Irish
Motor
Neurone
Disease
Association

CONNECT

ISSUE
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Spring 2018

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A NOTE FROM OUR CEO

On behalf of the IMNDA, I would like to welcome you to the first Edition of the Connect Magazine for 2018 and it is with a sad heart that I say this will be my last insert as I am leaving the IMNDA to take on an entirely new challenge away from the Community and Voluntary Sector. It has been an absolute pleasure leading the IMNDA for the last five years and we have achieved many things, I am leaving with our second Strategic Plan completed (2017-2020) and in the very capable hands of a dedicated IMNDA board and passionate IMNDA staff team. I would also like to extend my sincere thanks to all those families I have met throughout the years it has been an absolute honour advocating and working on your behalf it has been inspirational sharing the journey with you all.

Back to buisness... it has been a busy start of the year; we launched our 4th Sponsored Silence Campaign which saw many of our families taking part. We shared a photo online every day throughout the month of February and so far we have raised over €40k. The Good Friday Run was another huge success with over 650 participants showing their support. We are also thrilled to announce that we have been chosen as the Dublin Airport Authority and Irish Life Charity of the Year. This will see staff from both organizations running events for the IMNDA throughout the year so it has been a very exciting start to 2018.

We have also seen a rise in numbers accessing our services and in 2017 we provided services to 524 compared to 456 in 2016. As part of our Strategic Plan and in order to deal with the increase in numbers we have created a new post, Information and Support Officer. We feel this position will complement our services and provide a great resource to our families. We also launched a new and more user friendly information leaflet called: An Introduction to Motor Neurone Disease, for those that are newly diagnosed.

On a final note I would to extend my heartfelt thank you to the IMNDA Board for all their support, to the IMNDA staff for their pure dedication to the IMNDA community and to Professor Hardiman and her team for their visionary approach to care and research.

Aisling Farrell, CEO

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.

Irish Motor Neurone Disease Association

Irish Motor Neurone Disease Association
Coleraine House, Coleraine St, Dublin 7
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Freefone: 1800 403 403 **Fax:** 01 8731409
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www.facebook.com/irishmnd2011

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Contributions to the next edition of Connect:
If you would like to submit a story, photo, or something you would like to share then please contact the office.

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Disclaimer

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MEDICAL PATRON Dr. Aisling Ryan MB, PhD, FRCPI, Consultant Neurologist
PATRONS: Arthur McGuinness
DIRECTORS: Declan Mac Daid (Chairperson), Alison Gray (Hon Treasurer)
Bernie Conolly, Katie Hallissey, Jonathan Healy, Angela Hogan, Orla Clayton, Norman Hughes

Irish Motor Neurone Disease Association Events Calendar 2018

The IMNDA would not be here without the wonderful support we receive each year.

82% of our income comes from people like you.

Please check out some of the events & campaigns that will take place in 2018. We need your help to continue providing care and support to families affected by **Motor Neurone Disease**

We will be adding more to our calendar throughout this year so keep an eye on our website and Facebook page.

Awareness June

- Sunday 3rd June@ 2pm: VHI Women's Mini Marathon – run the race to make a difference (on a Sunday for the 1st time!)
- Saturday 9th June: Polo in the Park in The Polo Club, Phoenix Park, Dublin
- Saturday 16th June: D2K Cycle
- MND National Awareness Day is 21st June - Drink Tea for MND during June – tea packs available from the IMNDA
- Saturday 30th June: "Sunrise Up Croagh Patrick" is an annual fun walk and climb to raise funds for worthwhile charities fighting Neurological Diseases. For more see www.sunriseupcroaghpatrick.com

D-Feet July

- Saturday 21st July @ 11am : Walk to D-Feet MND in the stunning Phoenix Park, Dublin (start @ the Papal Cross) OR organise a walk in your local area
- Sunday 10th July – 6th August: Walk While You Can, a walk the length of Ireland! Join us and Fr. Tony Coote from Letterkenny to Dunmanway in aid of IMNDA and MND Research.

Seminar September

- Friday 7th September: IMNDA's AGM, Annual Conference and Patient & Carer Respite Weekend in the Clayton Whites Hotel Wexford.

Adventure October

- Saturday 13th October: Abseil off the roof of Croke Park's famous Hogan Stand, 100ft from top to bottom!
- Sunday 28th October: Run the Dublin City Marathon

More information on all of the events and campaigns taking place throughout 2018 is available from the IMNDA:-

IMNDA
Coleraine House
Coleraine Street
Dublin 7
Email: fundraising@imnda.ie
Phone: 01 873 0422
www.imnda.ie
@imnda
www.facebook.com/IrishMND2011
CHY 8510

Please contact the IMNDA prior to embarking on any fundraising activities. Thank you.

NEWS & RESEARCH

MND/ALS International Symposium 2017

The International Symposium on ALS/MND for 2017 was held in Boston, Massachusetts last December. The Symposium itself ran from 8th-10th December and before this was the Annual Meeting of the International Alliance of ALS/MND Associations and the Allied Professionals Forum.

The annual meeting of the International Alliance was held on 5th and 6th December. This was a great opportunity to meet with staff of other MND associations from around the world and to hear about the work they do and the services they provide for people with MND. The remit of the other associations was very varied as like Ireland some countries have only one MND association but other countries (such as United States) have number of different associations all of which have a different focus. After the official business (AGM) of the Alliance and an update on the activities of the Alliance in the previous 12 months there were presentations by the member groups. In total there were presentations from 18 groups representing 13 countries. The presentations were divided into 3 sections – Programming for PALS and CALS (People living with ALS/MND and Carers of people with ALS/MND), Partnerships and Collaborations & Research and Science. Although the main target audience of the presentations was the organisations themselves some were aimed at people living with MND. I'll give a brief overview of the most interesting and relevant presentations in each section.

Programming for PALS and CALS

Mixiton: The French MND Association (ARSLA) gave details of an app they have produced called Mixiton. This app is a collection of recipes and tips for tasty, attractive looking easy to swallow meals/dishes. In France (as in other countries) meals are very important moments of sharing and conviviality. Those with swallowing difficulties often shy away from mealtimes and ARSLA wanted to do something to change this. They invited caregivers and those with an interest in this area to submit a recipe and a photo of an attractive looking and appetising easy to swallow/pureed dish. They received 200 submissions which were all put on a dedicated page of their website. Following a voting process this was reduced to 30 dishes which had to pass a judging panel which included patients, carers, neurologists, nutritionists and restaurant professionals. Each dish had to be tasty, of suitable texture, appetizing and the price and availability of ingredients had to be realistic. These were to be meals for everyday not just special occasions. The app was launched in July 2017 and is currently available in French. An English version is on the way. It was hoped to be available in March 2018 but we'll keep you up to date on this. ARSLA are planning on a Christmas themed competition for this year.

Partnerships and Collaboration

This section was about how some of the MND Associations around the world are working together on specific projects to improve the services available to people with MND. The MND Associations in Argentina, Chile, Colombia, Brazil, Peru, Venezuela and Uruguay came together to form the first Latin American organisation of ALS/MND patient associations which is called UNELA (ALS/MND is referred to as ELA in Spanish speaking countries). Although UNELA is comprised of associations supporting people with MND it was inspired by ENCALS (European Network for Cure of ALS) which comprises of clinical and research groups.

Research and Science

ALS Quest is an online questionnaire designed to look at the risk factors for ALS/MND. It was launched in 2015 but is based on an adaption of an Australian paper based questionnaire from 2001 looking at chemical and lifestyle risk factors. The questionnaire will run for a further 10 years and the aim is to have 5,000 people with ALS/MND and 5,000 controls (people that don't have MND) complete the questionnaire. The survey questions include details of: occupational activities, chemical and pesticide exposures, physical activity, smoking, family sizes, medical history, ring finger lengths, personality types and life event stressors. The questionnaire takes 60-90 minutes to complete and can be done in multiple sessions with answers saved automatically. It is best to be done on a desktop computer or laptop as opposed to a mobile phone or tablet. No personally identifiable data is sought so all responses are anonymous. The survey and more information can be found on www.alsquest.org.

Day two of the Alliance Meeting began with details of and a workshop on the strategic plan of the Alliance. This was followed by a scientific and research update given by Dr Jonathan Glass, Professor Emory University Department of Neurology & Pathology and Director of Emory ALS Center, Atlanta Georgia. Dr Glass ALS/MND and Frontal Temporal Dementia (FTD). Dr Glass was also one of the speakers at the 'Ask the Experts' session that afternoon so I will try to sum up both presentations in plain English!

ALS/MND and Frontal Temporal Dementia (FTD)

Cases of Frontal Temporal Dementia combined with MND have been identified in medical journals going back to the 1930's. They weren't perhaps linked and genetic involvement wasn't known about at the time but looking back now knowing what researchers do there is a lot to be learnt from these old articles. The combination of FTD and MND is more associated with cases of familial MND (where there a genetic or family history). Although there are now many MND genes identified, the only one (so far) identified in Ireland is the C9orf72 gene. This gene is also prevalent in the United States where Dr Glass's research took place. He identified that where there is an unknown family history of MND 4% of people have the C9orf72 gene and where there is a known family history of MND 63% of people have C9orf72 gene. All gene mutations are responsible for 10-12% of cases of MND while C9orf72 is present in 40-50% of families who have MND in USA.

Research has identified that Dipeptide Repeat Proteins which are made by DNA (C9orf72 gene) are toxic to neurons. DNA can be made into RNA which can be made into proteins. The dipeptide proteins can get in the way of transportation of cells and of other substances within the cells. In pre-clinical (animal) models these dipeptide proteins can go away so this is paving the way for exciting developments in C9orf72 MND. This year will see a clinical (human) trial on Antisense Oligonucleotide for people with C9orf72. This means that scientists have a way of isolating the C9orf72 part of the gene (DNA) and inactivating it. Essentially trying to turn off the bit of DNA which causes Familial MND in Ireland.

Researchers are also looking at large scale protein studies (proteomics) in relation to the overlap between MND and FTD. They are now studying the brain from the following criteria: Control (no MND or FTD), MND only, MND & FTD and FTD only. It is hoped that this will identify new targets or proteins at which future research can be aimed.

Allied Professionals Forum

Day 3 was aimed at healthcare workers who work with People with MND but who aren't neurologists or medical doctors. There were 260 attendees and 16 speakers so it was a jam packed day. I'll give a brief overview of the most relevant and informative presentations.

Kaye Stephens, Care Information Manager with the MND Association of England, Wales and Northern Ireland presented on 'Developing an Eating and Drinking Guide to Improve Quality of Life for People with ALS/MND, their Carers and Families'. A lot of the presentation was about the development of the guide, how the information for the guide was researched, engaging with families. The MND Association had previously prioritised quality of life as a theme for care information. In particular the way MND can affect eating and drinking was highlighted as it can lead to health problems, increasing social isolation as well as affecting the sense of wellbeing for the whole family. The goal was to provide a friendly, uplifting 'cookbook' for MND that would help people manage nutrition, weight loss, swallowing physical difficulties, food preparation and eating out. It is very much more than just a cookbook!! It is written in plain English for families not professionals. It contains

gentle information that can help open up more difficult conversations. The guide/cookbook is available online from www.mndassociation.org/about-mnd/living-with-mnd/eating-and-drinking/. Phase 2 of the project was to compile the recipes into a web app. This part of the project has now been completed and more information can be found on **www.mndassociation.org/eatingwithMNDapp/**.

Medical use of cannabis has been making headlines in Ireland in recent times in relation to a number of conditions so I was interested to see a presentation on 'Cannabis and its Usage in Symptom Management of ALS/MND'. Leslie Ryan from the Rocky Mountain Chapter (Colorado) of the ALS Association conducted an online survey over a period of 6 weeks in 2017. She sent the survey to patients with ALS chapters throughout the USA and had 484 responses from 43 states. Of the respondents 87% were over the age of 50 and 80% attend or are linked in with an ALS Multidisciplinary Clinic. In answer to the question 'Do you use cannabis to manage symptoms of ALS?' 30% answered yes and a further 5 % stated that they did use it but had stopped. When asked why they weren't using cannabis the majority of respondents stated personal choice or cannabis is illegal in their state. However, 17% said it was because they were not offered it or they were not aware of the benefits. 93% of respondents who use/have used cannabis believe it is successful in reducing pain, cramping, spasms, anxiety, insomnia and weight loss. A variety of forms of cannabis were used by the respondents – including smoking, edibles, drops, spray and creams. Drops, sprays and creams were deemed the best to use as it is easiest to measure the dose and absorption into the body is more controlled. Of those using cannabis 44% haven't discussed this with their healthcare team. This isn't recommended as use of cannabis can have a negative effect on the respiratory system and exacerbate symptoms. It can also possibly lead to a cognitive decline over time. So while there seemed to be a lot of positive outcomes from the study what next? The main points that Leslie will now focus on are education & information, studies on effects/benefits and continuing the conversation. More research is needed in this area but the presentation definitely provided some food for thought.

Ashley Crook is a Genetic Counsellor working with the Macquarie University MND Clinic and Research Centre in Sydney, Australia so this is all from an Australian perspective. She is a member of the multidisciplinary team since August 2015. She works closely with the neurologist and the genetics research team. Genetic counselling is emerging in the care of people with MND, due to the increasing discovery of genes associated with a high risk for developing MND, Frontotemporal Dementia (FTD) or a combination of both. Decision making about genetic testing is complicated and is also complicated by technology. Genetic counselling is to promote informed choices and to increase support for people considering testing (people with MND and family members). Ashley's research showed that in Australia 30-40% of cases of familial MND had no identified gene and 3-10% of cases of sporadic MND have the C9orf72 gene. The gene could be a risk factor and not the cause as other research has shown that you can have the gene but not go on to develop MND. With advances in technology and genetic research, genetic testing for families may become available in Ireland. If/when this happens it will be essential to have experienced genetic counsellors as a resource for families making decisions on genetic testing.

My highlights centred around food and genetics but if you want more information on any of the above or on any of the other presentations from the 3 days you can watch videos of each presentation on **www.alsmndalliance.org/meetings/alsmndmeetings/past-meetings/2017-meetings/**.

The 2018 Alliance meetings and Symposium will be held in Glasgow.

Research Updates

The MND Research Group at Trinity College is led by Prof. Hardiman and has 7 thematic areas of research. These are epidemiology, phenotyping (putting patients into subgroups based on their symptoms and signs), imaging, brainwave signal analysis, new measurement devices, drug development and health services.

We have made significant progress in the past year in each of these areas. Our most recent developments are in the following areas:

Transcranial Magnetic Stimulation

- In March 2018 we began a new programme in **Transcranial magnetic stimulation**, commonly referred to as TMS. This is an elegant, safe, comfortable and non-invasive technique to activate specific brain areas for assessment. By applying brief pulses to the brain areas which generate movement, TMS can provide direct measurements of how well these cells are connected to each other and control muscle function. Therefore TMS can objectively measure how motor neuron activity in the brain is changed by MND. TMS can also be used to identify MND-related changes in cells which regulate motor neurons, which might be driving motor neurons to become dysfunctional. Recent TMS studies have demonstrated a decrease in the function of small intermediate regulatory cells in MND, particularly early in the disease. This has been suggested to cause motor neurons in the brain to become overactive, ultimately causing degeneration and motor disability.

- This work is being led by Dr.Bahman Nassereloslami Senior Research Fellow, and

- PhD candidate Roisin Mc Mackin , who is funded by the Irish Research Council. Using TMS, Bahman and Roisin will investigate how motor neurons, inhibitory interneurons and other lesser studied cells which control motor neurons are affected in the Irish MND population. The goal of this exciting study is to find more reliable, direct markers of MND, which could be used for earlier diagnosis and to monitor the progress of the disease when testing the new therapeutic interventions. The study will also investigate whether TMS could be used to identify different subtypes of MND, with the aim of allowing for more personalised predictions of how the disease progresses.

New study to examine meaningful overlap between MND and other Neurodegenerative conditions

- We know that MND is more than one condition, and that some people with MND have additional features including thinking trouble. We also know that there are genetic overlaps between MND and other conditions including schizophrenia, Parkinsons Disease and some forms of dementia. Understanding these overlaps will help us to find out more about how MND develops, and will also help us to find new and more effective therapies that are targeted to specific subgroups of MND.

- **BRAIN-MEND** is a new study starting this May. It is funded by the HRB through the European Joint Programme in Neurodegeneration. The project, which involves centres in the UK, Holland, Belgium, Italy and Australia, will combine information from MND, Parkinsons Disease, Dementia, Schizophrenia and other related conditions, and to try to re-classify these conditions using genetics, brain imaging and psychological data. This will involve the pooling and analysis of data that has already been collected in diverse areas including Genetics, Epidemiology, neuroimaging and neurophysiology. This is a collaborative effort between the Irish MND Research Group under Prof. Hardiman and specialist ND research groups in the UK, France, Netherlands, Italy and Australia.

Irish MND Group part of new European Research Initiative

- Project Mine compares DNA profiles between those with MND and those who are unaffected. This ongoing project has identified new genes that contribute to the risk of developing MND, and is already helping to guide new treatments. **Project Try Me** is a new European initiative that aims to reduce the use of animal experiments by focusing entirely on the human condition. By combining our genetic studies from Project MinE with additional studies including MRI, EEG, blood samples, and skin analyses we will identify subgroups of MND that share specific characteristics. This will allow us to search for new and more effective drugs for each of these groups by conducting better focused clinical trials for more patients. The idea is to make sure that we get the right drug to the right patient, at the right time in the right dose.

- Research Motor Neuron is about to commence a study to better **understand the impact of MND on respiratory function**. Respiratory function refers to the ability to breathe, cough and manage chest secretions and infections should they arise. These abilities become problematic in MND, particularly as the disease progresses.

- Therapies that improve respiratory function have the potential to improve both quality of life and possibly survival. However comprehensive measurement of chest infection rates, their management and impact in MND has not been investigated in detail. Also, knowledge is incomplete on the impact that weakness of the respiratory muscles has on factors such as physical activity, sleep, fatigue, work and quality of life. The study will recruit 300 people with MND across six sites in five countries; Ireland (Beaumont Hospital), Italy (Turin), Belgium (Leuven), The Netherlands (Utrecht), and England (Sheffield and London). Those who participate will have their respiratory function measured in detail every three months over a period of 18 months. Measurements will include cough and sniff strength, and measurement of the maximum amount of air that the individual can take in and out of their lungs, both gently and forcefully. Chest infection rates and their impact and management will be closely monitored. Fatigue, Sleep, Breathlessness and quality of life will also be tracked.

- The study is being led by Physiotherapists (Dr. Deirdre Murray, Dr. Dara Meldrum, Ms Rachel Tattersall) and will take place over the next 18 months. Ultimately, the knowledge gained in this study will assist the development of drugs that improve respiratory muscle strength. These would potentially enhance quality of life and clinical outcomes, both by delaying the time to introduction of supported breathing interventions (Non-Invasive Ventilation), and by improving cough and secretion management.

New project for caregivers of people with MND

- Recruitment will begin shortly on a new project, funded by the ALS Association, which aims to develop and evaluate group-based psychological interventions for caregivers of patients with MND, where the objective is to reduce anxiety, low mood, and caregiver burden.

- Thinking and behavioural changes can occur in MND and clinically these changes overlap with a dementia affecting the frontal lobes of the brain (Fronto-temporal Dementia). Cognitive difficulties and behaviour changes occur in up to 40-50% patients with MND. Thinking and behaviour changes can be difficult for patients, and they are also significant predictors of caregiver burden. There is evolving evidence that caregivers' psychological status may also influence the mental and physical outcome of patients. However, the presence of cognitive/behavioural changes in MND patients is often under-recognized by healthcare professionals, and the burden of care associated with these changes is not addressed.

- The overall purpose of this study is to evaluate the effectiveness and efficacy of different psychological interventions with this group; to inform best practice regarding the identification and management of caregiver burden in MND; and to create a formal psychological intervention tailored specifically to the needs and wants of MND caregivers. Further information is available in the MND Multidisciplinary Clinic in Beaumont Hospital through which recruitment to the study will take place.

For further information see:
https://www.tcd.ie/medicine/neurology/ and
www.mnd.ie

IMNDA Strategic Plan

At the IMNDA, we dream of a world without Motor Neurone Disease.

Until that dream is realised, we have to help those who get that devastating diagnosis.

In everything we do, the Irish Motor Neurone Disease Association considers the person first.

What do you need? When can we see you? How can we help?

Our new three year strategic plan is designed to ensure that the organisation will be able to deal with the future needs of people living with MND, and offer all appropriate supports in their hour of need.

We prepared this Strategic Plan following a structured review of our work under our previous plan and consultation process with our Board and staff.

Most importantly, we asked the community which benefit from our services and supports.

Informed by the results of this process we have three strategic priorities for the next three years. This a continuance of our work with a deepened emphasis on connecting with, and responding to, the needs of people living with MND

There are three key strategies;

1. **Strategic Priority One**
   Support People living with MND
2. **Strategic Priority Two**
   Connect & Communicate about MND
3. **Strategic Priority Three**
   Strengthen our Organisational Presence and Capacity

Following the consultation process, IMNDA has created a new Information and Support Officer role. This new position will act as a point of contact for people living with MND and their families as they deal with the many challenges arising from a diagnosis. This newly appointed staff member will work closely with our team of specialized MND nurses and services staff, and provide both support and advice by telephone and email.

We know that our work is valued by people living with MND. Through our research, you told us that you appreciate:

- Our presence and knowing that our team care and react to their needs
- Our support, through our dedicated nursing care, provision of equipment, information and advocacy
- Our empathy and understanding of MND and how it can affect lives
- The hope, support and encouragement that we bring to the lives of people with MND and their families

As a result, every member of the IMNDA organisation is committed to continuing that work;

- To be person centred, focus on the person living with MND, their families and carers
- To support people with MND, through all our vital services, nursing care, equipment, information and support
- To strengthen our communication at all stages of the disease
- To raise awareness and be the place to go to for all matters relating to MND
- To be an encouraging presence offering authentic information, reassurance and hope for those living with MND

The levels of support from the State, while welcome, only go some of the way towards funding the service needs of IMNDA. The vast majority of our fundraising comes from our MND community, without whom we would not be able to function. You trust us with your donations - and we will continue to be fully transparent in how that money is spent.

Our intention is to continue to be a well-governed, well administered charity that is guided by and meets good governance standards. The purpose is to build our capacity and resilience to advance our work in response to the needs of people living with MND, their families and carers.

We will do this by being a source of constant support for people living with MND, their families and carers from diagnosis and throughout their journey.

Irish Motor Neurone Disease Association

IRISH MOTOR NEURONE DISEASE ASSOCIATION (IMNDA)

STRATEGIC PLAN 2017-20

General Data Protection Regulation (GDPR) Update

We're currently improving our Data Protection and Privacy Policy to reflect recent changes to data protection laws and provide additional clarity regarding how we collect, store and process your information.

Updates in our Privacy Policy and Data Protection Policy (which we encourage you to read) will come into effect from May 2018. You can find our revised policies on our website at **https://imnda.ie/privacy-policy/**

We care about all our clients, families, supporters, fundraisers and volunteers a great deal and are deeply committed to protecting their privacy and respecting their data. We hope these updates demonstrate that commitment and we want to assure you that we will only use your data in the way you are happy for us to use it.

We want to continue sending you our newsletter and communications but if at any stage you no longer wish to receive any of our information, then all you have to do is email Maeve or any of the team at **info@imnda.ie** or simply Freephone us in the IMNDA office on **1800403403**.

Thanks for being a part of our community. Without your support, we would be lost.

VAT refunds on aids and appliances used by people with disabilities

If you live in Ireland and you have a disability, you may get a refund of Value-Added Tax (VAT) on certain special aids and appliances that you need. In some cases people who pay for aids and appliances that are for the exclusive use of a person with a disability can also claim the VAT refund. People with both physical and mental disabilities can avail of these refunds.

This scheme of VAT refunds on aids and appliances can also apply to adaptation and installation work being carried out to make a home more suitable for an older person or for a person living with a disability.

Rules

Under the Value-Added Tax (Refund of Tax) (No. 15) Order 1981, you can claim a VAT refund on aids and appliances that help you carry out daily activities at home or at work. You may need to produce medical evidence of your disability.

VAT refunds are **not** allowed on services for people with disabilities or on rented aids and appliances.
To claim a VAT refund you must:

- Live in Ireland
- Have a disability
- Need the aid or appliance to help with daily activities

The aid or appliance must be owned by the person with the disability and be for their exclusive use. If the VAT refund is being sought by someone other than the user of the aid or appliance, Revenue may ask for evidence that the aid is solely owned by the person with the disability and is for their sole use. In this case, these goods must **not** be supplied in the course of a business run by the purchaser of the goods.

Examples of eligible aids and appliances include:

- Domestic aids, for example, eating and drinking aids
- Walk-in baths
- Commode chairs
- Lifting seats and specified chairs
- Braille books
- Hoists and lifts, including stair lifts
- Communication aids

Assist Ireland has information on a wide range of aids and appliances for people with disabilities.

More information on how to reclaim VAT on aids and appliances for people with disabilities can be found on **www.revenue.ie**

Housing adaptations

If you are having your home improved or adapted to make it more accessible, you may be able to claim a refund of VAT paid on the cost of installation and adaptation work. You may also qualify for a grant, such as the Housing Adaptation Grant for People with a Disability, the Mobility Aids Grant Scheme or the Housing Aid for Older People Scheme. For more information on this please see **http://www.citizensinformation.ie**

Buying and adapting a vehicle

You can claim remission or repayment of vehicle registration tax (VRT), repayment of VAT on the purchase of a vehicle and repayment of VAT on the cost of adapting a vehicle, up to a maximum amount. You can find out more on this on citizen's information www.citizensinformation.ie and search for: Tax relief for disabled drivers and passengers.

How to Apply

To apply for a VAT refund on aids and appliances, fill in claim form VAT 61A (pdf) .

You must attach supporting documentation with your claim - for example, original invoices for all the goods in the claim or, in the case of imported goods, receipts for VAT paid at importation. In the case of a hire purchase agreement, you will need to supply a copy of the agreement and the invoice.

You must make your claim within 4 years from the end of the taxable period in which you purchased the aid or appliance. Taxable periods within each year are:

- January/February
- March/April
- May/June
- July/August
- September/October
- November/December

For example, a claim made in respect of an invoice issued in January 2015 must be made no later than February 2018.

Where to Apply:

For more information or to claim a refund on an aid or appliance contact:

Central Repayments Office
Office of the Revenue Commissioners
M: TEK II Building
Armagh Road
Monaghan
Ireland

Tel: 047 62 100
Homepage: http://www.revenue.ie

LIVING WITH MND

New MND Information Booklet

We have recently put together a new information booklet called 'An Introduction to Motor Neurone Disease (MND)'. This new booklet presents information on MND in simple terms and in a way that is easy to break down and understand.

Our new leaflet may prove very helpful for newly diagnosed people or for family members and relations who want to know more about the disease.

If you wish to receive a copy of this booklet please email **services@imnda.ie** or freephone **1800403403** and we will send you out a copy straight away.

"Hope 2018!"

As a person for whom Motor Neurone Disease didn't prove fatal in the prognostic time; three to five years, I have been given the opportunity to look at the disease, and at my life, in a new way, I developed characteristics that have given my life new meaning and hope.

When I was diagnosed with this disease in 1978, I was faced with the prospect of severe disability and a life span of just a few short years. I had two options - give up or else develop endurance characteristics. Immediately, I focused on learning as much as possible about MND before serious muscle wasting began. I took charge of my own life. I did this by drawing on the immense amount of strength that lies within my being. I adapted to new technology and succeeded in writing two books with voice recognition software.

After a pilgrimage to Lourdes with Casa (caring and sharing Association) in 1990, I found great spiritual strength to accept the disease and learn what I can from the experience. In short, that spiritual serenity empowered me with a power greater than myself.

I don't know just how this disease will progress, or how I will adapt, what my tolerance of dependency will be, what my comfort zone will be, what help from family and friends, I will get. But I do know that I am a prisoner of hope!!

You either have it or you don't.

Andy McGovern,

Cloone, County Leitrim.

Voice Banking for MND

In this edition of Connect we wanted to look more closing at the impact of losing one's voice. Below is an article written by top Speech and Language Therapist Lesley Doyle. We have also included notes from clients who got involved in voice banking so that you can get a few perspectives on how it works. If you or any of your friends or family has any questions on this article, please do not hesitate to contact our Services Team on freephone 1800403403 or email services@imnda.ie

Banking Your Speech by Lesley Doyle, SLT

MND and Communication

MND can affect the muscles used for speech, causing them to become weak or tight. Some people find that their speech sounds become less clearly pronounced or their voice becomes strained or maybe very quiet. This problem can become worse over time but if speech becomes very difficult to understand, alternative ways to communicate can be used alongside or instead of speech. Speech and Language Therapists (SLTs) give advice on communication tools. Alternative ways to get a message across include writing or pointing to letters on a printed alphabet chart. 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 software with built-in computer-generated voices that speak out words or sentences as they are typed on a keypad; this is referred to as a 'text-to-speech' function. It is also possible to save some frequently used phrases referred to as 'pre-stored phrases' which can make communication faster for these messages because they do not need to be re-typed each time.

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. Banking speech involves making recordings for potential use in the future on an electronic communication aid should speech become difficult to understand. There are two ways to record speech for such a use: message banking (which can be used to read out 'pre-stored phrases' when selected on a device) or voice banking (which can be used to read out anything typed using a 'text-to-speech' function). These are explained below. If a person completes one or both of these, it might never be necessary for them to consider using an electronic communication aid, but if they do, they will have created the option of incorporating their recorded phrases into their communication system.

For anyone with MND who chooses to bank their speech, an SLT can help and a technician from an assistive technology service can set up a communication system for you incorporating your recordings.

What is Message Banking?

Message banking involves using a voice recorder to record yourself saying everyday phrases and sentences in your own voice while your speech quality is clear enough to be easily understood.

Our voices are part of our identity so using your own recordings can be more powerful than using the built-in computer-generated voice for personally meaningful phrases.

The recorded messages that people choose to use on an electronic communication aid are often those that they currently use with people they have a very close relationship with such as their partner, children, parents, siblings and close friends. These are phrases that reflect the bond that they have with that person and include humorous comments, phrases of appreciation, expressions of love, greetings, nicknames, stories or songs for children or maybe phrases for pets. It can be hard to think of phrases that you say a lot especially if you have been using them all of your life so getting your

family and friends involved is a great idea and can add some fun to the project.

Voice recorders such as a Zoom H1 Handy recorder are recommended for recording more than phone/tablet apps because of the sound quality and compatibility of the recordings with a wide range of electronic communication aids. A small number of these Zoom voice recorders are available to borrow from the IMNDA or you can purchase one for up to €150. You can carry this voice recorder around with you so you can make recordings on the spot as phrases that really capture your personality come up in conversation. You can also make a list of your own ideas and other people's suggestions and record your phrases at a time when you feel your speech tends to sound best.

The phrases that are recorded are completely individual to each person so working from a standard list does not generally help but an SLT can help you to think of the type of phrases that you might like to record. There is no set number of phrases to record; you might prefer a handful of very personal messages or choose to record more to cover different scenarios. There is no cost involved in using your messages – the only potential cost is if you choose to purchase your own voice recorder rather than borrowing one.

Message banking does not appeal to everyone. Some people find the idea too upsetting and emotional. For some people who have already experienced speech changes, they do not like how their speech sounds now or do not feel it truly represents them. Message banking might be right for you if you feel enthusiastic about doing something proactive or if you think you are likely to feel very regretful in the future if you did not capture your personal phrases.

Voice Banking

Voice banking involves creating a personalised electronic voice that is representative of your unique voice. This can be used instead of the built-in computer-generated voice on an electronic communication device. The process of voice banking involves making a high number of recordings of your speech (up to 1,600) while reading set lines of a story or text to capture different speech sounds. Voice banking is done using Internet-based services. There are several services available at different prices; Modeltalker (US€100) and Cerevoice Me (£499) are the most commonly used options.

Voice banking needs to be done while the clarity of your speech is good. If your speech quality has already changed significantly, it is unlikely that you will be a suitable candidate for this process because of the amount of recording time required (several hours) and because it becomes harder for the software to recognise all of the speech sounds needed to build a voice that will be intelligible enough to use. As an alternative, you could nominate a relative/friend with a similar accent to record on your behalf.

The resulting likeness of the electronic version of your voice to your own natural voice can be variable. A synthesised voice created using voice banking will never sound exactly like your own speech because it is electronic. It will sound more robotic and with less intonation than natural speech. It will also sound 'choppier' than the built-in voice on an electronic communication aid but some people are happy to accept this quality in return for a voice that has elements of them rather than a standard synthesised voice with maybe a UK, US or Australian accent.

To carry out voice banking, you need a computer that can play and record sound, an email account, a reliable Internet connection and a microphone headset with a USB (not a jack) computer connection and a quiet space without background noise or echo.

Voice banking will not appeal to everyone. It requires very clear speech changes so the best candidates are people with no speech changes or a very mild problem, the sooner it is carried out the better. It can be a tiring process and it might feel stressful for people who are unfamiliar with computer technology. An SLT can provide you with information about the different services that are available but recording is usually done independently at home so it is important for you or a family member to be used to using a computer and the Internet.

Message Banking in Ireland

Message banking is a relatively new option for anyone with a possible progressive speech difficulty. New technology that can be used in the process is emerging but there are no standard international guidelines on the best way to do it. To address this, last year Research Motor Neurone supported an SLT research project to gather information to inform our Irish service delivery. This research was carried out by me, Lesley Doyle, through my role as SLT for the Beaumont Hospital MND service and Dr Caroline Jagoe of the academic SLT department in Trinity College Dublin. We recruited Irish people with MND, guided them through the message banking process and gathered their opinions about message banking and the best ways for SLTs to support them in this process. This new information has since been put to good use. We presented our findings at several conferences including the International Symposium of ALS/MND conference help in the Convention Centre in Dublin last December and two SLT conferences; Congress of the International Association of Logopedics and Phoniatrics in August last year and the Irish Association of SLT conference in Croke Park in May this year. Caroline was also interviewed on the Nicky Byrne radio show to explain message banking as part of the promotion for a Trinity College Dublin research event we participated in called Probe. Nicky asked for listeners to text in with phrase ideas and recording your laugh was a top suggestion.

In August this year, Beaumont Hospital ran the first message banking training course in Ireland for SLTs who work with people with MND and other conditions and our research findings from people with MND were a key component of the day.

For more information on the process of message banking, voice banking and recommended recording or communication equipment speak to your hospital SLT, community-based SLT or discuss it at an appointment with an Assistive Technology service. You should seek advice before making any recordings to ensure this is the right option for you and that you are using the right equipment.

Lesley Doyle
Senior SLT in Neurology
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That's what the experts have to say about the process but here is how some clients found it.

Niall Callan's Account:

On my first visit to the Beaumont MND workshop last November, Lesley Doyle explained the different options for Message and Voice banking. It surprised me that, according to Lesley, very few MND patients indeed were going for the Voice banking option: this provides you with a text to speech facility in your smartphone, tablet or other appliance which is recognisably in your voice, and not in that of some American or British accented zombie.

Anyway, I decided to take up the challenge, using the (U. S. based) Modeltalker system. To get the job done, you need a headset with USB connection (available for under €40, or possibly lying around the house if you are sharing with any Skype enthusiasts); you pay the Modeltalker people $100 at the end, and if you wish to use an Android device, you have to buy the Predictable app at a cost of €149.

For the rest, it's down to you. Ideally, Modeltalker would like you to input in your own voice 1600 sentences dictated by them; they also recommend you to create 20 sentences of your own to capture family names and places close to you. But, Modeltalker can produce a voice from a minimum of 400 inputted sentences. It took me just over a week to complete the 1600 sentence target in sessions of 1 to 1.5 hours per day.

One technical problem I had at the very start was that Modeltalker was rejecting the sound quality coming from the headset. The solution was to plug the headset in to a different USB port: apparently, they don't all have the same capacity! Overall, I didn't find the process too complex technically. As with any computer based project, expect a few obstacles, but call in the younger generation in case of problems.

I and my speech therapists are very happy with the quality of this text to voice product. I cannot comment on its usefulness as a substitute for natural speech, as I have not been relying on it yet. Nor can I presume to recommend it for particular MND patients: that is the job of speech therapists. But maybe my experience may make the Modeltalker option less intimidating for some of you.

Richard Logue's Article:

My name is Richard Logue. Unfortunately I was diagnosed with Motor Neurons Disease on October 1st 2016.

The nature of the disease means it is difficult to predict the speed or direction it will take with regards the muscle wastage. You can be fairly sure it will in time, take away your ability to walk or have any use of arms. It will target the muscles in your throat which will subsequently prevent you from eating which will mean you will be fed through a tube in your stomach called a PEG. Finally with most patients it will take the one thing that we all hold dear. Our ability to communicate.

My form of MND has been very progressive so all of these things have happened to me. For me the thing I feared the most was losing my voice. Luckily when I was diagnosed I was referred to an SLT. (Speech and language therapist) Now at this point I had only a slight limp and was not showing any other signs of the MND so I could not figure out why I would need to see an SLT. It was probably the best appointment I have ever made.

Her name was Sarah Curran and she was amazing. From the get go she was incredibly proactive in her approach to what was coming down the line. We spoke about this new software that was available for people with speech problems called Model Talker. It basically allowed you to use your own voice on whatever form of communication aid you were using. For me it was a device called an Eye Gaze. I think Sarah was probably more excited as I was as she understood what a difference this could make to the lives of people who rely on whatever form of communication aid they may use in the future.

Sarah took me through the initial set up process. This involved me reciting certain phrases that would appear on the screen in as much of a monotone voice as I could manage. It sounds easy but when you start you realise there is a certain skill needed to sound very boring. Once I had the knack of it I was able to bring the head phones and mic home with me and work at my own leisure. The environment where you do your recordings needs to be as quiet as you can possibly make it. No background noises as they will be picked up. You have 1600 phrases to record from the likes of the wizard of Oz and the jungle book. The fact that you have to concentrate so much I would only do 150 to 200 phrases a day so as not to get tired and spoil the recordings.

I had everything recorded within a week or so and I got the go ahead from Model Talker hq that everything was ok. Fast forward eight months later and I have this amazing machine called an EYE GAZE. This is my sole form of communication now. When I spoke my first words my family were gobsmacked. They had forgotten how my real voice sounded as it had been in a steady decline over time. I think we are at a point where they wished I would shut up a bit. The only way that will happen is to plug me out. People wonder how I can swear so much when I never recorded any swear words. That's the beauty of the software.

At the end of the day if I did not have my own voice recorded I would have had to use a computer generated voice. They were called Peter and Graham. They sounded like two middle aged English gentleman. I have been told I am the first person in the county to be using my own voice. Hopefully others will see how good it actually is. I have been extremely lucky to have met Sarah and only thanks to her having the foresight at an early stage and recommending it to me ,well we owe her a massive thanks and will always very grateful.

I would advise anyone out there who has the misfortune of potentially losing their voice and are apprehensive about taking that first step, please do it as you may only have a certain window of opportunity.

You won't regret it. I know I haven't.

Richard Logue sadly passed away shortly after writing this piece but his wife wanted to share Richard's words. May he Rest in Peace.

Paul Lannon's Quote:

The thoughts of a synthesised voice are not very appealing so I'm glad I now have my own voice recorded. It was easier than I thought. I just wish I had done it sooner!

My Speech by Patricia Sweeney

I struggle to speak and make myself understood where once words flowed effortlessly. It's hard to believe I once made a living through my voice first as a primary teacher for many years and later as a visiting teacher for the blind and visually impaired. I don't recognise or like this voice I now have and yet appreciate the fact that I can still communicate a little but I don't know for how long more. Technology is wonderful but it can never replace the voice you were born with and is such a part of your identity - people can even recognise you by your voice without seeing you.

Before I got my new phone and changed network I would secretly ring my mobile from the landline just to hear the short message in my own voice on voicemail. The voice I had taken for granted all my life now sounded beautiful to me and how I missed it. My throat would ache as I listened to what I had lost and would never have again.

Where once I contributed easily to conversations I now am silent except for the odd word or sentence that requires such effort on my part but my head is full of ideas and what I'd like to say but can't. I sang with a folk choir for years but my singing voice is completely gone and with it the pleasure singing brought me.

I watch my friends with their grandchildren and know that if I am blessed with any they will never know or hear my voice or I will never sing nursery rhymes to them as I did to my own children. Of course I will never be able to push them in a pram or buggy either or run and play games with them. I will even struggle to hold them in my arms. And yet I am lucky in comparison to many others of my MND family who can't speak at all, who are paralysed from the neck down, have to be fed through their stomachs and rely on a ventilator for breathing.

Speech is something we take for granted until we are deprived of it. Communication is so essential to your quality of life. My husband has now to be my voice at times - to ring and make appointments for me or ring around to get quotes for car or house insurance. It is so frustrating and disempowering not to be able to do these things for myself. I worry that if I was in hospital I would not be able to communicate my needs properly - it is quite scary if you are not understood.

I feel that when people who don't know me hear me talk with this new slow voice they think I have an intellectual as well as a physical disability and I find this hard. How can they know I still have a wonderful mind and brain that I was lucky to be blessed with and that are still thankfully not affected? You can be dismissed so easily by strangers when you have a physical disability and your voice is impaired. I know that some people are uncomfortable around me and that is understandable. Nonetheless it is difficult for me who once coped so easily and with confidence in all social situations whether I was with people I knew or with strangers and felt quietly assured they enjoyed my company.

Of course with friends and family I am still the unique individual I always was and loved for being me. Yet even they struggle at times to understand me if I am tired and my voice is weaker and I sound as if I'm speaking Swahili! If I am really upset - which is not too often - I can't speak at all - the words just won't come and all that comes out is a high pitched sound and my vocal chords hurt. I hate when this happens. I also hate knowing how heart-breaking it is for those who love me to watch the gradual decline MND is causing both physically and in my speech.

I never thought my son and daughter would push me in a wheelchair or that I would be dependent on my husband for so many things or that I would have to take early

retirement from the job I loved so much. However I still feel this is harder for those who love me than for me myself. I have accepted my new way of life and am surrounded by so much love and support from family and friends that I am happy even within the limits MND has imposed upon me. I want them to know that and not worry about me.

With support life and MND can co-exist. Technology and equipment - frequently very expensive and high tech - are needed to make life manageable or for those who have reached the stage of having swallowing and breathing difficulties essential for their very survival. This is where the Irish Motor Neurone Disease Association come in and provide this life saving equipment on loan and also support for those who need 24 hr care. In addition all MND sufferers benefit from the advice service of the 3 dedicated Motor Neurone nurses paid for by the association as they struggle to cope with the changes in their life and who find all too often they are the first case of Motor Neurone their GP has encountered in their practice. Yet there are so many questions they need to ask to cope with what is a life sentence as there is as yet no cure for this disease - all you can be sure of is that it will get worse. Yet this very necessary and essential support association for MND sufferers and their families receives only 17% of its finances from public funding and relies heavily on donations and fund raising to continue supporting the MND community. Without these generous donations – no matter how small - the necessary support cannot be provided.

ONCE as the sayings go, I could talk to the pope or for Ireland – NOT ANY MORE.

Sometimes Silence Speaks Volumes

Imagine an hour…a day….a week without speech. Imagine not being able to say 'I love you' this Valentine's Day. Unfortunately that is the fate met by most people living with Motor Neurone Disease (MND). Between 80-95% of people living with MND will experience some loss of speech during their illness.

This February we held our sponsored silence campaign #Voice4MND. Paul Carroll bravely fronted the campaign for us. Here is his story.

Monday 19th December 2016 is a day etched in our memories. Six weeks earlier feeling exhausted and out of sorts I had consulted my GP. I also had a slight speech difficulty which I found unnerving. After examination and discussion the doctor referred me to a neurologist. It was at this point that the thought of Motor Neurone Disease first entered my mind. Suffice to say that after meeting the neurologist and then having further tests the diagnosis was confirmed. I was 64 years old on the cusp of retirement and had never been ill in my life before.

The journey since then has been a bit of a rollercoaster. The disease has gradually reduced my ability to do ordinary day to day things which most of us take for granted. Having been a keen walker I now use a stroller to move around and a stair lift to get upstairs. I have some difficulty swallowing which limits my choice of foods. The most radical change for me however is a severe deterioration in my speech.

I would not like to give the impression that the journey has been all negative. Quite the contrary in fact as it has opened my eyes to the generosity of spirit of the many good people who have helped me along the way. I would firstly pay tribute to my wife Lilian who has been unwavering in her support and understanding. I know my illness has placed a heavy burden on her but she accepts me as I am.

My only sister and my brothers have also been of great help driving us to Clinic and Research appointments in Beaumont Hospital and St James's Hospital in Dublin and also giving us support at home. All my nephews and nieces on both sides have been cheerfully supportive with regular visits and texts. Lilian's family too are only a phone call away. We have been privileged to have had home visits from MND Nurses Fidelma and Bernie both of whom we would now count as friends. The IMNDA has been a tremendous support to us supplying equipment and generally acting as an advocate. We would like to return that support in any way we can. During the summer we were very generously supported by our friends and neighbours in Caherdavin when we hosted a tea and coffee day for the Drink Tea for MND campaign. In early November we had a lovely surprise when the parishioners of Christ the King had their own fundraiser.

When acknowledging all those who have been there for us on this journey, the list is very long. It would be remiss of me not to mention the community professionals: GP, SLT, *OT, Physiotherapist and our local Pharmacy. Finally I come to my many friends in Milford Day Care Centre. I have been attending the centre on Thursday mornings for some time and I have seen and experienced the compassionate and good humoured help given by all the staff there. We are indeed fortunate to have such a facility and great people in our area.*

Paul received an outpouring of support from right across Ireland! The local Caherdavin community came together in force and they raised over €6,500.

From all at the IMNDA, we just want to say a massive heartfelt thank you to Paul and Lilian. Their courage and spirit throughout the campaign was amazing. We also want to say a special thank to Michael and Moira Skeehan for putting on a benefit night for Paul. All the support was so appreciated.

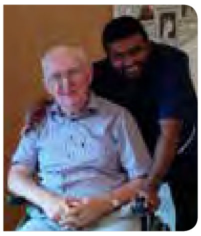
But Paul and Lilian were not alone in championing the silence. People living with MND took part right across the country!!! And here is what they had to say about it!!!

"Not being understood is very frustrating,"
said Bernadette Doherty ~ Tavneena, Charlestown, Co. Mayo.

"Losing my voice is hard for me and my family,"
said Edward O'Kane ~ Swords, Co. Dublin.

"I miss conversations with family and friends,"
said Fergus Hennessy ~ Collon, Co. Louth.

"My voice is good now but sometimes it can be difficult to get the words out. I will try to get it the out while I can for my grandkids, wife and family,"
said George Kenny ~ Blarney, Co Cork.



"I started life not being able to talk and I'll end life not being able to talk,"
said Jean Lacey Kerr ~ Cromwellsfort Avenue, Wexford.

"It was a huge shock to my family and myself and is still hard to come to terms with every day is a new battle. I will fight MND, will you fight to give us all a voice against MND?"
said Joan Byrne ~ Balbriggan, Co. Dublin.

"Having an itch...annoying! Having no movement and not able to scratch it...frustrating!! Having no speech as well and not able to ask for it to be scratched...TORTURE!!!"
said Paul Lannon ~ Dunleer, Co Louth.

"There is a limit to the amount of silence one can contribute to a conversation"
said Rachel Thompson ~ Ballycotton, Co. Cork.

"Of all the things this disease has robbed me of; losing my voice has been the worst,"
said Robert Leech ~ Drogheda, Co Louth.

Stephanie Moody from Rathangan, Co. Kildare misses
"not being able to chat to family and friends."

"The tone of my voice has changed completely and is hoarse. It's on my mind everyday wondering will I lose my speech,"
said Veronica O' Brien ~ Ferrybank, Co. Waterford.

"I have little or no function in my Legs and Hands, How will I communicate when I lose my Voice?"
said Vincent Byrne ~ Palmerstown, Dublin.

"The most important thing in communication is hearing what isn't said,"
said James Harte ~ Ballyjamesduff, Co. Cavan.

People took on the challenge at home, in work and in their communities. We had a great response from families, work colleagues and schools coming together to take on our silent challenge. The length people stayed quiet for ranged from 30 minutes right up to a few hours to a few days! Diane O'Neill stayed quiet for 48 hours!! This was her second year taking on the challenge.

Going into my Sponsored silence this year I was aiming to get a deeper personal glimpse as to what it might be like losing my voice to MND while also bringing more awareness out into the world for others as to what MND can bring to peoples' lives. What strongly struck me this time were the daily CHOICES I had to make about things I was passionate about and loved because I could not speak or communicate to the world. My Voice is definitely something I take for granted and overall this time I got a strong sense of how an MND Diagnosis ends up "Robbing someone of their basic human right of ***CHOICE*** *and that nothing in the world could ever prepare you for such a Diagnosis".*

James and Dolores Harte took our Sponsored Silence to one step further. Not content to just take on the challenge – they challenged their families, friends and loved ones to take on a Silent Walk! On Easter Sunday, James and Dolores Harte organised a Silent Walk from Virginia Rfc through Virginia Woods for our Sponsored Silence #Voice4MND. We just want to say a massive thank you to James, Dolores, Karen and everyone who participated in the walk and made the day such a success. We can't thank you all enough!! Well done!!!!

Thanks to Paul, James and everyone across the country championing the campaign it was a tremendous success. More people took on the challenge than last year. More people quit speaking and stayed quiet for MND. Huge thanks must also go to Emma Burke and everyone from Burkes Restaurant in Drogheda, Meadhbh Hayes, everyone in Sapphir Hair Design Drogheda, Ruth McNamara and all from Lilliput Montessori in Rhebogue – you all really went above and beyond.

Thank you, thank you, thank you to absolutely everyone for who took part - the word is now out, now our silence shouts!

Roisin's Story

My name is Róisín Foley. I am 30 years old from Drimnagh in Dublin. I'm a young single mum to three fabulous girls - Rosie who is 5, Sadie who is 6 and Rachel who is 12. On my 30th birthday, I bent down to do up my new shoes, and I couldn't tie the laces. My hands felt so weak I couldn't even pinch the lace. My sister arrived at the door to take me to my party and she had to lace them up for me.

I was rapidly changing and I could see my family getting worried. Rachel had started having to do her younger sisters' hair in the morning before school, and teach them how to do up their own buttons. Rachel would also have to unlock the front door for me as I couldn't get a grip of the key.

It took months of tests, but eventually I was told I had Motor Neurone Disease. My dad and sister were with me, and at first we all just sat there in silence. My dad put his arm around me, and my sister and I were crying.

The day I was diagnosed with Motor Neurone Disease, my family gathered around me, the kettle constantly on the go, and in between crying and talking, we just drank tea. My dad described it as being at my own funeral. That sounds awful, but it was really special. There were lots of tears but I knew we would tackle this as a family.

There are six of us siblings, with only six years between us, so we are really close. My dad called everyone, and they all left work and came home. We sat around the table, with tea constantly on the go, and I knew I wouldn't be going through this alone.

Not long after my diagnosis I got a visit from a specialist nurse from IMNDA. Eithne immediately became my emotional support and I know she is there for me, and will be, right through this journey. She also gave me advice on telling my girls.

They were already aware of the symptoms, and Rosie even called them 'Mummy's crooked hands'. So I just told them that I would need their helping hands more and more, and that doctors were helping me keep me well for as long as possible.

People go through life so stressed out about stuff that really doesn't matter, but I actually feel blessed I've been given an opportunity to enjoy myself while I can, and focus on the important things. So for now it's all about family and making memories.

It's a relief to know IMNDA are there, and will be with me for the time ahead. It's also a place my family get strength from. The IMNDA nurses came out and spoke to the whole family for hours, (there were about 10 of us!) answering all their questions. We had been focusing on the negative but we came out of that meeting positive and ready to tackle this disease, saying, "we can do this now."

I'm lucky that I have family and friends who will always give me a helping hand when I need it. And I will ask for help too. I love tea. I even get Kris Kindle presents of teapots and teabags! So I am happy to be asking you to help by simply making tea. This year I am fronting the IMNDA's National Awareness campaign Drink Tea for MND. Sometimes when there are no words, there is tea. **Please join me this June and Drink Tea for MND.**

FUNDRAISING

Drink Tea for MND!!!

As you know every year since 1997, the MND community worldwide has marked 21st June as the global day of recognition of ALS/MND - a disease that affects people in every country of the globe.

21 June is a solstice - a turning point - and each year the ALS/MND community undertake a range of activities to express their hope that this day will be another turning point in the search for cause, treatment and cure of this awful disease.

Global Day is important because it is one day that every member of the International Alliance has in common to reflect their dedication and role in the global fight against ALS/MND. This one day allows us to recognise that we are not alone in our fight against ALS/MND, and those patients, carers, former carers, scientists, health care professionals, volunteers and many; many others are all part of this fight.

We are looking for people affected by MND to talk about their experience on local radio or in their local paper to raise as much awareness of the disease and the work of the IMNDA as possible. If you would be interested in helping us with this we'd love to hear from you, please email us on **fundraising@Imnda.ie** or freefone **1800 403 403**.

As we have already mentioned, Róisín Foley is fronting our National Awareness Campaign and he is encouraging everyone to lend a hand and Drink Tea for MND in 2018!

Drink Tea for MND is a great way to gather round some friends and raise funds for people just like Róisín. Everyone loves a cuppa especially in Ireland so why not organise an afternoon tea / coffee morning in your home, local pub, restaurant, GAA club, workplace, community centre, garden... anywhere in fact!

We want as many people as possible drinking tea for MND throughout June. Tea packs, which have been sponsored by SuperValu, are available from the IMNDA office so call **1800 403 403** or email **fundraising@imnda.ie** to get yours today.

Let's Drink Tea for MND!!

The Difference We Make Together

To all our supporters and donors we cannot thank you enough. Your support is so important to us. It allows us to continue doing the vital work needed to help support the MND community. We are so lucky to have so many people who help to fundraise for us each year. Unfortunately it is not possible to thank everybody personally, to those who aren't mentioned here, please accept our sincere thanks.

FUN-RAISING

We would like to say a huge thank you to Pauline O'Donoughue, Clare McKeon and Mary Connell who opened a POP-Up Boutique for a week in Castlebar. A lot of hard work went into this from getting the shop set up to sourcing beautiful wears to sell – the ladies did an amazing job and an outstanding €12,806 was raised! Thank you to everyone who supported. Pauline also organised a brilliant mummers fundraiser in Castlebar over the Christmas with friends Susanna Kenny & Dolores Towey, they raised a superb €2,120. Well done ladies!

Jason Hunter cheered on the boys in green at the Ireland vs Denmark match in Copenhagen last year, sadly there was no win for Ireland but Jason came home with a brilliant €1,557.22. for the IMNDA that he raised by dying his beard green! Well done Jason

Thanks to Shaun Fox who took on the Movember Challenge and raised €420. Well done Shaun!

Well done to Leon Blance and all at Boylesports and the Evening Herald who raised €1,040 from their beat the bookie event. Amazing stuff!

Big thanks to everyone from Student University Support Ireland for choosing the IMNDA to benefit from their costume fun day. We are so thankful for the fantastic amount of €200 raised on the day.

Thanks to everyone from UL Bohemians RFC especially Joan Moloughney and all the minis! They very kindly raised €800 for the IMNDA from the sale of their Calendar. Michael Clancy gratefully accepted this fantastic cheque on our behalf. Well done everyone!

A massive well done to Pat Farrell who auctioned a pedigree texel sheep at the Livestock Mart in Cootehill which raised a baa-mazing €2,601.42!

Luke O'Dea and the students from Carlow IT organised a Skills Challenge along with a raffle and raised a fantastic €789.60. Thanks so much to all involved!

We would like to say a big thank you to all the staff and students from Regina Mundi College for choosing the IMNDA as their Christmas Charity and for raising the truly fantastic amount of €1,003 from a collection. A special thanks to Tara Bonus for nominating us. Also a huge thanks to Jennifer Bonus and all involved for organising a soccer tournament in memory Noel O'Donovan which raised a brilliant €1,015.

Thanks to DJ Moore and everyone from Naas Fianna Fail who organised a collection at Punchestown Racecourse and raised over €500!

The Farrell Family organised a BBQ fundraiser at The Yacht Bar in Longford on the day of the All Ireland Final and raised a sizzling €6,500. Thanks so much!

An enormous thank you and well done to everyone from Conary Clay Pigeon Club for raising an outstanding €9,200!! They held a Clay Pigeon Shooting contest with a large BBQ and raffle. Special thanks to the Moxley Family and Alma and Peter Dickenson. You all went above and beyond!

Teresa O'Hanlon once again held a successful book sale and raised a fantastic €560. Thanks Teresa and everyone who supported!

Greystones scouts served up almost 160 breakfasts as part of the traditional 'Bricfeasta Mór' at their den on St. Patricks Day. The hearty breakfasts went down a storm and raised over €1,000! Well done to all in the Greystones Scouts - we can't thank you enough!!

A huge thanks to The Whale Theatre in Greystones who held a screening of 'It's Not Yet Dark' in memory of Simon Fitzmaurice and very generously donated the proceeds of €826 to the IMNDA.

North East Vintage Car Club organised a very successful vintage car run which raised an amazing €2,276.58. Thanks to all involved.

EGG-STRA EGG-STRA!

We just want to say thanks to everyone who took an Easter Hamper this year and raffled it off in local bars, cafes, and shops across the country. The campaign did brilliant once again and its thanks to you, we look forward to updating you on the total raised from this campaign soon. Thanks again, we would be lost without our treasured supporters!

BENEFIT NIGHTS

Gerry O'Loughlin organised a céilí in Cois na hAbhna, Ennis in memory of his wife Mary. Attendants on the night were treated to music from two time Ireland champions, The Shandrum Céilí Band. An amazing €11,343.75 was raised for the IMNDA. Well done to Gerry and family and everyone who supported the event.

Elizabeth & Peggy Kelleher also organised a fantastic Céilí. A great night was had by all and they raised a superb €600! Thanks to everyone involved

Huge thanks to CRY 104FM who organised a Cheltenham preview night along with a raffle and auction in Youghal GAA Hall. The night was a huge success and raised a brilliant €1,600 for the IMNDA

Thanks to Gerry McGeough and all involved in the 4th annual Cheltenham preview night held at Cherrytree Pub in Walkinstown. A brilliant €300 was raised from the night. Robert Wilson & Charlie Boyle organised an Old Time Dance in Letterkenny and raised a phenomenal €9,080! Thanks so much to all involved and a special word of thanks to Logues for the use of their venue and the band Country Sound for providing music on the night.

Cathal O'Byrne organised a raffle and fundraising night in Elsie's Bar in Galway. They raised an amazing €2,900. Special thanks to Gerry Tunn and family who kindly presented our nurse Fidelma with the fantastic cheque.

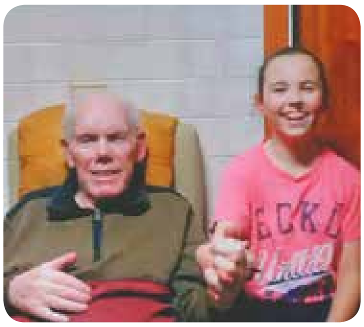
Big thanks to Jacqueline Murphy who kindly held 2 table quizzes for the IMNDA last year and raised a fantastic €683.50. Special mention of thanks to Ballybofey & Stranorlar Golf Club for donating the use of the club and for generously providing raffle prizes!

Mary Cunny & friends held a table quiz and raised a superb €1,500. Well done to all involved! Thanks also to Howth Golf Club who raised a fantastic €1,410.

MUSICAL MOMENTS

Big thanks to Kelly Peters who organised a night of music in Moroney's Pub in Lisvarrinane and raised a superb €800. Thanks to all involved

Massive thanks to Alan, Eugene, Maureen and the Mannion Family who organised a night of Irish music and dance at The Arch Bar in Loughrea. A fantastic night was had by all and an amazing €13,950 was raised. Alan also helped organise a darts exhibition along with Pat Kenny, they definitely hit the bullseye when they raised €3,015!



Niamh Kiernan treated family, friends & neighbours to some lovely music on St Stephens Day when she played songs on her guitar in support of her Grandad Luke Kiernan. She strummed up a fantastic €166! Well done Niamh! Sadly, Luke has since passed away, the IMNDA would like to extend our deepest condolences to the Kiernan family.

Pat Ryan treated everyone at the White House in Baldoyle to some lovely music and he managed to raise a superb €1,012.50. Thanks Pat!

CHRISTMAS CRACKERS!

Anne-Marie Smyth knitted a beautiful set of Crib figures & Noahs Ark which she kindly raffled for the IMNDA raising a truly fantastic €1,050. So much hard work went into this and we want to thank everyone involved, especially all at the Portershed in Galway. Ann-Marie even had a carpenter named Joseph make the crib!

The 6th class pupils of Scoil Sheosaimh Naofa in Ballinagar organised a hugely successful Christmas cake sale & raffle. The students also provided entertainment on the day and they decided to donate the brilliant proceeds of €1,000 to the IMNDA. Thanks so much to everyone involved!

Big thanks to Geraldine Collins and everyone from St. Fergal's Gospel Choir for bringing some festive cheer to the Dundrum Shopping Centre where they sang beautiful Christmas Carols and raised a fantastic €315. Thanks also to 65 Kitchen Choir who donated the jolly good proceeds of €1,000 from their Christmas shows in Portlaoise to the IMNDA.

Wexford County Council also donated the fantastic proceeds of €500 from their Christmas Carol signing in memory of John Lacey. Thanks to all involved.

William & Diana O'Donovan put on a spectacular display of Christmas lights at their house in Cork and raised an amazing €1,740! Thank you so much

Thanks to all the staff and students at Athlone Community College who held a Christmas Jumper day for the IMNDA and raised a fantastic €1,285.50. Todd Nugent kindly accepted the cheque on our behalf. Well done to all involved!

CARD TRICKS

Martin O'Dwyer organised a charity card game in Littleton Hall in support of John Delaney and raised a superb €3,339 for the IMNDA. Thanks John!

Big thanks to everyone from Rathfarnham Golf Club who held a charity bridge lunch in memory of Jean Colin and raised a fantastic €1,000. Thanks also to Elizabeth Ryan and friends who raised €175 from a bridge night.

AFTERNOON TEA

The ever popular tea and coffee morning proved once again a timeless treat! Pauline Costello and family held an Afternoon Tea and brewed up an amazing €3,180. Well done! Big thanks to Christine Scully and her colleagues at ESB for hosting a coffee morning which raised a tea-riffic €1,050. Thanks also to Sinead O'Meara and everyone in Waterford Institute of Technology for organising a bake sale which raised a brilliant €105. The LCA students in Mount St Michaels School in Rosscarbery held a coffee morning and raised a fantastic €184. Thanks so much to all the staff & students!

Claire Quinlan held a coffee morning at the Nano Nagle Community Centre in Carrick-on-Suir, she also held a raffle and had beautiful candles for sale, raising a brilliant €1,741 for the IMDNA. Thanks Claire!

A huge thank you to everyone from Irish Rail who held coffee mornings in their Athlone branch, CTC Building Connolly and Inchicore Engineering and New Works Building in memory of their colleague John Ryan. A staggering €4859.00 was raised and it couldn't have been done without the help from all the bakers, people who donated, bought raffle tickets and everyone who came along on the day for tea and cake – thank you! A special thanks to John's family who attended the coffee morning in Inchicore.

St Pauls Church in Glenageary held a coffee morning raising a superb €600. Big thanks to all involved and a special word of thanks to Roland & Annette Evans who kindly represented the IMNDA on the day.

CHURCH GATE COLLECTIONS

A huge thank you to all our collectors who shake a bucket outside their local church gates across Ireland as well as other street and match collections throughout the year. There are also far too many people to mention who donate to us throughout the year but we are so appreciative of all your donations, however big or small it all adds up.
As ever, the last few months have been packed full of great events so we applaud you all for your efforts and whacky ideas that truly keep us on our feet.

Couple Say 'I Do' for Charity

Mock Wedding raises nearly €130K for Motor Neurone Disease

On a Saturday night in February, 330 witnesses in Mitchelstown saw a Postman Priest preside over a wedding of a 70 year old Tipp lady and a 90 year old Cork man. Several objections were lodged by guests but it was all for a good cause. The priest Declan Dunphy 'married' the bride, Eileen Boland and the groom Tom O'Connor in a mock fundraiser for Motor Neurone Disease (MND).

The lavish affair in the Firgrove Hotel which was MC' d by broadcaster Jonathan Healy and filmed by Anne Cassin from Nationwide, raised over a staggering €129,000 for the Irish Motor Neurone Disease Association (IMNDA). This novel idea was brought about because of the creativity and courage of two families who were affected by MND, an incurable, terminal and progressive neurological condition.

Eileen Boland lost her husband Charlie and Tom O'Connor lost his wife Breda, to this devastating disease. They wanted to not only give back to a charity that helped during a very dark time but to remember their loved ones in a fun and happy way.

But this dynamic duo had help in making this the Mock Wedding of the Year! The local and business community came out in force to show their support. The cake was made by by Cashel Flowers. The dresses came from Helena Kirwan and suits were curtesy of Fitzgerald Menswear Clonmel. The main event sponsorship came from Tim and Tom O'Connor of O'Connor Utilities who gave a substantial donation in memory of their mother Breda O'Connor.

The whole magnificent event was recorded by RTE and filmed for Nationwide. From all at the IMNDA we cannot thank Eileen, Tom, Bernie, Joan and all the Boland and O'Connor Families enough. They truly went above and beyond. Surpassing anything we had ever hoped they could achieve. It is the largest amount raised from a single event ever in the history of the association. Words can't say how appreciative we are. Totally amazed!! But they were not alone – they also received immeasurable support from the local and extended community. Countless people got involved and made this event a roaring success. We couldn't mention everyone, but we really are so thankful. There were a few who we just wanted to note and say a special thanks to:

Breda Phelan
Colm Roe
Gordon Elliot
Larry O'Keeffe
Niall Boland
Norma Harte
Seamus McGrath
Sue-Anne O'Donnell
Mr & Mrs Tim Shanahan
Mr & Mrs Gerry Kelly
O'Keeffe Family
Sherry Fitzgerald Walsh

Star Fuels Farm Supplies Ltd
South Tipp Farm Relief Services
Hickeys Bakery, Clonmel
Daverns of Cashel
Clonmel Oil Company
Vale Oil Company Ltd
Clonmel Machinery Ltd
John Quirke Jewellers
Liam Wall Gents Hair Salon
Powerstown Sunday Choir
Rathkeevin ICA Guild
PJ O'Neill & all at Sureprint

Tipp FM Radio
Bethell Construction Ltd
Cusack Charity Foundation
Pat O'Connor
Leeds Irish Centre
P F Cusack Ltd
Tommy Gallagher
UK & Ireland Insurance Services Ltd
UK & Ireland Construction Ltd
Kelly Communications Ltd

Just again, to everyone who attended, donated, supported or organised the Mock Wedding – we are so grateful. Because of your help we will be able to help countless families living with MND. Thank you!

#walkwithtony

FR. TONY COOTE

WALK WHILE YOU CAN

JULY 10TH TO AUGUST 6TH 2018

SUPPORT RESEARCH AND CARE FIGHTING MOTOR NEURONE DISEASE

LETTERKENNY TO BALLYDEHOB

Walk While You Can is all about bringing people and communities across Ireland together to raise vital awareness and support for Motor Neurone Disease. We'll be walking the length of Ireland this July to generate funds and help highlight the need for more funding in this area – and it would mean so much if you could be there with us. By joining our walk, you are not only lending your voice to our call for better supports and services for people living with this condition but making those supports possible.

This walk is for everyone, of all ages, so, if you'd like to get involved, find out more about our route and let us know where you'll be joining Tony, on our website wwyc.ie

Irish
Motor
Neurone
Disease
Association

rmn
Research Motor Neurone

GET INVOLVED & DONATE WWYC.IE

JUNE POLO IN THE PARK

IN AID OF THE IRISH MOTOR NEURONE DISEASE ASSOCIATION

ALL IRELAND POLO CLUB
IN PHOENIX PARK
SAT 9 JUNE 3PM TILL LATE

JOIN US FOR THE GARDEN PARTY OF THE SUMMER
GOURMET FOOD, TUNES, POLO AND A WHOLE LOT MORE!
OVER 21S, TICKETS, LIMITED EB €75, GENERAL ADMISSION €95
FOR PACKAGES AND ALL INFO SEE JUNEBALL.COM

IMNDA
CARE AND RESEARCH

Thank you for getting active for your Association!

ON YOUR MARKS!

A big thanks to all of you who put on your trainers and ran, jogged or walked for the IMNDA! We appreciate each and every one of you!

Fiona Carr and friends Anna & Claire took on the Barcelona Marathon and raised an outstanding €1,974.50.
Lisa O'Donohue & friend Niamh took on the Dubai Marathon and crossed the line with a brilliant €991!

A massive well done to everyone who helped organise The Good Run on Good Friday. Over 650 runners, walkers, joggers, buggies and doggies took to St Anne's Park to support the fight against motor neurone disease! Thank you so much to everyone who came out and supported this fantastic event in aid of the Irish Motor Neurone Disease Association and Project MinE Ireland. A special thanks to Olivia & the Treacy Family for once again organising this brilliant event! We look forward to updating you soon on the total raised from this family fun day!

To all our amazing supporters who took part in the Cork Women's Mini Marathon, The Cork City Marathon and the Limerick Mini Marathon, thank you! Over €2,000 was raised from these Munster races. A special thanks to Patricia McNamara, Rose Keating & Team, Darren Geaney, Noelle Higgins & Anne-Marie Gahan O'Brien.

Thanks to all the fabulous runners who took part in the Dublin City Marathon. An amazing €36,000 was raised for the IMNDA! We cannot thank you all enough! You should all be very proud of yourselves. A special thanks to Donal & Eoin Hickey and Cormac Doody, Eamonn Farrell, Catherine Connor, Tony Weldon, Eleana Dunne, Eoghan McDonagh, Jack McCarthy, Karl Hogan, Martin Shiels, Paul Jordan, Caoimhe Galligan, Richard Leen and Risteárd Ó'Fuaráin,

REINDEER RUN

John O'Donoghue along with daughter Aoife, friend John Sweeney and a sleigh full of helpers organised the unbelievably successful Reindeer Run on 23rd December at various locations such as Killarney National Park, Caherdaniel and the beautiful Flaggy Shore. So much hard work went into organising these family friendly runs, and the reindeers raised a phenomenal €45,790! We just want to extend a heartfelt thanks to John and all involved, you really went above and beyond! Thanks also to everyone who supported this event from the participants to the local businesses and schools. Well done everyone!!

PEDEL POWER!

Huge thank you to everyone from the Killeshin Wheelers Cycling Club. They really put their foot to the pedal when they cycled from Achill to Killeshin in memory of Mark Attride. They raised €6,000 for the IMNDA! Well done everyone!!

We have to say big thanks to Michael Kenna & his colleagues from Glan Agua who organised a cycle from Citywest in Dublin to Galway and raised an outstanding €13,633.44. Thank you so much!

Thank you for getting active for your Association!

Kevin McGrath and Ronan Maher organised a cycle from Nenagh to Galway in memory of Frank Maher. The cycle was once again a massive success and they raised a fantastic €5,100. They will be doing it again in 2019! Well done guys!!

FUN-RAISING

Peter Walsh kindly donated the proceeds of his yoga classes for a week to the IMNDA. After a lot of downward dogs and warrior poses, Peter raised an amazing €525. Thank you so much!

Monika Flanagan took on the challenge of a lifetime when she climbed Mount Kilimanjaro for the IMNDA. She raised a phenomenal €1,356.80. Thank you Monika!

Massive thanks to Justin Ryan Fitness who held various charity boot camp classes and worked up an amazing €2,850 For the IMNDA. Thanks so much Justin!

Big thanks to Glenveegh National Park who picked the IMNDA as the chosen charity for their St Stephens Day walk. A fantastic €1,375 was raised on the day. Special thanks to Charlie Boyle, Pat, Marian & everyone who supported this event.

Owenmore Gaels GAA ran a charity match on St. Stephens day and raised a brilliant €914.15. Well done to all involved! Carol Murphy & Staff from People First Credit Union in Portlaoise took on a Couch to 5K for the IMNDA on St Patricks Day. They practiced hard and braved the cold raising a fantastic €763.50

Big thanks to Rathbane Golf Club who organised a collection and raised a brilliant €250

Stella Hickey and the team in Abco Kovex went to Hell & Back to raise funds for the IMNDA! The incredible team of 17 raised €6,875!! Well done guys - we can't thank you all enough!!

CHRISTMAS DIP

Fair play to those who braved the cold and left their cosy homes on Christmas Day for a chilly dip all for the IMNDA. Pauline Feeney & family did a Christmas swim at Balbriggan beach where they raised a fantastic €597.50. Well done! Big thanks also to everyone from Ballyshannon Branch of Irish Water Safety who organised a Christmas swim in memory of John Larkin and raised a brilliant €1,250.

ABSEIL

An overwhelming thank you to all our amazing supporters who climbed onto the roof of the Hogan Stand in Croke Park in October and abseiled the 100ft to the pitch! We were absolutely blown away by your bravery and the incredible fundraising efforts you all made. Over €45,000 was raised!!! A special word of thanks to Joan & John Ryan, Hayley Burke, Rita Doyle, Sinead McCarthy, The Mhic Dhomhnaill Family & Nicola O'Driscoll, Cora Nicholson & Amy Flynn, Robert Hennebry, Norbert Fitzsimons, Alicia Maguire, Julie Finlay, Howard Healy, Brenda Clehane & Anne Murphy.

The very best of luck to all our active fundraisers who are taking part in this year's many marathons – full, mini and half – walks, swims, cycles. ENJOY!

Sharon Byrne 7 Challegnes

In October of 2015, my family lost someone very special to us to Motor Neurone Disease, my uncle Domo. In July of 2016 I completed a skydive and raised €800 for the Irish Motor Neurone Disease. Following his first anniversary I wanted to do more and decided to set myself some challenges for 2017 to continue fundraising for the IMNDA. I signed up for the Waterford Marathon and paid for a trip to Nepal to trek to Everest Base Camp. I then signed up for the Dublin Marathon which would fall around the time of Domo's second anniversary. With three challenges already set, I wondered what more I could do and, after some brainstorming, came up with the 7 challenges for 2017.

In February, the challenge was titled "Facebook Free February" but for the month I logged out of all Social Media sites; Facebook, Instagram, Snapchat, Twitter, WhatsApp, the lot! While it was a challenge in the beginning, it turned out to be a cleanse. There were days I missed it and sometimes felt a little cut off but overall it was brilliant. I loved taking everything in and just enjoying the things around me. I loved not having my phone in my hand all the time. I wasn't reliant on my phone, I got to enjoy time with friends and family.

In April, I travelled to Kathmandu on my own, joined a tour group and set out on the 7 day trek up to Base Camp. This trip was completely self-funded and was one of the most incredible experiences of my life. There were some very tough days. I fought off minor headaches here and there and on Base Camp day, the altitude really got to me. I had a terrible headache and was so nauseous. I remember falling back on the trek and crying because I thought I wasn't going to make it and was thinking about everything I was doing it for. After lunch, after the medicine kicked in, I was back to myself and sang and danced my way to Base Camp! I made it. An experience and challenge I will never forget!

In May, I went vegetarian. This was very difficult for me as not only was it a complete change in my diet, but I was also training for my June challenge; the Waterford Viking Marathon. Tough as 26.2 miles is, the Waterford marathon was very enjoyable. I spent the final days of June indulging in junk food before having to give it all up for the July challenge; No Junk July. In July, I gave up all sweets and treats, take-away foods and alcohol. I underestimated just how much I would struggle with this challenge, but I managed to get through it without breaking my very strict rules. In August, I ran from Abbeyleix to Athy; almost 20 miles of hills, hills, hills! The end was in sight. One challenge to go; the Dublin City Marathon in October. I was lucky enough to have my aunt and cousin run on the day too, but it was an emotional run, particularly that last mile. Thinking of Domo made me fight through the pain and the support got me over that finish line.

Thanks so much to everyone for the kind words and messages of support. Thanks to those who liked and shared the Facebook and Charity fundraising page and an extra special thanks to everyone who donated. Together we raised €1,054.

The IMNDA would just like to say a huge thank you to Sharon, you really went above and beyond and we are so grateful for all your hard work. Well done!

Irish
Motor
Neurone
Disease
Association

The Irish Motor Neurone Disease Association

DARES YOU TO TAKE PART IN THE...

CROKE PARK ABSEILS!

Experience the ultimate adrenalin rush and abseil 100ft from the roof of Croker's famous Hogan Stand. Be a Croke Park Hero!

SATURDAY 13TH OCTOBER 2018

The IMNDA is looking for people to abseil from the roof of Croke Park Stadium, Dublin; 100ft from top to bottom!

Are you game?

Contact the IMNDA today for your application form!

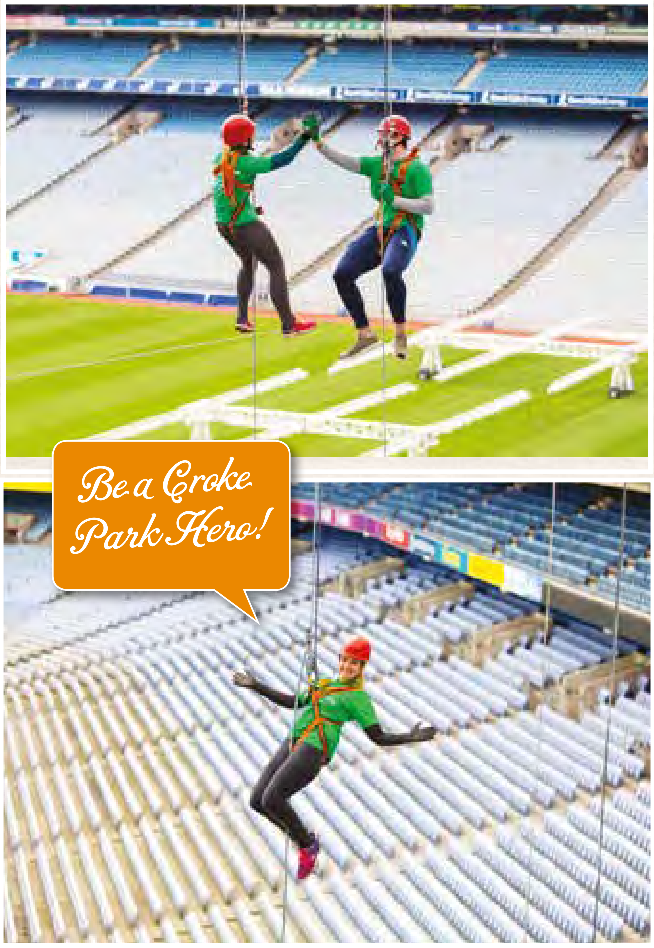
freefone 1800 403 403
email fundraising@Imnda.ie

www.imnda.ie

Over 18's only / no experience necessary / full training provided on the day.
Event is run in association with **www.adventure.ie**

……

Places are limited; a non-refundable deposit of €100 and fundraising is required of all participants. All proceeds raised will go directly to supporting people affected by Motor Neurone Disease; a progressive, incurable and terminal condition.



Charity No. 8510

Irish Motor Neurone Disease Association

Join the IRISH MOTOR NEURONE DISEASE ASSOCIATION for this summer's

Walk to D-FEET MND

SATURDAY 21st JULY 2018

@ 11AM, PHOENIX PARK, DUBLIN

(Start and Finish near the Papal Cross)

Register online for 20 per person at www.imnda.ie. Walkers will also be able to pay on the day.

Come together with friends and family (kids & pets welcome!) for a 5K WALK in aid of Motor Neurone Disease.

Under 12's walk for free & all walkers receive an IMNDA t-shirt and light refreshments.
The route is fully wheelchair & buggy accessible and you can run if you like! Can't make Phoenix Park on the 21st July?
Why not organise your own Walk to D-Feet MND in your local area?
Freefone 1800 403 403 or email **fundraising@imnda.ie** for more information.
Please note photos will be taken on the day. If you do not want your image used please notify the IMNDA. Thank you.

Every step makes a difference.
We walk for hope, we walk in support, we walk in memory and we walk so that one day we will see a world free of Motor Neurone Disease.
TOGETHER, LET'S TAKE STEPS TO D-FEET MND.

ffh Management Services

www.imnda.ie

Charity No. 8510

The Solo Run That's All About Others

St. Mary's Juveniles showed that a great solo run is really all about teamwork as they soloed the ball round the pitch for 100 kilometers in aid of a most worthy cause that is close to the hearts and minds of everyone in St Mary's on September 16th 2017.

Motor Neurone Disease is a progressive neurological condition that attacks the motor neurones, or nerves, in the brain and spinal cord, and hits people of all ages. There is currently there no cure for the disease.

Thanks to the efforts of the team and all in the community who sponsored them, over € 1,600.00 was raised by the event will be put to immediate use by the Irish Motor Neurone Disease Association (IMNDA), which is currently helping sufferers, and careers through advocacy, in the home, and by means of professional support.

For many years, St Mary's GFC has strong relations with IMNDA and according to Club Treasurer Eugene McLaughlin this latest club fundraiser is proof of the positive contribution sport can make. "St Mary's has always been about much more than a GAA club, and giving something back to worthy charities like IMNDA through these inspirational ideas is something that we are delighted to be able to do."

All teams from Nursery to U16s trained hard and practiced their solos at their weekly training sessions and at home in the buildup to this challenge. Each and every team member did their Club and community proud when they finished the 100K together showing that this bunch of players follows in the footsteps of many great St Mary's teams before them.

The Solo Run proved a great success not just for the team around the field, but the one on the sidelines as well: the parents, grandparents, brothers, sisters and mentors who cheered and clapped the players on every lap making it a memorable day of fun, laughter and fundraising.

Have you ever seen the rain

My aunt Breda was a beautiful person, kind, thoughtful and sharp as a button - my mam's sister and best friend. Breda moved to Egypt in her 20s after marrying Mohammad or as we know him 'Uncle George'. She adored her children Tomi and Sherena and dovated her life to caring for little ones as a kindergarten teacher in Cairo. My mam and Breda kept in regular contact by writing letters talking of life and love, of family to friends to the everyday extraordinary moments from across the waters.

The disease found Breda in her early 50s – Motor Neurons as they called it. We knew very little about it but from the tone of how it was said we knew the time ahead was going to be very hard for Breda and those of us who loved her dearly. My aunt's spirit and determination was unfailing throughout it all. She was a fighter, not letting the disease get her down (too much), always with a smile and a curious eye for life. Motor Neuron Disease is an unkind disease, maybe they all are, but I believe this disease is different. It slowly worked its way through my beautiful aunt's body, cells not talking to each other anymore like a wall being built between the mind and the individual parts of her body.

My mam travelled to Egypt every six weeks to be with Breda and for a period of time she lived with us in Ireland. Mam always says how grateful she was to be able to travel and be with her sister and how Dad was always there supporting her, knowing how important and precious life was. They made it work between them – knowing what mattered most.

Breda was such an intelligent person, she loved reading & writing. My mam and Breda would just sit together and read, more of often than not – books telling tales of love and romance. Those moments of quiet togetherness are vivid in my mams memory and she believes her interest and love of reading most definitely stemmed from that time.

I often think that although she was taken by something bigger than us, someone or something was looking down on her and just knew what would keep her with us for that bit longer. Even when her voice finally left her, her mind was as sharp as always and she found a way to express herself through the use of pen and paper.

The time Breda spent with us was supported so much by the Irish Motor Neuron Disease Association (IMNDA) based in Dublin. They give so much to the people living with this disease and to their families, helping people live on for as long as it's possible. We all believe they helped give Breda that extra time to be with those she loved so much and to be able to say all the things she needed to say. What you might call 'a thousand goodbyes'.

I remember my mam sharing a story from a visit to Egypt. Breda and mam loved to go to the shops together when Breda was able, pottering through the bustling markets. On one occasion the heavens opened, rain coming down on a sunny day in Cairo. Not an everyday occurrence as you can imagine. Breda loved Rod Stuart and one of her favourite songs was 'Have you ever seen the rain'. Instead of going indoors Breda looked to the heavens and in that special moment said she wanted to walk home……to feel the rain on her face. Sometimes I forget how special the little things are in life but my aunt Breda never did.

The day my aunt slipped away, my mam was sitting with her, Breda's hand holding a pen as always but this time her words drifted straight into the clouds above.

It's been so many years now since Breda passed away but she has never been forgotten. She is in our thoughts, the photos of her around my mams house, the many memories in the beautiful artefacts brought back from Egypt and most importantly through her children Sherena and Tomi.

My brother Tomas lived at home when Breda came to stay with my mam and dad in Mayo and she always had a soft spot for him. It's amazing how people grow and change over the years. My brother was shy and quiet as a child and the youngest in our family, surrounded by three sisters. Now a man of 28 he is one of the most thoughtful, dedicated and confident people I know and when he sets himself a challenge there really is no stopping him.

In January 2017 he did just that, and in memory of my Aunt Breda he decided to raise awareness of Motor Neurons Disease and raise funds for the Irish Motor Neurons Disease Association. This association is based in Dublin and provides information, support, aids, appliances and services to people living with the disease across the country. They really do amazing work and what Tomas' was planning was in a way a small thank you to them for all they did for Breda.

He decided to take a novel approach to raise awareness and funds by running a 5km each week for the 52 weeks of 2017 in order to raise 5,000. What was even more novel was that he aimed to have a different companion running with him each week and this was a big part of what he was doing. As you can imagine the first companions were family but once the word got out, more and more people wanted to be part of what Tomas was doing and offered their support.

Tomas set up a donations page and slowly but surely donations started to roll in. After each run he would post a picture of himself and his running partner with the details of how people could get involved and donate. This went out on Facebook, Twitter and Instagram. In addition his running partner each week and all his friends and family would share these posts out to their friends and followers – greatly increasing the number of people seeing Tomas' message.

After a few months it really grew legs when Global Payments, where Tomas works, heard about what he was trying to do. Not only did the Dublin office want to support Tomas and play their part in raising much needed funds, other offices across the globe wanted to get involved too. They decided that staff in each office would run the 5km on the same day, at the same time, in order to raise money and to promote the cause. This worked so well with at least one person in each office across the world taking part - a total of 209 runners from 30 different offices.

Over the course of the year local media also got involved, interviewing Tomas and helping to raise even more awareness of the cause. This included promotion to the readers and listeners of The Mayo News, The Connaught Telegraph, The Western People and Midwest Radio. All resulting in an increase in donations for the Irish Motor Neurone Disease Association (IMNDA).

It wasn't just in Mayo and Dublin where these runs took place, Tomas and his wife Aoife also braved the chilly weather in New York running a 5km at -7 degrees around Central Park and they also ran along the River Seine while in Paris. His dedication to the cause was always stoic and when my cousin Sherena, Breda's daughter, was home in Ireland for my wedding in October 2017, she and Tomas and a number of our wedding guests got up early after the wedding reception (with very little sleep) and ran a 5km around the beautiful grounds of Kilronan Castle in Co. Roscommon.

Fast forward from October to December and Tomas had organised a 5km run on Christmas Eve in our home town Foxford, Co. Mayo. This was his 51st run of the year and in true community spirit crowds of Foxfordians came out to support Tomas and his cause. It lashed rain but that didn't stop anyone from coming out and getting involved. It finished at the Foxford Woollen Mills where we were all treated to warm mulled wine and mince pies.

I am sure you would not believe it but just before Tomas' own wedding to Aoife they both went out and ran the final 52nd run of the year on the 27th of December 2017. She was a perfect companion to finish the challenge he set himself as Aoife was and is a rock to my brother always encouraging him to be the best he can be.

You are probably wondering now how much was donated in the end and thanks to the support of friends, family, supporters, colleagues and the general public, a total of 13,806.66 euros was raised for the Irish Motor Neuron Disease Association. This was presented to the great team there the day after Tomas and Aoife came back from their honeymoon.

Tomas is an inspiration to us all and we are all extremely proud of him and know that our beautiful Aunt Breda is looking down smiling at what he has achieved in her memory.

To finish on my mams favourite quote "Life is not measured by the breaths we take but the moments that take our breath away" and hats off to my brother Tomas as he certainly created many moments in Breda's memory.
Roisin Guiry

Everyone from the IMNDA would like to say a huge thank you to Tomas for all the hard work that went into these runs, we know it can't have been easy to brave the Irish weather week in, week out! Thanks also to everyone who joined Tomas along the way and to all who supported this event. We are deeply grateful. Thank you!!

Upcoming Events

VHI Women's Mini Marathon 2018
Come on ladies – join us, along with women from across Ireland and run the race to make a difference! Join the Fight against Motor Neurone Disease and sign up for the VHI Women's Mini Marathon on June 4th. You can register through the entry form in the Evening Herald or online at: **www.vhiwomensminimarathon.ie**

Once you have this done, call or email Gemma or Jackie on 01-8730422 or fundraising@imnda.ie and get your sponsorship pack which includes cards and a t-shirt.

On the day of the race we have a meeting place for everyone running in aid of the association. Do pop into us in Toner's Pub (upstairs), 139 Lower Baggot Street, Dublin 2 where we will be from approximately 12:30pm.

Please note the starting time for the mini marathon is 2pm. *All your belongings can be left in the lounge during the race, they will be safe and secure and light refreshments will also be supplied after the race.*

#FIFTYTWOWORDS2018

JOIN US FOR AN EVENING OF STORIES, PERSPECTIVES AND TALKS EXPLORING THE MEANING OF THE WORD #HOPE

FIFTY TWO WORDS

FRIDAY 29TH
JUNE 2018,
THE LIBERTY HALL
DUBLIN

TICKETS AVAILABLE AT
Eventbrite

IN SUPPORT OF IMNDA
Irish Motor Neurone Disease Association

EDITORS DESK

In Remembrance

Those we love remain with us

Those we love remain with us, for love itself lives on, and cherished memories never fade because a loved one's gone.

Those we love can never be more that a thought apart,

For as long as there is memory, they'll live on in the heart.

Kathleen Reid
Kieran Rafter
Monica Meaney
Patricia Thornton
William Ryan
Tim O'Brien
Michelle O'Brien
Kevin Keighary
Patrick Wickham
Simon Fitzmaurice
John Dalton
Michael Kirwan
Marie Kelly
Frank Kelly
John Moriarty
John Larkin
William Rafter
Kevin Dawson
Rita Mulchrone
Kevin Kavanagh
Catherine Keating
Sean O'Connor
David Kearns
Teddy McGoey
Patrick Reilly
Patrick Joseph McKeown
Mary Culhane
Tommy Flynn
John Taylor
John McGaley
Sean Cawley
Michael Brophy
John Lacey
Richard Logue
Patrick McLoughlin
Gerard O'Rourke
Andrew Lydon
Stella Horan
Alfred William Donnelly
Mary McNulty
Catherine Cahill
Linda Lee
Martin Stokes
Matthew Foley
Anne Murphy
Ann Bradshaw
Sharon Friel
Seamus Butler
Thomas Ryan
David Mellerick
Brian Ruane
John Ryan
Eugene Kennedy
Michael Walsh
Brid Daly
Christopher Morris
Noreen Dalton
Patricia Leahy
Jean Colin
Michael O'Connell
James Ryan
Michael Durkin
John Lynch
Marie Murphy
Martin McGrath
Mary Carroll
Rita Hynes
Patrick Kehoe
Peter O'Keeffe
Ciaran Flynn
William O'Neill
Luke Kiernan
John Oliver Burke
Vincent Carr
Breda Dunne
Kieran Coppinger
Donal Hogan
Roisin Lennon
Cait O'Mahony
Ann Murnane
Geoffrey Jerome
Frances Doyle
Sadie Canavan
Breda McElhinney
Joseph Hurley
Winifred Freeney
Patrick Cunningham
Stephen Carty
Joe Colgan
Michael Leen
Ayleen Stacey
Monica Brooks
James Ritchie
Joseph Callanan
John Dolan
Pat Langton
Ita Moriarty

Staff Update

We have a few goodbyes to make at the IMNDA. Our CEO Aisling Farrell is leaving us after 5 years. She joined in 2013 and really guided us through some periods of great change. We can't thank her enough for her wisdom, direction and dedication. She is leaving the IMNDA to take up a post in the corporate sector. We wish her the best of luck with everything and thank her for her service. We know she will do amazing things in her new role! Thanks Aisling!!

We also must say a goodbye to Shauna. Shauna joined us as part of the Arthur Cox Placement last year. She worked her socks off for the year and was a treasured member of the team. Well done Shauna! Best of luck with the studies – we will miss you!

To both Aisling and Shauna, from all the team – thank you, good luck and goodbye!

Corporate Updates

GOODBODY

Our 2 year partnership with Goodbody continues and we are so appreciative of all their support and fundraising events which has so far raised a fabulous €50,000 from events including a 'Fire and Ice' Challenge, boxing event, Spring Balls, Drink Tea for MND and their involvement in the annual Good Run. We look forward to working together for the rest of 2018! Thank you!

DAA

We are delighted to be one of the chosen daa charities for 2018 along with Laura Lynn (Ireland's Children's Hospice) and Snowflakes (Autism Support). The daa Staff Charity Initiative has been running since 2007. In that time staff fundraisers, the generosity of members of the public and donations from daa have raised almost €3 million for nearly 25 charities. Massive thanks to all daa staff who lobbied and voted for the IMNDA. This is a huge opportunity to raise awareness of the IMNDA as well as vital funds. We are really excited about working with the daa throughout 2018!

IRISH LIFE

We are delighted to announce that alongside Remember US we have been chosen as a charity partner for Irish Life for 2018. We can't thank all the staff enough for voting and choosing the IMNDA to benefit from their 2018 charity fundraising. We are thrilled to be picked especially because Irish Life employees are always so supportive of the chosen charities through payroll giving and events like Hell and Back. Thank you!

FFH Management Services

ffh Management Services
A FAIRFAX COMPANY

The staff in FFH are very much looking forward to getting involved in some of the IMNDA's annual events after teaming up as one of our corporate partners. They will be hosting a Drink Tea for MND in June and have very kindly agreed to be a sponsor for our Walk to D-Feet MND. Thanks so much!

Do you have any contacts in companies who might be looking for a charity partner in 2019? Please contact Marie on mreavey@imnda.ie

Awareness Video Appeal

This summer we are hoping to record an awareness video. We always want to give the real life story of MND and demonstrate the impact it has on people living right across the country.

To highlight the support that is required to keep people living at home, we are hoping to film with someone living with MND. It would require a few hours of recording in your own home. If you feel this is something that you would like to get involved with – we would love to hear from you! All you have to do to register your interest is email pr@imnda.ie or call Maeve on 018730422 ext 6.

Thank you!

Leave your gift for the future, leave a legacy

Irish
Motor
Neurone
Disease
Association

After providing for family and friends, leaving a legacy to the IMNDA in your Will is a thoughtful way of ensuring that families coming to terms with this life changing diagnosis have as much support as possible.

It costs approximately €1.7 million for the IMNDA to operate each year and over 80% of our income comes from donations and fundraising. Legacies of all values help to sustain our vital services to ensure we are here for as long as we are needed.
Make **YOUR** legacy **OUR** fight **AGAINST MND**.

Simply contact a solicitor and let them know you would like to make out a Will which includes a legacy to the IMNDA. You will require our registered charity number, which is CHY 8510. Please let us know if you are leaving a gift to us, we would love to say thank you!

For further information on My Legacy Week which takes place every Oct/Nov and a list of participating solicitors in your area visit www.mylegacy.ie

Thank you for considering leaving a gift to the IMNDA.

IWAI

Carrick Cares Day

Inland Waterways Association of Ireland

Fun Activity Day 2018

for people with limited mobility

Lough Key Forest Park

Boyle County Roscommon

Wednesday August 29th.from 12 to 6pm.

Activities include

Cruise around the lake

Fishing from the jetties

All fishing equipment supplied

Fun land based games for everyone

Tree top walk & Moylurg Tower

Now fully accessible

Ducks and Swans to be fed

Followed By

BBQ and Music and Dancing for all

All activities are free of charge to all ,including carers

For further information and bookings

Contact Linda @ 086 2529290

Please let us know if you are coming
by the 15th of july

and please bring suitable rain gear for the day

Waterways Ireland
Uiscebhealaí Éireann Watterweys Airlann

With the Support and Sponsorship of Waterways Ireland

drink tea FOR MND

Everyone needs a helping hand... and sometimes it's as easy as making a cup of tea.

> *My children are slowly becoming my hands.*
>
> *Thankfully, for now, I can still make a cup of tea and give them a hug.*

Róisín Foley (30) - living with MND

Please help the Irish Motor Neurone Disease Association (IMNDA) continue to provide vital services to people like Róisín by hosting a tea party this June.

Contact the IMNDA for your free 'Tea Pack'

Irish
Motor
Neurone
Disease
Association

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

www.imnda.ie

CHY 8510