loyal community who have been incredible at arranging local community initiatives and we are eternally grateful for the generosity and continued backing that they received from their donors and supporters, often their close family members, neighbours, and friends.

We know that this year has been a particularly difficult year for many with cost-of-living pressures and we know that many charities ask for support and help.

Thank you to everyone who supported our work during the last year. We simply could not achieve our mission without your generosity.

Finally, on behalf of the entire team here, I would like to extend our sympathies to those who have lost a loved one during 2023. Our thoughts and prayers are with you at what is an incredibly difficult time, and we hope that you remain part of our close community for the future.

All my best regards,

Lillian McGovern
Chief Executive Officer

21ST JUNE GLOBAL MND AWARENESS DAY

On 21st June, IMNDA and The Academic Unit of Neurology, Trinity College Dublin held a reception in Trinity Biomedical Science Institute (TBSI) to mark MND Global Awareness Day and to hear of developments within IMNDA and MND Research. The event was a great success and lots of people turned up to the event to hear about the developments and ask questions of the experts.

The day started with a welcome and introduction from our Community Engagement Manager, Tracy Hutchin followed by Maeve Leahy, Head of Communications & Advocacy who spoke about our Voice4MND campaign held in June. Our Director of Nursing Naomi Fitzgibbon then proceeded to give an update on nursing and services within the IMNDA and introduced our new MND nurses to everyone in attendance.

The Academic Unit of Neurology then took to the floor where we had Dr Conor Hayden deliver a presentation about Clinometric/Objective Measurement Device Development for MND in two areas; hand dexterity and respiratory function.

We then had Lesley Doyle Speech and Language Therapist (SLT) talk about the MIRANDA PhD Programme which involves gathering information and sharing it to inform digital solutions.

Dr Roisin McMackin delivered a presentation on Brain Signal Analysis (EEG/TMS) which looked at research into brain function in MND, including movement as well as cognitive functions in the brain.

Dr Emmet Costello then spoke about how MND affects memory language and planning after which Dr Julie Kelly provided information on Drug Development in ALS/MND and the challenges that researchers face, given they don't know the root cause of the disease.

With a background in physiotherapy, Avril McTague was next to give a speech on Public & Patient Involvement opportunities in ALS research (PPI). Avril is also one of the MIRANDA PhD students.

Finally, we had Prof. Orla Hardiman give an overview of the Research Programme including the Precision ALS initiative.

In case you missed and would like to listen back on the event, it was streamed live and is still available on our YouTube Channel: MNDireland – just go to the live section and you will see it there.

21st June

MND Global Day

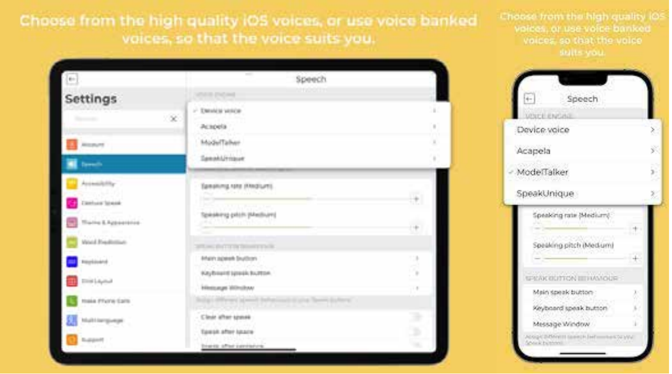
VOICE BANKING FOR MND

Lesley Doyle is a Speech & Language Therapist (SLT). She was the senior SLT in Neurology in Beaumont Hospital for a number of years specialising in MND/general neurology. She is currently on career break from Beaumont Hospital, having joined the Academic Unit of Neurology in the School of Medicine in Trinity College Dublin in November 2022. She is undertaking a PhD within the MIRANDA programme, which is a HRB clinical doctorate award-funded programme for HSCPs that focuses on exploring how digital technologies can potentially enhance care for people living with MND. In this article she talks about voice banking and different types of recordings available to people with MND.

Voice Banking – what is it?

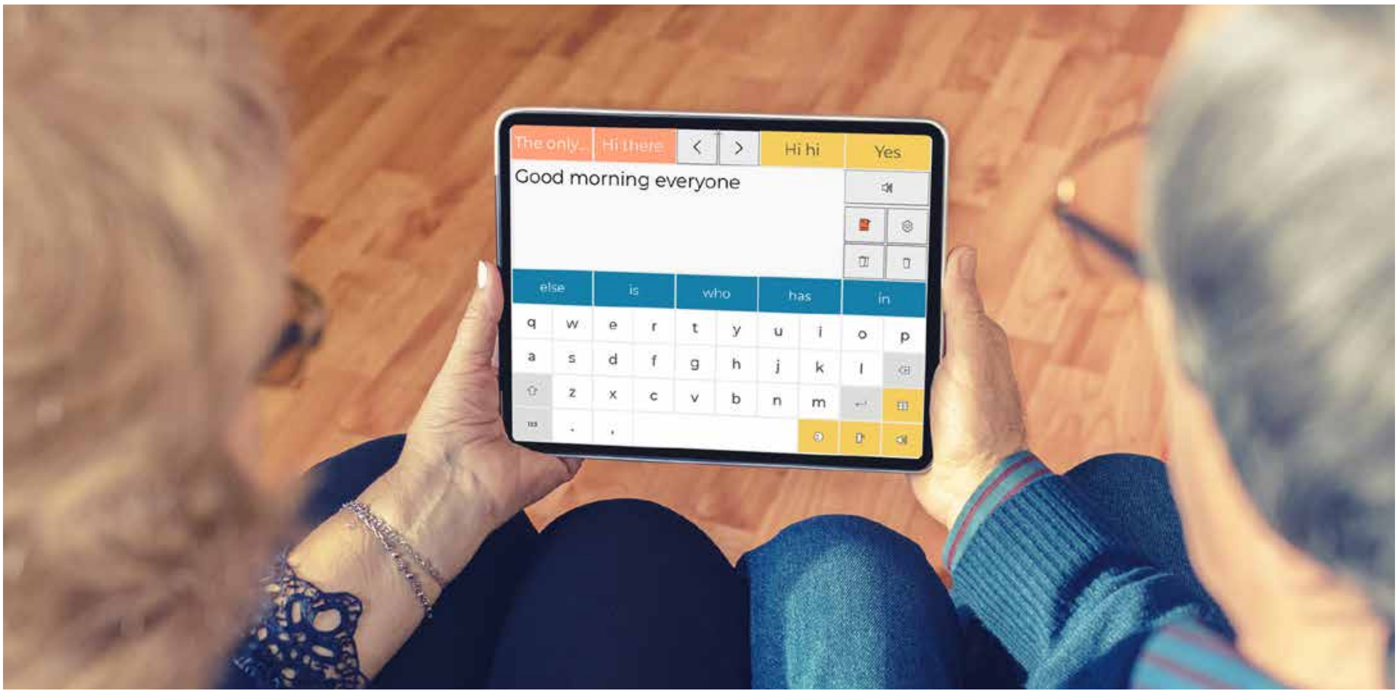
Voice banking is when a person creates a computerised representation of their voice, sometimes called 'voice cloning'. It can be done using an online voice banking service and usually involves the person recording a sample of speech by reading aloud set lines of text that capture different speech sounds in different parts of words. The voice banking software then creates a digital representation of the person's voice based on their recordings.

Anyone can bank their voice but globally, people with MND are the biggest consumers of voice banking services. This is because we know that MND can affect the muscles used for speech and over time, for some people, speech can become difficult to understand. If this happens, speech and language therapists give advice on communication tools that can be used alongside or instead of speech. There are simple alternative ways to get a message across such as writing but many people also use an electronic communication aid such as a touch screen tablet or a computer that can be controlled by a mouse, joystick or eye-gaze reader if hand movement is difficult. These devices have apps/software with inbuilt computer-generated voices that speak out words or sentences when they are typed by the user; this is referred to as a 'text-to-speech' function. If a person had previously completed voice banking while their speech clarity was good, they have the option to use their own personalised computer-generated voice for 'text-to-speech' instead of one of the generic options that are available within the communication app/software. The reason why many people prefer to use their own personalised electronic voice instead of a generic one is to preserve the aspects of their identity that are conveyed by their own unique voice.



Voice banking providers

The number of companies providing voice banking and the ability of their technology has rapidly expanded in recent years. This means that while it might be harder to know which company to use, typically, the resulting voices are of a much higher quality now when compared to results from even five years ago. It is still important to note that this type of computerised voice will sound somewhat more robotic with less intonation than natural speech because it is electronic and cannot convey emotion. For some people, the resulting voice sounds just like them, however, the quality and likeness continue to vary between people. While all voice banking companies charge a fee that ranges from about €100 to over €1,000, most allow you to make an account and record for free. They will then build an electronic voice that you can listen to and payment is only required after that point to complete the process. This means that if you are unsure about doing voice banking, it is possible to try it out and learn what the process involves. Some resources are outlined at the end of this article including where to find information on service providers and an IMNDA voice banking grant.



What you need to record

To carry out voice banking, you need a laptop or PC (not a smartphone or tablet), a reliable internet connection and a headset microphone that connects to your computer through a USB cable. The end outcome of voice banking is a file that can be downloaded onto a computer or into a communication app/software that has an option (not all do) for you to use your own electronic voice. To use your banked voice on a compatible communication app/software is go into that app's speech settings and enter the username and password you created for the voice banking service you used.

When to record

The biggest impacting factor on the quality of the electronic voice created by voice banking is the clarity of the person's speech at the time when they make recordings. For this reason, if you decide that you want to do voice banking, it is advisable to do it as soon as possible when your speech clarity, rhythm, loudness and breath support are as good as possible. To get the best results from voice banking, you ideally would be able to clearly pronounce speech sounds, comfortably achieve easy to hear speech and say a phrase without straining for breath. If your speech fluctuates but tends to be good at a certain time of the day, record during your best speech window. Most people record in blocks over a few days rather than completing the full set of sentences in one sitting because, even for strong speakers, our voices become tired when continuously reading aloud.

By the nature of MND, 'as soon as possible' can mean different things for different people. Some people first notice a change to their speech quality as one of their first symptoms and by the time they come to meet a Neurologist who makes a diagnosis of MND, perhaps their speech clarity has noticeably deteriorated. Other people first note symptoms in their limbs so they have other priorities to address or just need time to come to terms with their diagnosis and perhaps their speech has become less clear before they have any energy to give to thinking about voice banking. If any of these are the case for you, you will find it difficult to complete voice banking with many suppliers but the good news is that you still have multiple options. The first one is voice banking 'by proxy'. This is when a friend or relative with a similar accent does voice banking on your behalf so you can use their electronic voice and still capture some of your speaking identity captured by your regional accent. Another option if your speech quality is quite reduced but you would be able to record sentences with some clarity is 'voice repair'. For this, you need the same equipment as for voice banking and in the same way, you record a set of given sentences, but the service provider company then blend your recordings with ones they have on file from a donor 'healthy' speaker who has the same self-identified gender and regional accent as you. This patches up a slurred or breathy speech quality. Because the resulting electronic voice will be based on your voice blended with someone else's, it will sound less close to your natural voice than voice banking but can still capture elements of your own voice and accent.

Some voice banking companies can also work with voice recordings you might happen to have from before your speech changed. The success of this is much more variable than making voice banking-specific recordings and it tends to be more expensive because it is more complex for the company. Some factors influencing success are the quality of the recordings, background noise, length of the speech sample and range of speech sounds that occur in the recordings. These recordings would have to be edited by the voice banking company to cut out pauses or other speakers and the contents all need to be transcribed so the software can match speech to words. If you have queries about this, you can email voice banking companies to tell them about the type of speech sound files you have and they will let you know if they can offer you any bespoke options.

Other options

Message banking is another possibility that is suitable whether your speech is strong or has changed, even significantly, as long as it remains understandable to a listener. This can be done as well as or instead of voice banking/repair. Message banking involves thinking of your own phrases that are personally meaningful to you and recording yourself speaking those phrases. The type of phrases that people tend to record are terms of endearment, sarcastic comments, phrases used mostly with close family/friends or catchphrases that others would associate with them. Some people like to make slightly different types of recordings that are not intended for use in conversation but are maybe the retelling of life stories, reciting favourite poems or prayers or singing songs. Message banking is free to do, all you need is a good quality dictaphone. The typical model of dictaphone that is used for message banking is a Zoom H1 (or the updated H1n model) Handy recorder that is set to record .wav sound files. To use the recordings, they are transferred off the dictaphone and uploaded to a communication app/software. Whereas voice banking creates an electronic voice, when message banking recordings are played out on a communication app/software, they are in their original state and sound exactly the same as the person's voice when the recording was made. For this reason, if your speech quality has reduced, the most important consideration for message banking is that you are happy with how your speech sounds at the time when you make the recordings and that you feel that it sounds like and represents 'you'. If you are unsure, you could make a couple of trial recordings and play them back to see how you feel when you hear them. Some communication apps/software also have features that allow the user to record phrases directly into the system. This is a less used method for message banking because, unlike with dictaphone recordings, you cannot extract the phrases and transfer them if you were ever to switch to a different communication app/software.

In summary, banking speech can be considered as a 'vocal insurance'. It is a way of planning ahead to preserve a part of personality that is captured by a person's unique speaking voice. There are several options for how to record but the overall principle is to make recordings while speech clarity is good for potential future use on an electronic communication aid should speech become difficult to understand. If you make voice recordings, it might never be necessary for you to consider using an electronic communication aid, but if you do, you will have given yourself the option of incorporating your own banked speech. Many people with MND who recorded their speech have told me that they feel reassured knowing their recordings are there on hand 'just in case'. However, if you decide that you do not wish to bank your speech, the inbuilt generic computer-generated voice options in modern communication apps/software are also reliable options that are clear and easy to understand. Most offer only one Irish-accented voice which is female, there are no options for regional Irish accents but British, American and Australian accents are typically available.

Available Resources

If you want to bank your speech, do not be put off by any uncertainties you might have about the process or equipment. There are lots of Irish resources in the format of clinical expertise, information, equipment, and funding grants that are available to you.

1. Speech and Language Therapists (SLTs):

- **What's right for you:** If you have noticed changes to your speech, it would be a good idea to chat to your SLT before you make any recordings to discuss what the most suitable options will be for you.

- **Support:** SLTs can support you with the process of voice or message banking, help you to access microphones or dictaphones and request an IMNDA voice banking grant on your behalf.

- **Account information:** It is a good backup for you to allow your SLT to make note of your voice banking login username and password in their record as it is very common for people to forget these details.

- **Communication technology:** Your community or MND clinic SLT can help you to explore potential communication technology options for the future including ones that support the use of voice or message banking. If needed, they can also make an onward referral for you to a specialist assistive technology service such as the one in the Central Remedial Clinic. Assistive technology services have expertise in ways to operate technology if you find it difficult to type using your hands and can incorporate a communication system with technology for other everyday activities so you have everything on one device. Should you have reason to use one in the future, your SLT or a clinical engineering technician in an assistive technology service can help you to set up an electronic communication system including incorporating your banked speech.

2. Message Banking information leaflets:

The Irish Message Banking Project developed a 'toolkit' of resources. The project was funded by Research Motor Neurone. The working group involved SLT collaboration between Beaumont Hospital and the ATSS department of the Central Remedial Clinic with research expertise from the Clinical Speech and Language Studies centre in Trinity College Dublin. The toolkit contains information leaflets about steps in the process and specific ones to help you think of phrases to record and how to use the Zoom H1/H1n dictaphones. All leaflets are free to access and download from the Research Motor Neurone website at: www.rmn.ie/message-voice-banking (or go to www.mnd.ie; click on 'Clinic-related Support' and from that menu, choose 'Message & Voice Banking')

3. Voice Banking information leaflet:

You can find an overview of a selection of four of the most frequently used companies by Irish voice banking customers via the same Research Motor Neurone link given above; scroll down to article 8. 'The Voice Banking Process' – see the comparison table on the last page of the document.

4. Message and Voice Banking Animation:

As part of the Irish Message Banking Project, a 3-minute animation was developed to provide a simple overview of message and voice banking. You can watch this animation for a refresh of the information or suggest it to someone you know for a quick explanation. You can view the animation on the Research Motor Neurone website as per the link above or on the IMNDA website (go to www.imnda.ie; click on 'Living with MND' and choose 'MND and Communication').

5. IMNDA supports:

- **Equipment loan bank:** The association has a stock of headset microphones that can be used for voice banking and Zoom H1 or H1n Handy recorders that can be used for message banking. Usually, your SLT requests a piece of equipment on your behalf for you to borrow and use while recording.

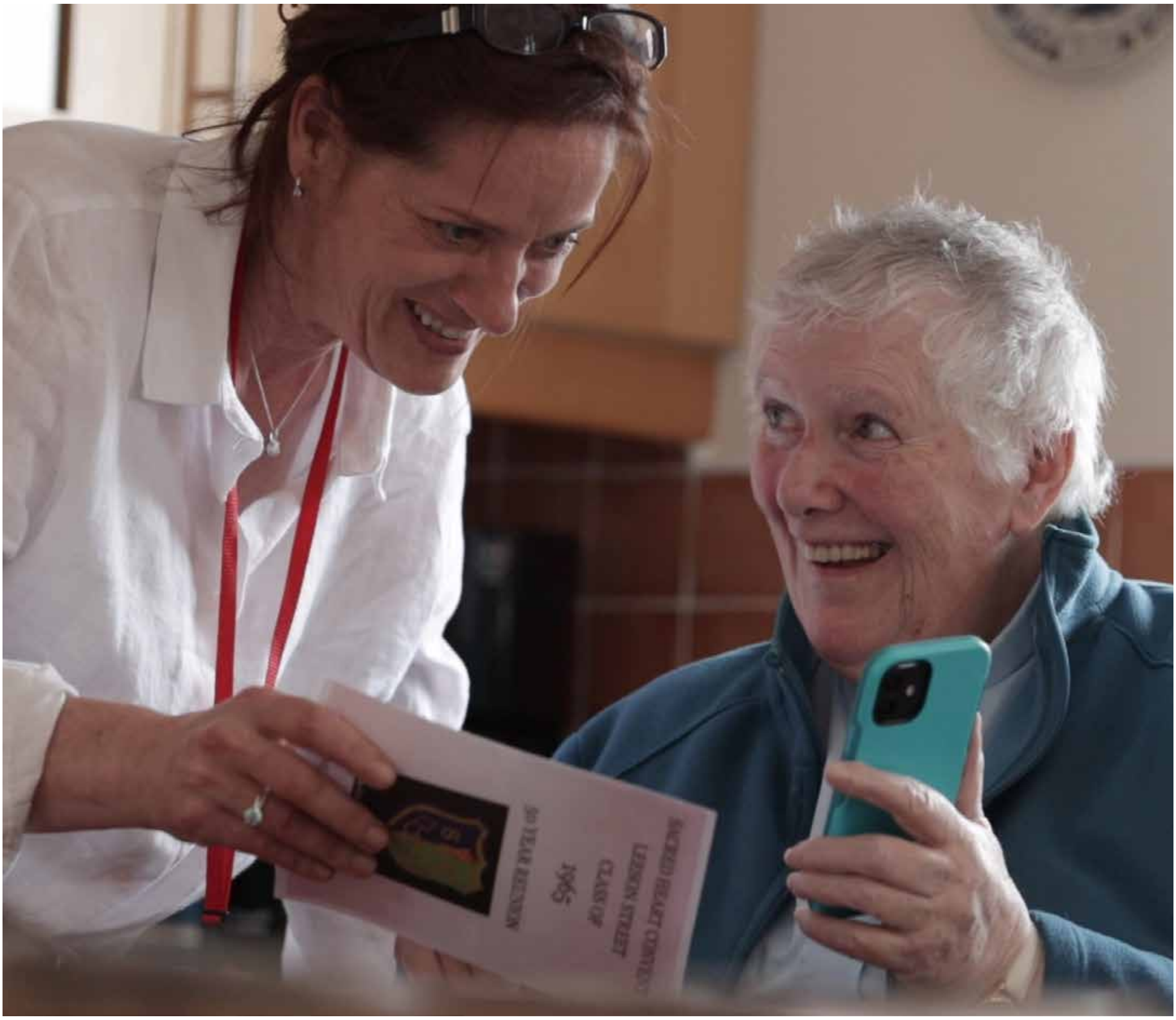
- **Voice banking grant:** Thanks to the wonderful fundraising achievement of Charlie Bird's 'Climb with Charlie' campaign, the IMNDA were able to launch a voice banking grant. Your SLT can apply to the IMNDA for the grant on your behalf. The company Speak Unique (www.speakunique.co.uk) are the IMNDA's preferred voice banking service provider; this company also offers voice repair for Irish accents which is included in the grant. The grant will also apply to the 'I Will Always Be Me' service which involves reading aloud a short book about the experience of having MND and Speak Unique then using the recording as a speech sample for voice banking.

- **Webinar:** If you have been diagnosed with MND or are supporting someone who has and would like practical advice around equipment and recording for voice banking, with a specific focus on how to complete the process using Speak Unique, I will be presenting a free webinar on this on behalf of the IMNDA on 8th November.

by Lesley Doyle

Clinical specialist Speech and Language Therapist, currently undertaking a PhD with Prof Hardiman's research team in Trinity College Dublin. Clinical lead on the Irish Message Banking Project.

PALLIATIVE CARE WEEK 2023



Palliative Care Week took place from the 10th-16th September. During this week, people in communities across Ireland were encouraged to have conversations about palliative care.

The Palliative Hub in association with IMNDA and several other organisations took part to highlight the week long campaign.

IMNDA Nurse Fidelma Rutledge participated in the campaign as well as Maebh O'Herlihy from Achill who is living with MND. Both talked about palliative care and its benefits.

Over the week the campaign addressed issues such as misunderstandings about palliative care that persist, meaning some people who could benefit are less willing to link with services, potentially missing out on improved quality of life.

Fidelma and Maebh were invited to talk about MND and the campaign on RTE's DriveTime, the podcast is available on the RTE website.

More information can be found by visiting www.thepalliativehub.com

THE LATEST UPDATES FROM THE ACADEMIC UNIT OF NEUROLOGY, TRINITY COLLEGE DUBLIN.

Dr. Roisin McMackin of Trinity College Dublin recipient of prestigious $400,000 grant. It was announced recently that Dr. Roisin McMackin, of Trinity College Dublin was one of only seven recipients globally to secure funding from a partnership between ALS Finding a Cure (ALSFAC) and The ALS Association, who have awarded grants in total worth $2 million to support the development of early diagnostics for ALS.

More than 150 years after the disease was first defined, there are currently no universally accepted diagnostic approaches for ALS. To receive an ALS diagnosis, patients must first undergo several tests designed to rule out other conditions. This is highly problematic because it can take a year – or sometimes even longer – for a person with ALS to receive the correct diagnosis.

Commenting on the grant Dr. McMackin said "Currently we are trying to treat ALS/MND when it has already caused a huge amount of damage to the nervous system. It's like trying to stop a runaway train, and so far, there has been almost no success. This grant provides us with a really exciting opportunity to explore if we can use non-invasive, low-cost measures to test for, and detect, ALS/MND before it starts to cause its devastating effects. At such an early stage, there is much less damage to remedy, and we have a much better chance of effectively treating it."

The $400,000 funding secured will be used by Dr. McMackin in research to measure nervous system function of individuals with C9orf72 mutations but no ALS symptoms using electroencephalography (EEG) and transcranial magnetic stimulation (TMS) to identify which functional changes can help predict disease development. (C9orf72 mutations are the most common genetic cause of ALS.)

If you would like to participate in this study, please contact - MCMACKRO@tcd.ie

Neurophysiology and Neuroimaging of the Nervous System - Dr Gabriel Costa

Dr. Gabriel Costa is a dedicated scientist specialising in neurophysiology and neuroimaging of the nervous system. His research focuses on exploring the connections between these fields and the underlying biological factors. Dr. Costa's exceptional work has earned him a prestigious 2-year NeuroInsight postdoctoral fellowship, jointly funded by the European Commission's MSCA program and the SFI Research Centers (FutureNeuro and Insight).

In this fellowship, Dr. Costa will delve into the intricate neurobiological aspects of ALS (Amyotrophic Lateral Sclerosis) by harnessing the power of neuroelectric brain activity, specifically brainwaves (EEG), in conjunction with advanced data analytics.

Dr. Costa's dedicated efforts will be channelled within the EXG Research Group, which finds its home within the Academic Unit of Neurology. Here, he will collaborate closely with esteemed individuals including Dr. Bahman Nasseroleslami (Fr Tony Coote Assistant Professor), Prof. Orla Hardiman, and Prof. Madeleine Lowery of UCD (University College Dublin).

€370,000 in funding secured for refinement of biomarker candidates for ALS. Dr Bahman Nasseroleslami and other Principal Investigators of the EXG Group and the Academic Unit of Neurology received €370,000 in funding from the Health Research Board of Ireland in 2022 to work on the refinement of biomarkers in candidates with ALS. A biomarker is a molecule that can be found in the blood, any tissue or other body fluid. Biomarkers can be measured to work out whether someone has a specific disease or condition and to measure their responses to treatment.

This grant will facilitate the support of two PhD students to further advance biomarker discoveries previously made to measure the level of motor and cognitive decline in people with ALS.

One of these researchers, Ms. Serena Plaitano, has an educational background in Neuropsychology and Neuroscience and will be pursuing her PhD to find effective biomarkers of cognition in ALS. The second researcher, Ms. Zahra Eshagh Nimvari, is a neural engineer with prior experience in analysing neural signals in conditions such as stroke and will also be joining the EXG Group as a PhD student.

Together, Ms. Plaitano and Ms. Eshagh Nimvari will collaborate to refine measurement techniques that can accurately quantify the altered function of brain networks in ALS. Their efforts aim to contribute to the development of biomarkers that can be utilised in clinical trials, ultimately advancing the understanding and treatment of ALS.

The momentum of the project continues to build in 2023 as the team members embark on their research endeavours.

Pioneering project gauging physical function in individuals with MND - Dr. Conor Hayden

A recently concluded PhD project, based in Trinity College Dublin, has taken a significant stride forward by concentrating on the development of tools that are both sensitive and meaningful in gauging physical function in individuals with MND. This pioneering endeavour has spotlighted two vital dimensions: hand dexterity and respiratory function (breathing).

Led by Dr. Conor Hayden, a talented biomedical engineer, and overseen by Dr. Deirdre Murray from the Academic Unit of Neurology along with Prof. Bruce Murphy from the School of Engineering, this project has illuminated new avenues for enhancing the lives of those affected by MND.

In the pursuit of advancing treatment strategies for MND, measures are needed which can detect small but meaningful changes in function. Current measures, which are mostly questionnaires are not sensitive enough to pick up small changes and reliable for use in clinical trials.

A standout achievement of this project is the creation of a novel hand-worn sensor. This sensor 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). This breakthrough device has been tested on a group of over 250 individuals, including more than 50 living with MND. It has demonstrated remarkable reliability and sensitivity in swiftly and effortlessly detecting changes in hand function.

Envisioning a future where this device can extend beyond research environments, the project's trajectory includes further development to broaden its applications. To underscore this vision, a patent has been filed to safeguard this inventive technology.

This remarkable research endeavour has been supported by funding contributions from esteemed organisations such as Research Motor Neurone, the Health Research Board, and Enterprise Ireland. Together, they have enabled the transformation of ground-breaking ideas into tangible tools that can significantly impact the lives of those suffering with MND.

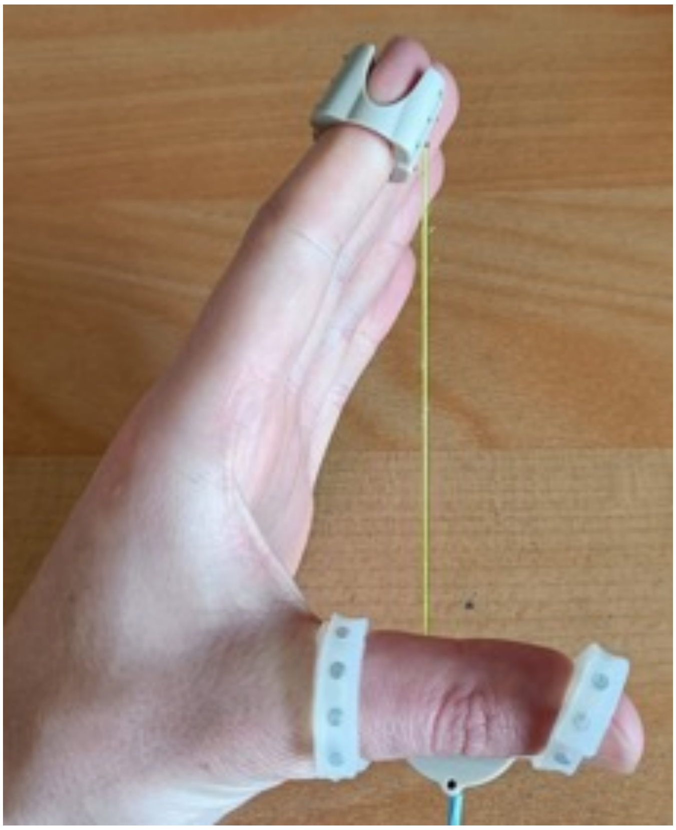


Figure 1: Image of the device on a person's hand showing a finger tapping test.

MND Researchers in TCD Currently Seeking Interest for a Public and Patient Involvement Panel - Lesley Doyle Speech & Language Therapist (SLT).

The Academic Unit of Neurology in Trinity College Dublin (TCD) are offering an opportunity for anyone who has been diagnosed with MND or a family member/caregiver of someone who has been diagnosed to give their opinions and perspectives to help shape the MND research carried out by the unit. Public and Patient Involvement (PPI) gives a voice to people who are directly impacted by a medical condition, so they have a say in how research is carried out for that condition. The MND researchers in TCD are in the process of setting up the first ever MND PPI panel in Ireland.

Research involves many stages such as planning how a study will run, gathering data then analysing and sharing the results. PPI is different to being recruited to sign up as a participant in a research study in the data gathering stage; it does not involve following a protocol to provide data for a research study or recruiting participants to a study. With PPI, contributors are frequently involved in the planning stage to help identify research priorities and design studies in a way that is not too burdensome to potential participants and provides ways of measuring results that are meaningful to them. Sometimes PPI contributors are also involved in analysing the results, and often they help to share the research findings in a way that is accessible to the wider MND community. In this way, PPI creates more of a partnership between participants and researchers.

PPI contributions can take several formats, for example attending group meetings, trialling surveys to check that the meaning of the questions is clear, trying out technology, devices, or assessments, emailing feedback about the clarity of information leaflets, helping to write newsletter reports to share research findings with the MND community. This means that there will be many ways to contribute whether you prefer to do so through a conversation or find it easier to give written/typed answers when you have more time, perhaps if you have a communication difficulty. We plan to make as many meetings as possible virtual so they will be in the format of video calls rather than in-person to maximise accessibility for people who find it challenging or fatiguing to travel. If you are not confident with using technology for video calls, we will offer help with a practice run.

Right now, the MND researchers in TCD are gathering initial expressions of interest. If you have been diagnosed with MND, are a family member/caregiver for someone living with MND or a bereaved family member/caregiver, they would like to hear from you. There will be an initial information event to explain the areas of research where PPI involvement will be needed and to discuss how the PPI panel will operate. It is hoped that members would aim to commit to the panel for at least one year. However, the researchers fully understand the challenges of life with MND so you can opt out before then if needed and recruitment to the panel will be ongoing with new people continuing to join over time so if right now is not right for you, you could consider it again in the future.

If you would like to register your interest to receive further information about the panel, you can email Aisling at researchmnd@tcd.ie.

AGM AND ANNUAL CONFERENCE 2023 - ATHLONE

In October of this year, IMNDA's AGm & Annual Conference event took place in Hodson Bay Hotel in Athlone. We had a wide range of speakers and exhibitors at the event. It was well attended with almost 200 delegates joining us in person and 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 2022.

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 members Jonathan Healy and Norman Hughes. We were very excited as Jonathan introduced Maria Walsh MEP and proud Mayo woman. Maria opened up the conference and welcomed us all to Athlone. We were also delighted to welcome RTE news to the conference to highlight MND and a new voice banking technology that has come to Ireland. RTE interviewed John Daly who is living with MND and uses voice technology on a daily basis. They also interviewed Prof Orla Hardiman and CEO Lillian McGovern.

Up next, we had Lillian McGovern, CEO of IMNDA. Lillian talked about the outcomes of "Climb with Charlie" campaign and how people living with MND made the decisions on how the funds from this wonderful fundraising event would be spent into the future. She spoke about the funds that were presented to Prof Orla Hardiman for MND research for a three-year European research programme looking at targeted therapies.

We were then treated to an in-depth presentation on Benefits & Finances by Clare Duffy, Family Carers Ireland. Clare has been the Policy and Public Affairs Manager with Family Carers Ireland for the last 15 years and is responsible for leading her organisation's policy and public affairs functions. Clare has a particular interest in welfare, health and pension policy. She delivered her presentation on Carer's benefits.

We then had the pleasure of listening to Ethel Wallace who is a complementary therapist with over 15 years' experience working with a variety of client groups from elite athletes to those who just need space and time to relax and recoup their energy levels. Most recently she has been working with the Westmeath Palliative Care team as their complementary therapist. This role allowed her to visit clients in their own home offering a range of treatment options. Ethel delivered a fascinating talk on the history and biology of massage as well as the importance and benefits of touch and how important it can be for mental and social wellbeing.

Next up on the podium was Prof Orla Hardiman, the Professor of Neurology at Trinity College Dublin, and a Consultant Neurologist at Beaumont Hospital. Prof Hardiman delivered a most interesting overview of current MND Research. She spoke of how in the last 3 to 4 years the whole field of how we look at clinical care of MND has changed and that we should be very optimistic. Ireland has become a lead in international clinical research into MND with over 50 brilliant young researchers and world class scientists. She also spoke about the 20 plus PhD students in the past 10 years who have worked in innovative cross-disciplinary projects, in areas such as neurological evaluation, genetics, mathematics, health services research, new drug development, clinical trials and many more. However, technology isn't there yet and there is a lot more to do still but it is all about investing in talent and excellence to achieve results. More information on Prof Hardiman's presentation is available on our YouTube channel @MNDireland.

Up next, we had Naomi Fitzgibbon, Director of Nursing & Services at IMNDA. Naomi delivered a talk on a survey which was conducted by IMNDA and MND Scotland. People living with MND and caregivers as well as those who have lost someone to MND, participated in the survey earlier this year. Naomi thanked everyone for their responses that will help us to shape the future of our services. In case you missed it, a more in depth look at the survey can be found in the news and research section of the magazine.

We then had a presentation from Teresa Leahy who is an Advanced Nurse Practitioner (ANP) with the University College Hospital Galway. She has worked in UCHG for nearly 20 years in Neurology with a specific focus on MS and MND. Teresa spoke about Living Well with MND – A Team Approach. In her presentation, she talked about the multi-disciplinary team in Galway and how she was the instigator of the MND Clinic there. Teresa spoke of the importance of the collaboration of the different specialities coming together to provide better standards of care. She spoke of symptom management and cognition in MND as well as much more.

Finally, a panel discussion took place, and this included Teresa Leahy once again along with Norman Hughes who chaired the discussion. They were joined by Prof Orla Hardiman, Naomi Fitzgibbon and IMNDA nurses Louise Hennessy & Maire Hayes. The overarching point of this discussion was to share experiences and advice to people living with MND. Prof Orla Hardiman's final point on this was to always see a way through this condition with humour.

A light lunch followed where our guests got the chance to mingle and chat to fellow clients, IMNDA staff, board members and speakers. It was also an opportunity for people to meet with exhibitors that had stands at the event this year.

Later that afternoon, we had Optional Afternoon Workshop Sessions which were held in person and these all ran from 2.15pm-3.15pm. There were 3 in total; Hand & Arm Massage: Learn the Techniques with Ethel Wallace, Self-Care for Caregivers with Mary Scarff and also a talk with IMNDA Nurses Eithne Cawley & Fidelma Rutledge.

The evening entertainment resumed later that day when everyone spruced themselves up and met at a drink's reception followed by a delicious 3-course meal and some music.

Thanks to everyone for making it such a memorable event, we hope you enjoyed it, see you next year! You can visit our You Tube Channel @MNDireland if you would like to see all the presentations from AGM & Annual Conference 2023.

WHAT MATTERS TO PEOPLE AFFECTED BY MND - NAOMI FITZGIBBON

We here at IMNDA partnered with our colleagues in MND Scotland and worked together to design a survey to collect information so we could get a better understanding of the needs and experiences of people living with Motor Neurone Disease (MND), their families and caregivers. An online survey was distributed between January and March 2023.

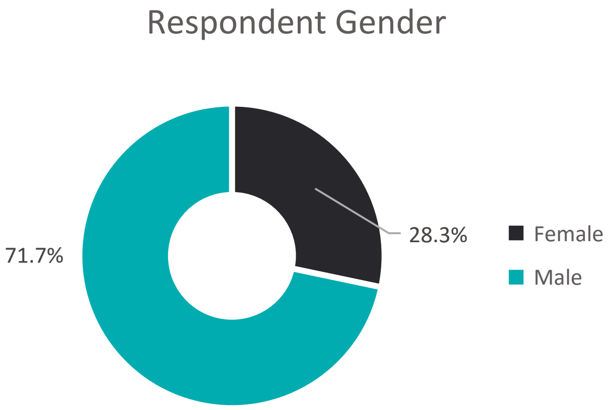
IMNDA analyzed the data from the survey respondents, assisted by Dr. Miriam Galvin, Academic Unit of Neurology, Trinity College Dublin. We would like to thank all those people living with MND, their families and caregivers for taking part in this survey and letting us know their experiences. The outcomes from this survey will inform us of the services needed nationally.

Surveys were sent to people living with MND and caregivers, the responses were anonymous. The findings are presented in 2 sections (1) People with MND (2) Caregivers.

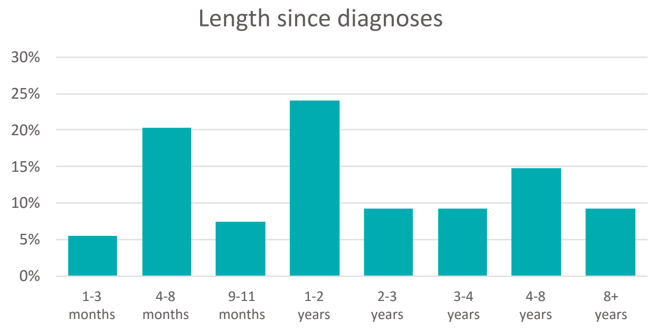
1. People with MND

What matters to you?

54 people with MND completed the survey, the majority were male (Fig 1).



The respondents' ages ranged from 30 to over 70 years, and approx. 30% lived in Dublin with a good representation nationally. Almost one quarter of all respondents indicated they had PMA (Primary Muscular Atrophy), and 20% ALS (Amyotrophic Lateral Sclerosis). Several respondents had been diagnosed within the last year, others had been diagnosed 8 years and over. (Fig. 2)



People were asked the question, what feels important to them now. Most people responded with family and friends. Continuing to maintain a routine were mentioned as being important along with "visiting family and friends and being able to go for a pint."

Most people that were surveyed are currently engaged with IMNDA services, in the form of contact with nurses – in person, or via phone and email, and receiving practical support.

Respondents commented that peer support (be that online or in group meetings) would be beneficial as an additional service. "Group meeting would assist with acceptance and discussion of our various symptoms; it might be helpful to have opportunities for meet ups especially for people living alone."

In terms of important research areas- clinical trials, new drugs, information on genetics, financial stress and symptomatic treatments were outlined as important areas for research according to respondents.

Finally, people with MND were asked what advice they would give or what they would have liked to have known earlier. Their responses are outlined here below.

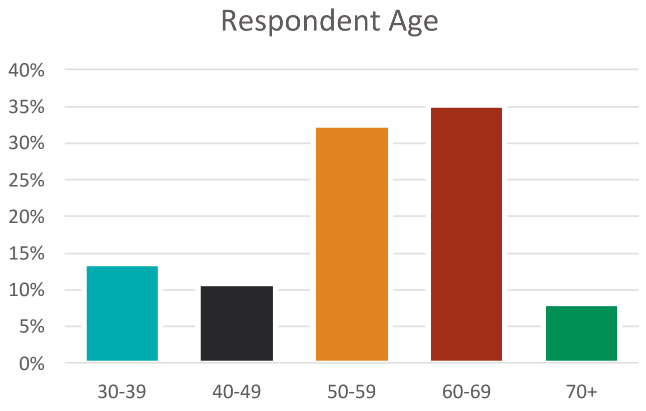
- Keep Healthy
- Enjoy Life
- Talk to people
- Keep going as much as you can
- Explore medical drugs
- Go on holidays
- Get services involved as soon as possible
- Tell people about your diagnosis at your own pace and don't let anyone else tell you how to do that
- Treat every day as a new day, don't give up

- Know that everyone is different
- Keep positive, communicate and involve your close family
- Try and have time with yourself and loved ones where MND isn't discussed

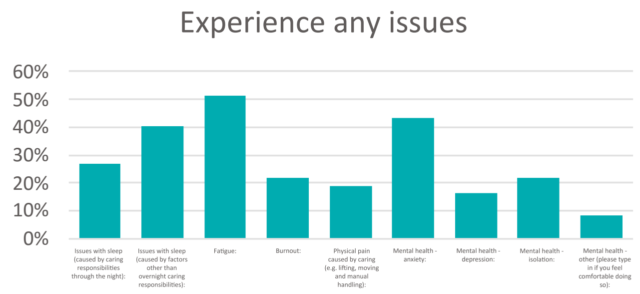
2. Carers/Families

What matters to you?

Over 60 people responded to the survey, of which 37 completed all questions. 70% of carers were female, 30% were male. Most were aged between 50 and 70 years (Fig. 3). In terms of their relationship to person with MND over two-thirds were spouses/partners.



Carers live across the country, a majority in Dublin with 10% living in Cork, followed by Galway, Limerick and Wicklow. They told us about a range of issues they experienced as a family member and carer (Fig 4). They experience fatigue, sleep problems due to overnight caring responsibilities and other factors, such as anxiety and feelings of isolation.



80% of respondents felt able to take time out to look after themselves. When asked about options provided included; 'time out', regular hours away from caring responsibilities each week, availability of overnight care and respite as relevant, and regular time for hobbies.

Just over half of respondents had been told about hospice services. Some were anxious and saw this as indication of a terminal disease phase, however others indicated the subject was discussed in a more positive way and that it fitted in with a range of support services offered.

The services provided by IMNDA were used by approx. 78% of the respondents; home visits and phone or email contact with IMNDA nurses were availed of by most respondents. In addition, practical support through equipment loan, and finance for home modifications services were utilised. 30% availed of the free counselling services provided by the organisation. Respondents commented that the nursing supports in particular is invaluable and very responsive. "Services are fantastic and excellent", "warm and caring", "interested and helpful", "the reassurance that all staff give us knowing we are not alone". Additional assistance would be helpful specifically: peer support, befriending, overnight respite, support for other family members (extended family for example). There were suggestions that IMNDA should provide education for other health care professionals and the public, and information on health service availability in local areas/regions, and on genetic testing.

Finally, carers told us some of the information they would like to have received or would have found helpful, in addition to information on disease progression and symptoms. The list included information on social welfare entitlements, home modifications, financial advice, information they could give to family and friends, and on clinical trials.

We also conducted a survey with people who have lost a family member to MND. The results of this survey are still being analysed and we will have the outcomes of this in the next few weeks. This will be available on our website, imnda.ie.

CHARLIE BIRD DEVELOPMENT FUND – UPDATE

We are so thankful to Charlie and Claire who have dedicated all their time and energy to making "Climb with Charlie" so successful. It is their wish that monies raised for IMNDA go towards a project that makes a difference to the lives of those who live with this disease. Charlie was keen to provide additional comfort to those affected by MND and their families, as well as ensuring that journeys to hospital visits are made easier for those who travel long distances. Charlie also expressed a desire that the Climb with Charlie fund contributes towards a research project, such as a clinical trials programme.

We know the importance of ensuring we keep people affected by MND at the heart of everything we do. We wanted to understand the impact of our work from your perspective and hear your suggested improvements.

To do this, we commissioned Amárach Research to undertake a survey of people living with MND and their family caregivers. Bereaved families, and members of the IMNDA Board & staff also completed the survey. The primary objective of this survey was to understand future requirements, that would be funded by the monies raised through "Climb with Charlie". A tailored questionnaire was created for each group. Surveys were online, with the support offered to all invitees. Overall, we received 493 responses.

Once the findings were analysed, we enhanced our current services to include:

6th IMNDA Nurse

Contribute funding towards a clinical research project into improved treatments for MND, Professor Orla Hardiman, Trinity College: Phase 3 Lighthouse Trial

Fund voice banking service

Fund 'Recharge' grant for a hotel stay.

Fund transport grant to enable clients attend MND clinic appointments in comfort.

A caregiver respite grant to alleviate the burden of care.

We would like to take this opportunity to thank everyone for their time and contribution in taking part in the survey and we hope that many people will benefit from the new services into the future.

The iNua Collection, So Hotel Group and IMNDA partner to launch short breaks initiative for family carers and those living with Motor Neurone Disease, thanks to Climb with Charlie!

We are delighted to announce our new partnership with The iNUA Collection and the So Hotel Group which is aimed at providing short breaks to individuals and families affected by Motor Neurone Disease (MND), with thanks to funds from the Charlie Bird Development Fund. The fund was set up from monies raised from the phenomenal Climb with Charlie initiative, and this is one of the many projects that the fund hopes to assist. This will provide people living with MND and their loved one's effortless support and additional care.

As part of this partnership, The iNUA Collection, So Hotel Group and IMNDA will provide complimentary hotel break experiences to those living with MND and their families, assisting them to make cherished memories together as well as providing relief breaks for family carers of those with MND, giving them the opportunity to take time out from what can often be a stressful journey.

The Charlie Bird Development Fund was created following a national consultation process with the MND community. Thanks to Charlie and Claire Bird, and everyone who climbed and donated towards Climb with Charlie in April 2022. The overarching objective of the fund is to provide the necessary supports to help those with MND live as independent a life as possible in their own home and within their own community. More access to IMNDA nurses, access to voice banking, support with travel and transport, support for carers and access to respite care were also top of the list for those living with MND.

"We're excited to partner with IMNDA to provide memory-making breaks and carer breaks to those living with Motor Neurone Disease and their families," said Brenda Murphy, Group Director of Revenue, PR & Marketing at The iNUA Collection, "We believe that everyone deserves a break from their everyday challenges and struggles, and we're honoured to be able to help in providing some respite and relief, and to assist in creating lasting memories."

We here in IMNDA are very grateful for the support of The iNUA Collection. "Part of what we do at IMNDA is not only to support those living with MND, but also those closest to them who are impacted by the diagnosis. We are immensely grateful to Charlie Bird for his tireless fundraising efforts, and to The iNUA Collection, who have been tremendously supportive throughout our engagement to date," said Jonathan Healy, IMNDA Chairperson.

"I am so happy that part of the funds from Climb with Charlie are being used for this purpose," said Charlie Bird. "I am very thankful to The iNUA Collection and So Hotel Group for joining up with IMNDA to provide this short break initiative. Motor Neurone is a dreadful disease for people living with it and indeed for their carers as well, so anything that can give people a short break is a lovely idea. I always wanted the funds raised from Climb with Charlie to directly benefit those who are suffering from this terminal illness and also those who are caring for them, so — well done, I love this initiative and please, please, I would encourage anyone experiencing MND to go for this lovely short break. I know what people with MND are going through as well as those who are caring for us, and I believe even a short break would be welcomed and of benefit."

The grant available to our families is called the recharge grant. As a result of the Charlie Bird Development Fund, we will provide a grant of max €600 per family, per year to have a hotel break in Ireland. For more information on how to apply for this recharge grant, please visit our website: www.imnda.ie

New Travel Grant announced to Help Families with the expense of attending Medical Appointments

The Travel Grant is another service that is being provided because of the Charlie Bird Development Fund.

IMNDA's mission is to support people living with motor neurone disease (MND), their families and carers through advocacy, home and professional support. We keep clients at the heart of everything we do so we understand the impact of our work. After our survey with clients, family and carers, on their needs, we are thrilled to announce that we have established a Travel grant to assist with some of the expenses of traveling to medical appointments. This is a once off grant, maximum of €400.

To apply for Charlie Bird Development Fund (CBDF) Travel grant, you will have to contact your MND Nurse or a Healthcare Professional such as a medical social worker, or another healthcare professional involved in your care.

More information on the terms of the grant can be found here: **imnda.ie/healthcare-professional-hub/imnda-grants**

DRINK TEA FOR MND

This year we swapped our summer tea parties for a nice spring cuppa of something special,

Drink Tea for MND took place in March for the first time ever and it was a huge success with over 100 tea parties organised around the country, the event was an enormous success again as it raised a staggering €150k. Lily Chen from Termonfeckin in Co Louth was this year's ambassador so a massive thank you to her for her help with the campaign. Read on for more on Lily's story…

LIVING WITH MND – LILY CHEN

"My first encounter with MND was over 30 years ago. As a teenager reading about Prof Stephen Hawking, I was puzzled by the "weird" disease he had. I remember thinking: "this disease is so rare that it probably only happens to geniuses like him."

It all started a few years ago and it almost came out of the blue. As a busy mother and the owner of our tea business, I was health conscious. Most mornings I would run a 5k on our beach. I felt invincible. One day in 2016 I noticed my left arm suddenly could not lift the cooking pot. Then in May 2019, my voice got slightly slurred. I stumbled and fell a few times when I was out running. I spent the next few months doing all sorts of tests, which didn't find anything wrong. With horrible anticipation, eventually, my husband Dom and I were given an appointment to see Prof Orla Hardiman and her team in January 2020, who empathetically gave us the diagnosis. I have a slowly developing form of Motor Neurone Disease called PLS. They didn't know the cause. There is no cure. Neither did they know how it would progress. I learnt that it doesn't just happen to geniuses, it could happen to anyone as rare as it is. Most patients were remarkably healthy.

The last 3 years after diagnosis have been extremely challenging. All the natural abilities I took for granted such as swallowing, speech and mobility started weakening, like an invisible hand that is turning down my power gradually. Communication is getting difficult; I miss Irish banter. Small things like giving away all my high heel shoes are heartbreaking. They are the constant reminders that this MND is not a nightmare that one day I will wake up from. Now instead of high heels, I am online searching for a powerful wheelchair that can be as light as a feather, and easier to transport; if only such a thing existed! My regular online chats with my mum in China are more like a silent old film now with me doing all the nodding. Although travel will be a big challenge, I am still secretly hoping after Covid I can one day travel again to China to see my mum.

Eventually, after all my online research pointed to the conclusion that this indeed wasn't a misdiagnosis, I am now determined to live life as normally as possible. This would not be possible without my husband Dom. Unlike me, he accepted every item of equipment offered by the IMNDA and HSE early to assist my speech and mobility. Dom has taken over most of the manual tasks such as gardening, house cleaning, and driving the kids to their training clubs. As a foodie, I insist on cooking most of the time, albeit at a much slower pace.

We sell our range of tea in Supervalu stores Nationwide. They have been tremendously supportive after we broke the news to them. Thanks to Supervalu, and some brilliant local independent retailers, we can keep running our tea business which we enjoy doing, although it's challenging, like every small business.

Our family went camping together around Ireland, France and Spain in 2021 and 2022. These trips are not only treasured times with our kids, they are also a defiant statement I feel compelled to make in fighting this disease. I also got to see our daughter excel in her leaving cert last summer and is now studying Medicine at Trinity College. Our son recently passed his senior-grade piano exams. I am counting all these big milestones …

I don't think there is any silver lining in MND. However, it brings my friends closer. They rally around and make a routine to have tea with me regularly. I get to see them more often now than I did before, which is lovely.

I can't finish my story without talking about Irish Motor Neurone Disease Association and the great work they do. IMNDA always help generously. We enjoy the visits from Louise and Aisling, who understand what it's like in every patient's life. We have laughter over a cup of tea without dwelling on doom and gloom. They like to say: every MND patient is unique. Keep your hope up.

While I am not the one who would fall for false hope, I have yet to find a better alternative. So we live as positively, and as normally as possible.

So here I am, raising the teacup with a small bit of hope and loads of love. Let's all drink tea for MND. Donate whatever you can so that the IMNDA can continue with their brilliant work to help people who live with this horrible disease."

A massive thank you to Lily, Dom and their two children for getting involved in the campaign and raising awareness of MND and funds for IMNDA to help support the services we provide around the country to those living with MND. Drink Tea was a great success and the final total to date from this event is €150k, a huge thanks to all of our supporters once again.

#VOICE4MND

For the first time Voice4MND took place in June this year! #Voice4MND is our annual sponsored silence campaign where we raise awareness and aim to give people with MND a voice by standing with them. During the month we asked people to stay silent for a period of their choice so they could briefly experience how it feels to not be able to speak.

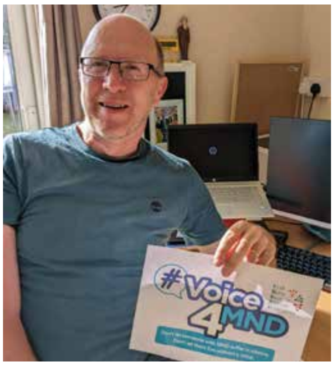
MND can impact significantly on a person's speech. More than 80% of people living with MND will experience some form of speech difficulty during their illness – some will lose their voice completely.

This year Caleb Sheehan from Cork and John Daly from Dublin helped us with the #Voice4MND campaign. Caleb kindly shared his story with us and allowed us into his home to take photographs and video recordings of him and his daughter Lucy. He agreed to record an advert which was aired on his local radio station Red FM as well as Newstalk and Today FM. Caleb also helped us by asking Munster and Ireland rugby player Peter O'Mahony to get involved in the campaign and he too recorded a video that was shared across our social media channels.

John Daly also helped us with the #Voice4MND campaign, and he and his wife Deirdre kindly welcomed us into their homes. We also took some photographs and recordings of John in his lovely garden, and we got some picture of John on this bike as this is one of his favourite past-times.

We had a very successful campaign and the fantastic sum of almost €60k was raised from this event. Both stories featured in local and national newspapers as well as local radio stations who interviewed Caleb and IMNDA nurses. We would just like to take this opportunity to say thank you to Caleb and John and their families for allowing us to share their stories. Raising awareness of Motor Neurone Disease is pivotal to the association so that the public can get a better understanding of the condition.

We would also like to take this opportunity to thank a few other people who kindly allowed us to share their pictures along with a quote on our social media channels to raise awareness of the event: Valerie O'Carroll, Aileen Healy, Agnes Mary Bonner, Siobhan Hogan, Andrew Tobin, Michael Clancy, Andrew McNicholas and Diarmuid Hickey.



Caleb's Sheehan's story….

"My name is Caleb Sheehan. I'm 51 years of age. I'm married with two grown-up children. I'm a retired teacher and I live in Cork.

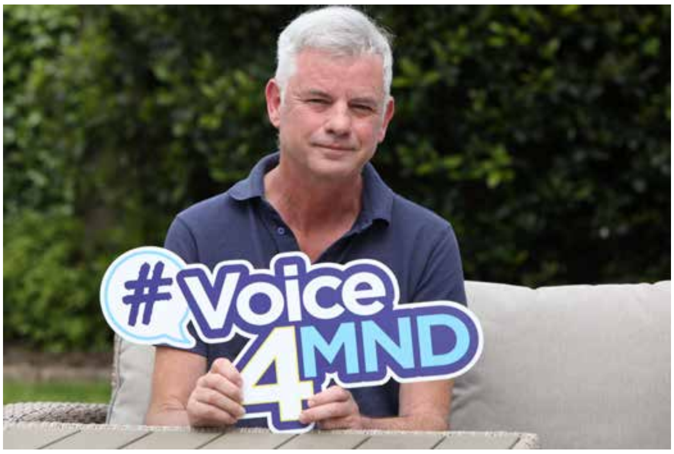
My MND journey began in late spring 2021 when I noticed a tremor in my right shoulder. The muscle seemed to be rippling under the skin. It wasn't until the tremors also began in my left shoulder that I sought medical advice. After 6 months of tests here in Cork I was referred to Professor Hardiman in Beaumont. My first visit proved inconclusive, and a second visit was scheduled for January 2022.

On the 19th 2022 of January Professor Hardiman carried out a set of strength tests on me. I failed one of the tests. I had lost some strength in my right hand. Professor Hardiman reluctantly informed me that I was in the early stages of MND. The news came as a complete shock to me and my wife who had accompanied me to the appointment. We were devastated. I returned to Beaumont the next day and attended my first MND clinic and drove back to Cork that evening where we broke the news to our families. We did not tell our kids at that point, and we decided to wait until the end of the school/ college year. The next day I went back to work and quickly realised that I needed some time to process what was happening to me physically, and emotionally to us as a family.

In the weeks and months that followed I felt a deep sense of grief for the life I had lost and the simple things that made up that life. The plans we had made for retirement and the future. More than that, as the disease progressed, I began to miss the everyday routine things that I can no longer do. I missed kicking a ball around with my son or training my daughter's football team, walking the dog or cooking a meal, the simple everyday things we all take for granted. I grieved for my old life until one day it struck me that I wasn't living and that wasn't fair to my family and friends. I knew that I had to get back to living so that is what I have being trying to do. I now have a very simple philosophy that can be summed up in four words. Accept, Adapt, Survive and most importantly Hope.

It is now 17 months since my diagnosis. I have lost most of the strength in my arms. I have difficulty walking. My speech is significantly impaired, and my swallowing has become more problematic, but I'm alive! I have hope. I have a wonderful wife and great kids. My extended family are unbelievably supportive. My friends and colleagues have been brilliant at keeping my spirits up, and I know now that I'm loved. The IMNDA has also been a constant support and a source of hope.

At this time, I am part of a clinical trial that aims to slow the progression of the disease. I'm very grateful to be part of the trial and for the support of Professor Hardiman and her team of researchers at RCSI in Beaumont. Being part of the trials keeps hope alive. I am 100% confident that given the time science will provide the answers and a cure for MND. In the meantime, my responsibility is to be as well as I can and wait for the day when science finally triumphs over this disease."



A personal account of the onset of MND (ALS) of the voice and throat (Bulbar Region) by John Daly

"Early summer 2022 the sailing season begins and I crew on a friend's yacht as we race around Dublin Bay. A vigorous affair followed by a nice pint and a lift home with my wife Deirdre who was a little surprised by my slight slurring of speech, after only one.

August and our two Canadian grandsons have spent two weeks with us and I am returning them to Toronto.

My son's sister-in-law, Sara, a Consultant Neurologist in Toronto, spots something worrying and suspicious about my speech.

Through the Autumn there are tests and meetings with Professor Orla Hardiman at Beaumont and a steady deterioration in the clarity of my speech. This all ends with the dreaded conclusion that I have MND of the throat region (Bulbar) though it is at an early stage.

I had no proper appreciation at that time of what life is like without my voice, but I did manage to record a now shaky version of my voice on a voice replacement app called SpeakUnique. I spent hours reading phrases supplied by the app. Then with some artificial improvements from the app, I now have a way of speaking phrases and even whole paragraphs that I type into the app. I can use it on my iPhone and iPad and I can amplify it a bit, for social settings, using a small Bluetooth speaker on my waist.

I apologise to those who have not had speech for all or much of their lives. Like many people, I had no proper appreciation of what that life involves. I wonder are we too old or is there a possibility of learning signing.

My life before MND took talking completely for granted: -

- *40 years as a science teacher,*
- *Ten years of retirement, visiting schools with a demonstration chemistry lecture,*
- *Workshops for teachers at the start of their careers,*
- *Writing and singing songs with guitar and keyboard,*
- *Visiting friends for coffee and chats.*

My life was centred without thought, on talking: -

- *The oh-so-important everyday dialogue with my love, Deirdre and close friends and relatives,*
- *Special Facetime moments and shared visits with our two terrific sons, their wives, and extended families and of course our five very special grandchildren,*
- *Even the simplest interaction, as the car is serviced, or purchases are requested.*

Now I am suddenly isolated, in a world of my own, even with the enormous efforts of those all around me who love, care, and help. If a casual question is asked from across *the room, I must write or type a response and show it to the other person or get Speak Unique to say it. Conversations after all, are full of interjections and rapid changes of topic, and typing falls far behind, and my laborious remark becomes irrelevant by the time it is announced.*

People are so kind and caring and make great efforts, but you are no longer part of the swing of things. Sitting in the dining room of Ballymascanlon Hotel yesterday, and listening to the great buzz of conversation, was very dispiriting. I have, especially with Deirdre's help, and that of all our friends, made great efforts to remain upbeat almost all the time, but every now and then it gets too much to deal with. It all sinks in, what I have lost, and there are inevitable, short and private collapses of moral.

There are associated problems as well with this form of MND. Swallowing becomes increasingly difficult. Food choices reduce and eating times increase. Even drinks including water, need to be of a thicker consistency, to go down. It is not possible to eat and carry on conversation, as the mind must really concentrate on swallowing. This is another source of isolation.

Sometime in the next few months, I will need to have a direct line put into my stomach for the delivery of food supplements. Otherwise, I would become dehydrated and lose weight, neither of which is desirable.

Now for the "good news" relatively speaking. In saying this, I am very conscious that there are MND patients with other forms of the disease, who have much decreased mobility and dexterity, who are suffering much more than I am.

This being 2023, I can make maximum use of technology and social media.

- *Email for oldies,*
- *WhatsApp until META becomes too unforgivable,*
- *Facetime & Zoom,*
- *Speak Unique (funded by the IMNDA) on iPhone and iPad,*
- *Swipe and Speak (artificial voice) on any Apple device,*
- *LCD button-clear boards on which I can write with a plastic stylus.*

I have the unbelievable professional, kind, caring support of the MND Clinic at Beaumont Hospital and the equally wonderful support of HSE nurses, speech therapists, dieticians, working in the community and of course the wonderful voluntary work of the Irish Motor Neuron Disease Association. My mind is unaffected, I can walk miles in the Wicklow hills, cycle (an electric 50 KM) until my battery runs out, swim, crew a racing yacht, and write poetry. Let my deterioration be as slow as possible.

So, this account is written, not as a moan, but to show you what can happen in life and to ask you on behalf of the IMNDA to support their work for other people caught up in this particular situation. It is also written to acknowledge the enormous and almost overwhelming swell of goodness and kindness that has come my way, since the news spread.

Oh well why not end with a slight moan. Not being able to speak does not mean I am unable to think. Just we like we all raise our voices when talking to someone with poor English, some people automatically treat one's situation as that of intellectual disability when it is not. I'm sure I have been guilty of this in the past myself, so I apologise for this and ask you also to please think twice when being nice."

Once again, a massive thank you to all for helping us to raise awareness of MND through our voice4MND campaign. If you would like to get involved for 2024, please contact pr@imnda.ie

#Voice4MND

CELEBRATING YOUR FUNDRAISING TRIUMPHS 2023

As we dive into another remarkable year of community-driven support, it is our privilege to spotlight some awe-inspiring individuals who have truly embraced the spirit of generosity. So many fundraisers and supporters ignite a beacon of hope for our MND Community and for that we are so thankful.

While it's impossible to extend personal gratitude to everybody, please know that your efforts hold immense value within our MND Community. **Thank You Each & Every One of You!**

Young Heroes Making a Big Impact

We commence our accolades by shining a spotlight on two exceptional young souls who have set an extraordinary example of philanthropy. At just age 10, Alex Estevez of Dublin orchestrated a lemonade and cake stand, which has raised an impressive €1257!!

Equally remarkable is 8-year-old Siobhan McManus from Dundalk, who fearlessly transformed her lustrous locks into a gift of compassion, raising the wonderful sum of €1,050 after snipping 17 inches off her hair.

Alex and Siobhan, we are immensely proud of you guys!

Soaring Heights: Unveiling our Top Achievers

With the bar set exceptionally high, we are thrilled to acknowledge three extraordinary undertakings that have surpassed all expectations.

Brian and the rest of the O'Connor family in association with their local GAA club, Saint Patricks GFC, have so far raised over €50K through a number of planned events, including a hugely well supported family day on the 26th August. Thank you to all involved.

The memory of John Gayer was honoured once again this year by Sarah Ryan & the Claremorris community's auction in Co. Mayo. An event that raised over 31K.

On the opposite coast, in Co. Wicklow, Adam Brennan's Spinathon whirled into action, propelling the fundraising journey with an equally impressive sum of over €30,500.

Miles of Dedication for a Worthy Cause

James Tolan embarked on an awe-inspiring journey in early July. Running 4 astounding back-to-back ultra marathons, James traversed the distance from Dublin to Foxford, Mayo, clocking in close to €23,000 in support. Your feet might have touched the road, James, but your actions have touched countless lives.

Joe's Donegal Ultra 333 Cycle took him around the picturesque coast of Donegal in under 20 hours. The determination of Joe Hunter is a source of inspiration to us all and thank you for the €4,750.

In August, Monica McElhinney, Enda and a group of incredible people took part in Sligo's Warriors Run in memory of a special lady, Trisha. Together they raised an outstanding €36,372 which they handed to IMNDA's Nurse Eithne Cawley.

On behalf of Trisha's family & close friends Enda and Monica, extend a huge heartfelt thank you to everyone of Trisha's Warriors and to those who supported us and donated so willingly and generously in Trisha's memory.

A Salute to Exceptional Evenings

We extend our heartfelt gratitude to two remarkable women whose dedication led to nights of joy and giving. Teresa Flatley's Benefit Night shone brilliantly, raising an incredible €28,000 in support of our cause.

Equally deserving of admiration is Marilyn O'Connor, whose Dance While You Can Valentines Ball twirled its way to an impressive €18,000. Teresa and Marilyn, your devotion is a testament to the impact that can be achieved through community spirit.

Golf Classics Shine Bright

John Considine, a longstanding supporter of IMNDA, continues to amaze us with his unwavering commitment. This year, he orchestrated a series of fundraising activities, including a beard shave, a Golf Day and a Flag Day, all of which contributed to an impressive total of €23,000. Thank you, John, for your exceptional dedication and hard work.

John Amerlynck and Rush Golf Club exemplify the spirit of giving. They raised an incredible €22,300 in honour of their member and friend, Larry Halpin, and in support of the IMNDA. Your generosity truly warms our hearts.

Karin and Joe Abbott, Fiachra and Alan Maher, with the support of the Lyons Club and Edenderry Golf Club, organised a golf classic which raised a whopping €14K. The

Lyons Club's donation of prizes for a raffle and Edenderry Golf Club's kind offer of a free venue exemplifies the spirit of community and giving. Thank you all.

The Sky is the Limit

A special mention goes to the incredibly brave Norah Murphy, who, at 80 years of age, undertook a skydive to raise funds for IMNDA. Notably, three generations of her family joined her in this thrilling endeavour! Well done to Norah, Cat, Margaret, and Katie for your courageous efforts, resulting in a massive €11,197 raised.

Another remarkable feat that deserves recognition is the incredible journey of Alice Donovan, her father, and sister, who embarked on a challenging climb to Everest Base Camp, raising an impressive €15.3K along the way.

Cycling Fundraisers

Cavan's Angela Brady's extraordinary initiative, Sunrise to Sunset Cycle for Mary truly stood out, bringing in an unbelievable €31K. Angela's remarkable efforts, spanning several tireless months, were instrumental in rallying widespread support for this event.

Also, in the world of cycling fundraisers; the O'Neill Industrial Charity Cycle in Ardnacrusha, Co Clare, contributing €10K and Michael Leech and the Smuggler Cycling Club's Ring Of Cuilcagh endeavoured to raise €8.5K are deserving of a huge applause. We cannot express how grateful we are to all of you.

A Shout Out to Businesses Who've Made a Difference

We want to extend a special thank you to our corporate friends who have actively fundraised in various ways.

We commend the TU Dublin Students' Union, who selected the IMNDA as their RAG Charity of the Year for 2022/23. Their dedication and hard work resulted in nearly 13K being raised on our behalf.

Our current charity partner Hays Recruitment have undertaken a variety of fundraising activities, from coffee mornings to their Giant's Causeway hike with the impressive sum of nearly €30k raised to date.

The Grafton Group and Permanent TSB respectively, also chose the IMNDA as their charity partner for 2023 and they have been busy organising monthly events amongst their staff members.

We are also delighted to be working with Network Ireland this year through a number of initiatives and special events.

So many successful and fruitful corporate and workplace-based events have taken place over the last year. PWC Dublin organised a table quiz in memory of their colleague, raising a phenomenal €15K.

Huge thanks to BT Ireland for choosing IMNDA as a beneficiary of their annual Activity Day and donating €6k.

We have had some serious corporate climbers this year! The Chadwicks Group 4 peaks challenge saw a team of 19 hike 4 peaks in 4 provinces over 4 days. The gang tackled Carrauntoohil, Mweelrea, Slieve Donard & Lugnaquilla and raised over €7,500 for the IMNDA – fantastic!

16 hikers from HDD UK LTD & MTFitness took on a 3 peak challenge and handed over €21k to the IMNDA – well done one and all on such a magnificent achievement!

We are also very thankful to avail of some wonderful Corporate Volunteers this year – Google assisted us at our Services led events.

We are absolutely delighted to announce that William Fry Law Firm has chosen the IMNDA as a charity partner for 2024-2026!!! Thank you to everyone who voted for us and we simply cannot wait to work with you for the next 3 years!

Every single fundraising event, regardless of its scale, makes a real difference. Every unique contribution is a source of inspiration, reminding us that collectively we really can make a positive impact on the lives of families living with Motor Neurone Disease.

So, to all who have walked, ran, climbed, cycled, golfed, skydived, danced, sang, knitted, swam, baked, donated and even attended an event in your local area over the last year **Thank you so very much!!!**

WALK WHILE YOU CAN ON TOUR!

Walk While You Can kicked off early this year when Kieran Coote along with a group of friends headed off to sunny Spain and walked the Camino in Memory of Fr Tony Coote. Tony started Walk While You Can back in 2018 shortly after his MND diagnosis and sadly passed away in September 2019.

> **"We, his family and many friends, are lucky to have the WWYC campaign to rally around and help keep a positive memory of Tony in our lives. This is what the WWYC campaign has come to mean for us. It has helped and continues to help ease the pain and sense of loss. It has allowed us to slowly turn a negative into a long lasting positive"**
>
> Kieran Coote, Tony's brother.

We think Tony would be super proud Kieran and Co. after your Walk While You Can raised a whopping €9,600!!

Thanks also to everyone who is raking on Walk While You Can this October, we are so grateful!

DRINK TEA FOR MND 2023

From Donegal to Cork and from Dublin to Galway, Tea parties were organised during the Drink Tea for MND campaign and we thank everyone who rallied round with tea and cakes in March and beyond.

A staggering €150k was raised from this event overall, which is truly magnificent.

This is all down to you, our wonderful supporters who made it all happen for us this year. THANK YOU!

This was first year the campaign was moved from June to March and we look forward to drinking tea once again next Spring. So please save the date for March 2024 and come and join the tea party fun! Details for all our upcoming events as always will be on our website imnda.ie.

ONE WEE FELLA'S STORY OF MOTOR NEURONE DISEASE – BRIAN O'CONNOR

Brian O'Connor, his family, friends and his community from Lordship in Co Louth approached the association to do some fundraising because his brother Padraic has been diagnosed with Motor Neurone Disease. They organised a very successful fundraising walk with St Patrick's GAA in Lordship. But they want to do more to raise funds, so they are organising a **Monster Draw**…. Read on more for Brian's story and how you can enter the monster draw.

"My life began in November 1953, the following year in December of 1954 my brother Padraic was born, previously to that my bother Jim was born in November of 1950, at this point we had four other siblings, and later to be joined by two down syndrome siblings and one other sibling, making a grand total of ten children in an old two bedroomed stone built house.

The family was categorised into different age groups by my mother, our group was made up of Jim, Brian & Padraic, we were called the "wee" fellas.

The "wee fellas" worked on our small farm, played the same games when work and time permitted, we went to the same schools, in fact Padraic and I were always in the same class, and were genuinely described as Irish twins. I might add the wee fellas always got into same trouble together.

This remained the way of life right into our twenties, when we all got married, but we stayed close, living very close to each other. I always looked up to Padraic, because of his kindness to our parents, and the beautiful way he had with his own family, and he always when in company had his arm around his wife Vera.

The other reasons I admired him was his good looks, and his 6ft 3ft height. His talent on the football field and his business ability, and his love for the GAA, with him being the Louth County GAA chairman for 5 years, and chairman & treasurer of St Patricks GFC.

Time passed, when we had, both been invited to a wedding in Lanzarote in October 2022, I noticed Padraic had developed a limp, he was worried about this as was his wife Vera and family.

Then to hear the news he was diagnosed with MND in January 2023, we were as a community in total shock.

Padraic then suggested we come together to raise much needed funds for the IMNDA, to show some little appreciation to these wonderful people, who rely on 85% funding raised by the community to provide this loving care and facilities, who cater for all the 450 plus patients who have MND in Ireland today.

We took ads out in local papers also and we passed word through the GAA clubs in Louth, all to highlight the need to support a sponsored walk-in favour of IMNDA on 26th August 2023, and hundreds of people turned up. We were humbled by the generous donations by those taking part, and by local business who sponsored prizes for a raffle/draw on that day, we managed to raise €20,000.00 plus then, with all going directly to IMNDA. None of the fundraising could have happened without the help and facilities of our local GAA club of Patricks GFC and the GAA family generally https://www.facebook.com/stpatricksgfclordship

*But we knew more had to be done, so we decided to come up with the **Monster Draw** so again we approached local businesses, who again gladly sponsored the wonderful prizes in our online draw. Have a look at the prizes, with absolutely no gain for anybody except for those wonderful people of the IMNDA, so besides from wining a fantastic prize you are also supporting an excellent cause, & you will see the tickets are not badly priced either, give it a go, the IMNDA need our help," my regards Brian O'Connor.*

Thanks to Brian and all the community in Lordship for their wonderful support so far. Their **Monster Draw** for IMNDA is featured on the back page of the magazine where you can see the prizes that are on offer along with a QR code to enter. Good Luck!!!

CONGRATULATIONS ALL ROUND…

Congratulations to our Fundraising Executive Jackie Martin, who gave birth earlier this year to a little baby girl. Baby Imogen was born in March of this year, sending Jackie and family all our best wishes.

Congratulations to our Head of Advocacy & Communications Maeve Leahy, who also gave birth to a new baby girl very recently. Baby Sadhbh was born in August, sending Maeve and family all our best wishes too.

Congratulations to our Information and support officer Johanna McGrath who gave birth to Baby Fionn.

Congratulations to our Services Co-Ordinator Lisa McNally, who became a granny recently. Lisa is enjoying her lovely new grandchild, baby Maya.

And finally, congratulations to our CEO Lillian McGovern, who too became a granny, she is delighted with the arrival of her lovely new grandchild, baby Bobby.

Since our last edition of Connect we have added 3 new nurses to the IMNDA team and we would like to welcome Maire Hayes from the south of the country and her areas include Wicklow, Wexford, Waterford, Tipperary, Carlow and Kilkenny. We would also like to welcome Kathryn Foley who too is from the south and her areas include Kerry, South Limerick, and Cork. We would like to welcome Aine McFadden who comes from the midlands and her areas include Dublin West LHO, Kildare, Westmeath, Meath, Laois.

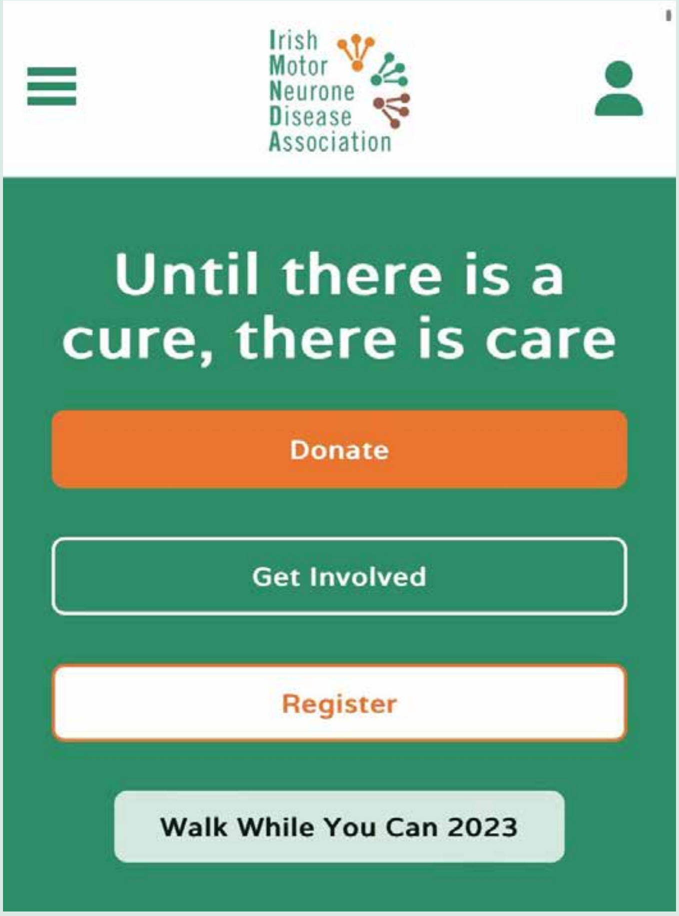
We would also like to welcome Nafisa Brennan to the fundraising team. She will be looking after the corporate section for the association. So if you have a corporate connection, please do get in touch with Nafisa fundraising@imnda.ie, she will be happy to have a chat with how we can further the relationship.

Fiona Thornton has taken on the role of interim Head of Communications and Advocacy at the IMNDA where she will be responsible for all aspects of communications including media relations and advocacy for the association.

Welcome to Audrey Charleton, who too joined the team this year. She took up the position as Accounts Assistant helping the Head of Finance and Compliance.

A fond farewell to Maria Hill, our Head of Finance & Compliance here at the Association, she joined IMNDA in January 2019. She will move to Science Foundation Ireland (SFI), we wish her all the luck with her new position. She will be sadly missed by all her friends at the association.

NEW LOOK WEBSITE AT WWW.IMNDA.IE



Until there is a cure, there is care

This year we gave the website imnda.ie a new look to bring it more up to date and make it look fresher.

We have divided it into sections; About IMNDA this gives you information about the organisation structure, where does the money go, staff and board.

The next section is the About MND section; this gives you information about MND, different types, symptoms and effects and more facts about MND.

The next section is the Healthcare Professionals Hub which gives information about IMNDA services, how to order equipment, grants, physiotherapy, psychosocial care and useful links.

Then we have the Just Diagnosed section which includes help available, registering with IMNDA, our nurses and FAQ's.

Up next is the Living with MND section which includes movement and mobility, MND and communication and more information on MND.

Then we have the Help Available section which contains all the information on the supports available to the MND community.

The News & Updates section all recent news and events that have taken place.

The Get Involved section is where supporters can go if they are looking to organise a fundraising event. We also have a thank you wall which is a new feature, this is for people who have organised events and would like us to acknowledge their event.

And finally we have the Contact Us section, this is where you can get in touch with the association. We also have the Shop section where you can purchase IMNDA merchandise and christmas cards.

If you have any feedback, we always appreciate what you have to say, you can email it to pr@imnda.ie.

CHRISTMAS MEMORY TREE

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

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 €20 including postage and packaging.

Christmas Cards

Our charming traditional Christmas cards are €10 per pack of 12 cards (postage will be added on at checkout) and each pack has 6 different designs (2 of each design).

Buying a pack and sending our cards is a simple and effective way for you to help us raise awareness and also show your family and friends who are thinking about them over the festive season.

Both decorations and cards are available to purchase at imnda.ie/shop/or by calling the Fundraising Team on 01 670 5942.

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

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Unit 3, Ground Floor
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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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We will remove you immediately from the mailing.

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CHY 8510 R.C.N: 20021009

MONSTER HOLIDAY DRAW

in aid of The Irish Motor Neurone Disease Association

1ST PRIZE – Week long Mediterranean Cruise on the MSC World Europa Liner (www.msccruises.ie), including return flights to and from Barcelona, (Friday 5th of July to Friday 12th of July). *Sponsored by Protection and Prosperity Financial Services with a little help from Peader McDonald*

2ND PRIZE – 1 Week in a 3-bedroom villa with private pool in Benalmadena Spain for two people in the last week of August 2024 (date TBC), including return flights to and from Malaga, including one 10kg carry-on bag each. *Sponsored by O'Connor Roofing Supplies*

3RD PRIZE – 7 night stay in the Royal Marine Hotel (www.royalmarine.ie) including breakfast between February and November 2024 (date of your choice), subject to hotel availability. *Sponsored by Alltech Fibre*

4TH PRIZE – 2 Premium Level Coldplay tickets for Thursday 29th of August.

5TH PRIZE – 2 Premium Level Coldplay tickets for Sunday 1st of September.

TICKETS PRICES: €10 FOR ONE, €20 FOR THREE, €50 FOR EIGHT, €100 FOR TWENTY

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To enter visit **www.idonate.ie/raffle/MonsterHolidayDrawforIMNDA**
or scan the QR code below right to visit raffle page.

Irish Motor Neurone Disease Association

The draw will take place in the offices of the IMNDA, Merchants Quay, Dublin 8 and will be live streamed on the **Irish Motor Neurone Disease Association** Facebook page. The winners will be announced live. Draw date: 3rd May 2024. The entire proceeds of this draw are going to the **IMNDA**

For more information Telephone: 0876487466 or 0872595557

Terms and conditions apply, the organisers reserve the right to change the draw date, there are No Cash Alternatives to these prizes. Full T & C Listed on the St Patricks GFC Facebook page (https://www.facebook.com/stpatricksgfclordship), this draw is being promoted and organised by St Patricks GFC.

Permission Granted, Garda Permit no DKDO_62-327001/23