Irish
Motor
Neurone
Disease
Association

CONNECT

ISSUE 21

SPRING 2019

IN THIS ISSUE...

A NOTE FROM OUR CEO

It gives me great pleasure to be able to share some very exciting news with you – our new MND nurse has started! Having a 4th nurse on board will totally transform our outreach nursing service, allowing our invaluable nursing team to reach more people in the community more often. The difference this will make across the country in the years to come is simply immeasurable.

It would be remiss of me not to mention the man who made this happen, so I would like to recognise, and thank, the dynamo that is Fr. Tony Coote. His sheer determination, along with his army of friends, family and followers made this happen. There are not enough words to describe how thankful we are.

Which brings me to more exciting news – Walk While You Can has now come onto our calendar of events and we will have a series of 5k walks taking place around the country this September. See page 32 for more details on this.

It's been another great year for our Sponsored Silence campaign, fronted by the inspirational Mairead Coleman from Mayo. It is such an important awareness campaign for our organisation. It allows us to raise our voices in support of those who can no longer speak or are at risk of losing their voice. I would like to thank everyone who allowed us to share their personal story and made some noise in February. It's so important to keep the fight going and be heard. Please read Mairead's personal journey with MND on page 16. She truly is a remarkable lady.

In recognition of the vital role our family caregivers play in the lives of people living with MND, we have now introduced a new Family Caregivers Program for 2019. These wonderful funds were made available thanks to the success of last year's Drink Tea for MND campaign. With Global MND Awareness Day fast approaching on June 21st we do hope you will stand with IMNDA once more and put the kettle on. To find out how you can get involved in this year's Drink Tea for MND campaign and read all about Roy Taylor, our new campaign Ambassador, please go to page 20.

Huge thank you as always to everyone who goes out of their way to champion our work and help us raise awareness. We simply couldn't do it without your support.

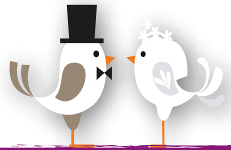
R Duffy

Roisin Duffy, Chief Executive

2019 Calendar of Events/Diary Dates

May

- Getting married this summer? Donate in lieu of wedding favours. Wedding Cards available from our online shop www.imnda.ie/shop.



June

- Sunday 2nd June@ 2pm: VHI Women's Mini Marathon – run the race to make a difference.
- Thursday 20th June @10am – 10pm: RiverDanceAthon day outside the Gaiety Theatre, Dublin.

- MND National Awareness Day is 21st June - Drink Tea for MND during June – tea packs available from the IMNDA.

July

- Get adventurous and take on a muddy challenge this month! www.toughmudder.ie.
- Saturday 13th July: Cycle (70km @10am) or Walk for John (5km @ 1:30pm) – start & finish at St Mary's GAA, Leixslip, Co Kildare

August

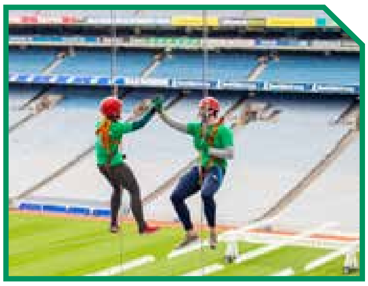
- Help your Employer to choose their 2020 Charity Partner and nominate the IMNDA! We would love to have the opportunity to apply and/or present to the Charity Committee.

September

- Saturday 14th September @11am: Walk While You Can in the Phoenix Park, Dublin. After the massive success of WWYC 2018, we want to bring people and communities across Ireland together again and it would mean so much if you could be there with us either in the Phoenix Park or by organising an event in your community.

October

- Sunday 20th October: Abseil off the roof of Croke Park's famous Hogan Stand, 100ft from top to bottom! Join us for our 10th anniversary abseil year!!!!
- Sunday 27th October: Run the Dublin City Marathon.



November

- Saturday 23rd November: Annual Memorial Service – Capuchin Friary, Dublin 7.
- Send some Charity Christmas cheer and purchase a pack of IMNDA Christmas Cards from our office/website – brand new design for 2019!!
- Purchase one of our exclusive beautifully hand crafted wooden stars in memory or support of someone special for your Christmas tree – just €10 from the IMNDA.

December

- Support our Annual Grand Raffle Draw by selling tickets on our behalf.
- Christmas Coffee Morning - Details TBC. Join us for some festive refreshments and our Grand Raffle Draw.

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Alliance Meeting & Ask the Experts by Tracy Hutchin

The 2018 ALS/MND International Symposium was held in Glasgow and was attended by over 1,000 delegates. The Symposium is an opportunity for all of those working with MND throughout the world to come together and share their research on a cause/cure/treatment for MND. Healthcare professionals also shared what they have learned in practice from working with people with MND. Ireland was one of the founder members of the International Alliance and there are now members from over 40 countries. The International Symposium is the pre-eminent meeting bringing together leading researchers and health care professionals from all over the world to present and debate key innovations in their fields.

One of the presentations that really stood out was given by **Craig Stockton of MND Scotland**. The presentation gave details on some educational videos that MND Scotland have recently created. They produced a suite of animated videos, featuring the voices of real people affected by MND, and accompanying written materials, to help patients cope with living with some of the common symptoms and challenges which an MND diagnosis can bring. The videos give advice on dealing with choking, guidance on avoiding trips and falls and advice on when to get a feeding tube fitted.

Trips and Falls

Did you know that the most common cause of hospital admissions for people with Motor Neurone Disease is due to simple trips and falls?

This video features advice on preventing trips and falls inside and outside of the home, including useful tips for modifying your living with MND.

Choking

A choking episode can be extremely distressing for carers, family members and people with MND when an episode occurs. Healthcare professionals advise that people with MND won't die because of a choking episode – but it doesn't always feel like that when it occurs.

This video features contains information on coping with choking from health and social care professionals.

Feeding Tubes

Having a feeding tube inserted can seem like a scary thought. Fraser, from West Lothian, shares his own real life experience of getting a feeding tube inserted and why it was important for him to get his tube fitted while he was still fit and healthy.

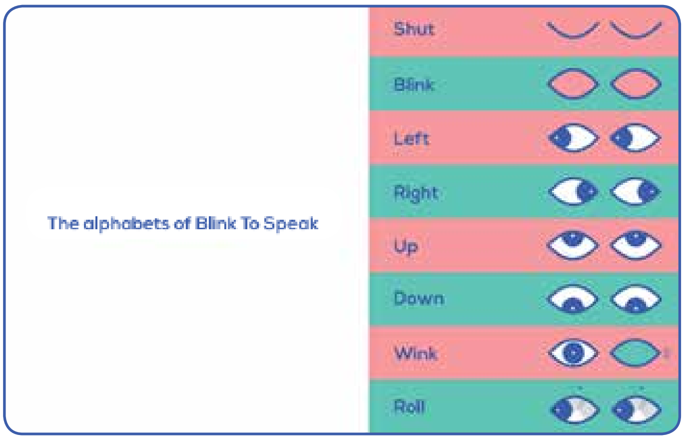
This video contains guidance for people who are recommended to have a feeding tube inserted.

The videos are all available on the MND Scotland website and are all about two minutes long or less. The aim of the videos is the allow people to make informed decisions based on high quality, accurate and accessible information.

Asha Ek Hope, of the Indian MND Association, gave a very insightful presentation on a fascinating new eye language that the Indian MND Association was involved in creating. Blink To Speak, is now the world's first eye language and is a simple communication method created to help paralyzed people who have difficulties with speech. It is helpful for patients with an alert mind but a paralyzed body. This language will ease communication between patients and caregivers and family members. It can be a permanent or temporary aid for communication.

Blink To Speak uses basic eye movements such as blinking, winking, looking up/down etc. Following consultation with people with MND and carers, 50 commands and phrases were identified and a combination of eye movements were assigned to each command/phrase. These were all compiled into a phrasebook which is now available online at **www.blinktospeak.com**.

Some of the combinations are a bit complicated but it could certainly be beneficial to have some of the simpler ones for those times when fatigue makes using technology difficult to communicate. The phrasebook is available in a number of languages including English.



The alphabets of Blink To Speak

Dr. David Taylor, Chair of the Alliance Scientific Advisory Committee gave a research update on why he is so hopeful about the direction research is going. David took up his position on the Scientific Advisory Council in 2012 and in his words "if at that time someone told me of the scientific discoveries made in the field of MND by 2018, I simply wouldn't have believed that research had progressed so far"

Scientists are constantly making progress and often make exciting breakthroughs and discoveries. However, these don't make it to mainstream media as they aren't prominent enough, i.e. they haven't found the definitive cause of MND or its cure. Potential therapeutic tools must be tested in the lab first to see that they are effective and safe before sharing knowledge of them and giving false hope.

Advances in technology have laid the foundations to have hope. The first big breakthrough came in 1993 with the discovery of the first genetic cause of MND. Following this it was obvious to researchers that more tools were needed. Further genetic discoveries have been made since 2006.

mnda
motor neurone disease association
29th international
symposium
on ALS/MND

At MND meetings now, David senses a palpable feeling of getting somewhere from the researchers although they all agree that there is a long way to go. Breakthroughs from researchers are helping to build the story of MND. The six arms of the foundations for research are – Understanding MND, Collaboration, Clinical Trials, Quality of Life, Visibility and Technology.

Clinical trials are making dents on the armour of MND. In the last six years there has been a massive emphasis on improving trial design. Development of clinical trial guidelines for MND is seen as a really important achievement in the field. 2018 has seen the development of some high profile trials with a phase 1 clinical trial of C9orf72 just 7 years after the discovery of the gene.

This is impressive in research terms. There are at least eighteen pharmaceutical companies doing trials or developing potential treatments for MND. They are looking at many areas including genetics, muscle reaction in MND and synthetic hormones.

As therapies are developed that slow down the progression of MND, focus needs to broaden to incorporate symptom management and improvements to quality of life. Visibility of MND varies around the world but the one thing that has happened in the past few years is an increase in global awareness of MND, thanks to the Ice Bucket Challenge. Funding for a world without MND won't happen without visibility.

Technology plays a pivotal role in research. Developments in artificial intelligence, gene editing, biomarker detection limits, the ability to hold virtual meetings, data sharing and social media all play a part in research developments. We are on the cusp of a huge jump in computer power which will open up even more potential developments in research and quality of life such as accessibility to brain computer interface technology.

Next on the agenda was **The Ask the Experts** session, which is organised by the host MND association. This session involves a panel of experts on MND giving presentations on various aspects of MND and who are then available to answer questions from the audience. The audience is made up of local people with MND and their carers and family members, attendees from the International Alliance meeting and any other interested parties. The session was also live streamed online and the recording can be viewed here **www.mndscotland.org.uk/research/ask-the-experts-2018**. The aim of this session was to improve understanding of MND, its causes, treatment and research into the disease.

Mixiton
Le plaisir de la table retrouvé

Update on the French app called Mixiton.

The app is now available on Apple and android devices and it contains recipes for easy to swallow meals. The recipes chosen for the app were winners of a competition and all were created by people living with or caring for someone with MND. Recipes include goat's cheese and smoked salmon soufflé, lamb curry, black forest mousse and many, many more. The recipes are divided into starter, main meal, accompaniment or dessert. There is definitely a dish on here for everyone so it is well worth a look.

Annual Allied Professionals Forum by Johanna McDonagh

The 16th Annual Allied Professionals Forum was held in Glasgow on 6th December 2018. This seminar is specifically for allied health and social care professionals. The aim of the day is to foster the exchange of information about good practice and to facilitate the highest standard of care for people with ALS/MND and their carers. The day was broken up into four sections, with four speakers in each section. Overall it was a very interesting and educational seminar and I'd like to share with you highlights from some of the presentations.

Dr. Rachel Tams, Consultant Clinical Neuropsychologist in the UK, presented on 'What do children need when a parent has MND/ALS? A review of existing psychological support interventions and suggestions for further developments.'

The outcomes Dr. Tams hoped the audience would take from the presentation were:

- To have increased awareness of issues affecting children who are living with MND in the family,
- To kick-start thinking about what good support for children might look like,
- To highlight the importance of further research, development of services and networking in this area.

Dr. Tams spoke about the challenges facing children when MND is present in the family. These challenges may include living with a loved one who is experiencing profound and complicated losses. She highlighted how the psychological support needs of children who have a parent with MND have received little attention. We know little about how having a close family member with MND impacts on children, how children cope with the experience of MND in their parent and how best they can be supported.

Dr. Tams discussed the reciprocal relationship between children and their loved one with MND, how the children's reaction can impact their loved one and vice versa. She described children as the 'hidden victims' and stated that in the research literature children appear overlooked in service provision. There is sparse research on children's needs and therefore guidance on how to support them is lacking. Some of the key issues for children she identified are:

- Understanding the diagnosis - its causes and implications.
- Understanding and coping with the changes and gradual loss of the parent.
- Restrictions of life experiences e.g. studying closer to home than they had wanted.
- Fearing the reaction of others when the relative dies.
- Conflicting emotional responses and little life experience to draw on.

Having identified what is lacking in resources for children, Dr. Tams then went on to describe what it is that children need. She explained that based on their clinical experience and wider (but related) research, we know that the relationship between familial illness and how the child copes is complex!

Children's responses can be mediated by a number of positive coping strategies and having age-appropriate information is key. It is important to target other issues central to building resilience - connection, coping and enhancement. Also essential is to identify family information and support needs early after diagnosis in order for us to help the child build capacity to sustain themselves through the process (building family resilience).

Dr. Tams concluded that we need extensive research to guide the context of all this work to ensure it is based on good practice and on the child's lived experience. She feels that positive relational outcomes can be achieved, especially positive personal growth in children and that the challenge for us is to increase children's visibility in service provision, literature, research and clinical practice.

In last years Allied Professionals Forum article we touched on the use of cannabis with MND patients, with a summary of the presentation on cannabis Usage in Symptom Management in MND. This year we explored this further with Gill Craig, Specialist Nurse in MND in the UK, presenting on 'The

Use of cannabis Extract Spray (Sativex) in ALS/MND'.

The three outcomes Gill wanted from the presentation was Understanding cannabis, the Tayside Model and looking to the Future. She began with the basics of what is cannabis:

1. It is a generic term for drugs made from the cannabis plant.
2. An annual dioecious flowering herb indigenous to Central Asia.
3. As a drug cannabis usually comes as a dried flower bud, also known as marijuana, as a resin aka hashish and as various extracts collectively known as hashish oil.

Cannabis plants produce a group of chemicals called cannabinoids. Synthetic cannibinoids are manufactured artificially and an example of this is Sativex, which is a cannabis extract spray.

Gill talked us through a case study from NHS Tayside, which is one of 14 health boards. Tayside has 57 patients living with MND. In this case study the MND patient had presented with uncontrolled spasticity and had a complex symptom burden including pain, stiff limbs, involuntary movement, difficulty moving and painful spasms.

The team had initially followed the NICE (National Institute for Heath and Care Excellence) guidelines. These are evidence-based recommendations for health and care in England which set out the care and services suitable for most people with a specific condition or need, and people in particular circumstances or settings. The team had attempted to treat the symptoms with medication for pain, muscle stiffness and cramps. It took 5 months to trial all available medications, at which point they moved to the final guideline which is to consider referral to specialist service for treatment review. The patient's quality of life over this time was affected by physical, psychological and emotional pain.

In this case they found that cannabis was the solution but there were a number of issues to using this as a treatment plan:

- Cannabis is not licensed in the UK for MND.
- There is only anecdotal evidence of the results.
- The current classification of cannabis is an issue.
- Public/professional perception differs.
- NICE do not recommend the use of cannabis.
- Cost issues related to cannabis.

A plan was devised to allow the patient to safely start using the cannabis extract spray Sativex and after 4 weeks of use the following improvements were noted:

- Cramping and muscle spasms decreased.
- Pain disappeared.
- Improved sleep.
- Appetite and ability for day to day living improved.
- Anxiety decreased.
- Discontinuation of all pharmaceutical medication.

NHS Tayside now have 7 patients on Sativex and they hope to produce other cannabis based treatments which they feel would be ideal for MND.

They would also like to address attitudes and behaviours towards this treatment option. Gill finished by stating that cannabis has been used safely for thousands of years. There are no documented cases of death due to the side effects of cannabis and in any case what possible side effects could cannabis and its derivative have that would make living with unnecessary symptoms the more favoured option.

The next presentation covered a subject that some people still find difficult to discuss, sexuality. In order to have a holistic approach to our health, this topic needs to be covered alongside all the other aspects of our lives.

'Breaking the conspiracy of silence: A presentation for professionals on how to discuss sexuality and intimacy with ALS/MND patients and their partners' was presented by Sandra de Moree from the Netherlands. Sandra began the presentation by explaining that sexuality has a big impact on an individual's quality of life. In cases of a chronic/progressive illness there can be negative consequences for sexual functioning.

Sexuality is an important and problematic issue for a large number of ALS patients and their partners. This topic is rarely discussed in a medical setting. Counselling and information should be made available in order to better address this important aspect of quality of life (Warner et al, 2004).

There are many barriers to talking about sexuality with patients and their partners. Our reaction can be influenced by knowledge, sexual problems, sexual response cycle, MND specific symptoms, how to listen and creative thinking. Another factor can be the health care professional's response/reaction. This can be affected by their personal attitude, awareness, culture, own history and experiences, and sex education. The ideas and opinions of health care professionals

about sex are heavily influenced by their personal experiences. It can also be affected by socially accepted myths by both the patient, their partner and health care professionals.

Sandra discussed how sex is not just about intercourse but also about intimacy and showing affection. For most people it is important and for some even more important especially when you know you have a life-limiting illness. MND does not directly influence sexual functioning and sexual needs do not disappear but things do change due to changes in the relationship. There might be practical problems, adjustment problems and medication. She also pointed out that you cannot rule out patients who are single, they are/can be sexually active on their own or with friends with benefits or otherwise.

Health care professionals should check if there are any issues with the patient's sex life which are a result of their diagnosis like all other life issues. The Health Care Professional could approach the conversation as follows:

1. Is the patient experiencing sexual problems because of MND? If not continue and go on to the next subject.
2. If they are, do they want to discuss it? If not tell them they are welcome to discuss it some other time
3. If they would like to discuss it, explore further and invite them to elaborate.

If the Health Care Professional does not broach the subject the patient should equally feel free to ask questions and start the conversation.

Sandra discussed some factors related to diagnosis which may cause issues in terms of intimacy and some practical solutions to these such as:

Saliva/Swallow problems – you could consult your GP to discuss medication to assist with this issue. Also changing body positions can also really help.

Bodily changes due to muscle atrophy - wearing some clothing could make you feel more confident rather than being totally naked. Maybe try dimming the lights to make you feel more comfortable.

Role change and dependency - communication is really key here. Don't be afraid to ask your partner to take a more active role in sex play.

Practical issues such as less muscle power or fatigue - try adjusting the time of day to suit your energy levels. Also experimenting to find more comfortable body positions or less intense sexual activity might make things more enjoyable.

Finally, there may be a need for new 'recipes' and communication, experimentation and creativity so that touch stays intact.

Research Update by Mark Heverin

Research Study Update: REVEALS- Registry of Endpoints and Validated Experiences in ALS

This study is being undertaken by Research Motor Neuron in collaboration with Cytokinetics (Inc) as part of **TRICALS:** Research into the Course of ALS Registry. It is now in its second year and the recruitment is progressing well. The aim of the study is 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.

To date the study has recruited 180 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 are participating have their respiratory function measured in detail every three months over a period of 18 months. To date, 50 people with MND have been recruited in Ireland. Measurements 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.

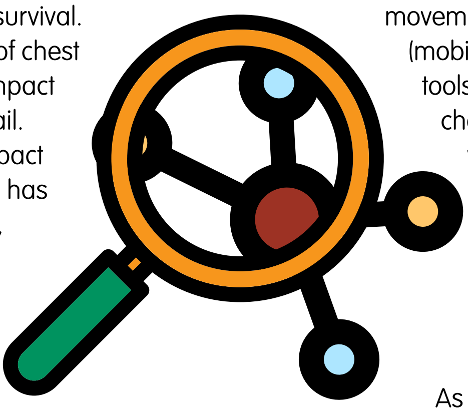
The study is being led by Prof. Orla Hardiman and a team of Physiotherapists (Dr. Deirdre Murray, Dr. Dara Meldrum, Ms Rachel Tattersall, Ms Lauren Fenton and Dr. Jennifer Fortune) and will be completed in the next year.

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.

Developing Sensor Technology based Tools for meaningful measurement of physical functioning in MND

A new study co-funded by RMN and the HRB under the MRCG-HRB scheme commenced in December 2018. Dr. Deirdre Murray, Physiotherapist in Beaumont Hospital is leading the study with a team including a biomedical engineer (Conor Hayden), social researchers (Dr. Muiris Houston and Dr. Miriam Galvin) and Physiotherapy researchers (Dr. Dara Meldrum, Lauren Fenton and Dr. Jennifer Fortune).

The aim of the study is to use new technology and sensors to develop novel, sensitive ways to track physical functioning in MND. We are focusing on measuring hand movement (dexterity), walking and activity (mobility) and breathing. We hope that these tools will allow more sensitive detection of any changes that occur in clinical trials so that we can pick up meaningful changes if a drug is effective. We also hope that there may be potential in the future for remote monitoring so that any significant changes in functioning can be picked up between clinic appointments.



As a first step we are consulting with people with MND and their carers about how they feel about current measurements taken at clinic and in trials (SNIP, FVC, ALSFRS-R questionnaire etc) and their opinion on new measurement options. We are inviting people to take part in focus groups which will be carried out in different locations around the country. We hope that 12 people with MND and 12 carers will take part. If you would like to take part please send a text to the research team expressing your interest with your name to 085-1312292.

Prof. Orla Hardiman takes up new role as Clinical Lead for Neurology with HSE

Prof. Hardiman has taken up a new role as Clinical Lead for Neurology within the HSE Clinical Strategy and Programmes Division. The aim of this Programme is to improve quality, access and value of healthcare in the country. Prof. Hardiman, in collaboration with clinician colleagues and the Neurological Alliance of Ireland, has agreed that the aim of the Neurology programme is that patients should have equitable access to a high quality responsive service which provides accurate diagnosis and appropriate management for all neurological conditions.

As part of this initiative, a Business Case to support a **National Centre for MND** has been submitted to the HSE. The business case recognizes the importance of providing care for those with MND as close to home as possible, while also ensuring the patients have access to expert opinion and care through a sustainable national centre. Working with the IMNDA, Prof. Hardiman, in her capacity as Clinical Lead, will now seek to enhance care for those with MND by incorporating the business plan into the real world delivery of care for MND in the longer term. This will be achieved in 2019 by building the case for support and funding for additional specialist MND nurses to join the existing IMNDA nurses and Nurse Bernie Corr from Beaumont Hospital. These nurses will provide expert outreach and coordination of care. The business plan has also identified the need to support and enhance the multidisciplinary team within the national centre to ensure longer term sustainability, and to build on the expertise that has already been established within the centre.

New collaboration between the MND Research Team at the Academic Unit of Neurology and ADAPT SFI Research Centre.

The MND Research Team is working with a leading computer science centre on two new and exciting projects around developing a precision medicine approach towards new treatments. **The ADAPT Centre** is funded by Science Foundation Ireland, and focuses on developing next generation digital technologies that transform how people communicate by helping to **analyse**, **personalise** and **deliver** digital data more effectively for businesses and individuals. The ADAPT centre is providing high level computer science based expertise to the MND Research Team at Trinity college Dublin, that will help to build a platform as part of a new European initiative to improve clinical trials for patients with MND. This initiative will allow European MND Centres to conduct clinical trials of new compounds in a streamlined and efficient way.

ADAPT researchers are also helping with an international study called **BRAIN-MEND, funded in Ireland by the Health Research Board.** This project is pooling large datasets from across participating countries collected from patients with one of a number of different neurodegenerative conditions including motor neurone disease, Parkinson's disease and Alzheimer's disease. The aim of this study is to better understand the overlap between neurodegenerative conditions. This will in turn will give us a better insight into each of the conditions themselves.

Walk While You Can Funds are Put to Good Use

Funds from Fr.Tony Coote's epic walk from Donegal to Cork have been matched by a private donor to allow the creation of a permanent academic post in MND by the School of Medicine at Trinity College. The post will be called the Fr. Tony Coote Lecturer in MND, and will focus on understanding brain networking changes in MND that could be used to develop new drugs. This position has been advertised and the new lecturer will take up their position in the summer.

Family Caregiver Support Program 2019

We are delighted to announce that thanks to the success of our Drink Tea for MND campaign 2018, we are unveiling a fantastic new program aimed at our primary family caregivers available for 2019.

A "family caregiver" is anyone who provides any type of physical and/or emotional care for someone with MND who is being cared for at home. There are different types of family caregivers:

- Parents
- Adult children
- Spouses
- Family members
- Neighbours
- Friends

Visit imnda.ie to download the booklet and apply

We hope that this new Family Caregiver Support Program will be of benefit to carers right across Ireland over the coming months. We truly respect and appreciate the enormous impact that caregivers have on the lives of their loved ones on a daily basis.

For more information about the program please see our website. We have implemented a range of new initiatives for family caregivers including:

- Respite (both day and night)
- Counselling including bereavement counselling
- Funding towards holistic therapies to give caregivers some much needed 'me time'
- Funding towards everyday household duties such as cleaning
- Transport funding for families who may struggle in meeting the cost of travelling to medical appointments

If you or your main caregiver would like more information on the Family Caregiver Support Program, please do not hesitate to contact Johanna, our Information and Support Officer, on (01) 871 7800 or email services@imnda.ie and put Family Caregiver Support Program in the subject line.

****These funds are limited and only available in 2019***

Introduction to Our New Medical Patron

We are delighted to announce that we have a new medical patron. Professor Peter Bede is a neurologist and an Associate Professor in Trinity College Dublin. He received his PhD from TCD and currently leads a research group focusing on the pathological and imaging features of Motor Neurone Disease. With his team, he collaborates closely with international partners in France, UK and Canada to develop accurate diagnostic, prognostic and monitoring protocols for clinical trials in MND. His main interest is the characterisation of early ALS-associated pathology and disease propagation through advanced neuroimaging.

He is a member of the UK MND Association (MNDA) Research Advisory Panel, the steering committee of Neuroimaging Society in ALS (NISALS) and the American Academy of Neurology (AAN). Peter holds a number of prestigious research grants from national and international funding agencies and his research to date has contributed to the characterisation of extra-motor changes in MND, the contribution of deep brain structures to clinical symptoms, and how cortical patterns of pathology define clinical disability. His vision is to translate emerging academic insights to develop viable therapeutic strategies.

We are really looking forward to working with Peter over the coming few years.

LIVING WITH MND

Planning for the Future

By Rebecca Lloyd, Irish Hospice Foundation

Think ahead
Speak for Yourself

Everyone should plan for the future, regardless of illness, age or stage of life they are in. Thinking about the future can be difficult for us especially when that involves decisions about our end of life. But thinking and communicating our wishes is important and can have long term benefits for us and our families and friends.

We would encourage people with Motor Neurone Disease to talk through options for care and preferences for end of life. Before the need is urgent or before you find it too difficult or tiring to communicate. You can do this by using the Irish Hospice Foundation's Think Ahead booklet. Think Ahead is a guide to help you think, discuss and record your preferences of all aspects of your end of life care.

Think

By using Think Ahead, your wishes will be clear to you, those caring for you and those who manage your care.

We have also produced a booklet to guide you in Planning for the future with the Neurological Alliance of Ireland (NAI). The booklet is a direct result of one of the key recommendations from joint the NAI/IHF report. The booklet contains information on advance healthcare directives, planning legal affairs, palliative care needs and a list of organisations that can help. You can access the booklet from the Irish Hospice website.

Let us talk about thinking and planning ahead

Thinking, planning ahead and advance care planning is a series of conversations with your family and other people close to you about your wishes, values, and beliefs about your current and future medical care and treatment.

It is not a single process. It is easier to manage as a series of tasks and conversations to have over a period of time. Thinking and talking about advance care planning helps you make sure that people who are involved in your life understand your wishes about medical treatment and health care.

Advance Care planning involves; (Think, Talk, Tell, Record and Review)

Think how you understand your wishes. How you might communicate them with those people important to you. These conversations can be a guide if a time comes when you are unable to communicate your own decisions about your health care.

Think about what is important to you. What treatments you would want to have that may prolong your life. What treatments you would not like to have.

Talk

Tell your family, doctor and other health professionals about any medical or health issues you have. Ask about the available treatments. Discuss the choices you would like to make about your medical care. Talk to your solicitor about Enduring Power of Attorney and Power of Attorney, and making a will.

Record your wishes. We have a tool and a programme called Think Ahead which is a useful guide. (Tell someone you have written your preferences down)

Record an advance healthcare directive (there is one in our Think Ahead booklet)

Review your preferences. You may change your mind. For that reason, we encourage you to review your Think Ahead form.

An Advance Healthcare Directive (AHD)

Is a voluntary written document that sets out what you would not like to happen in relation to certain medical care treatments.

An AHD is legally binding (if printed and signed and witnessed).

An AHD can include requests for specific treatment to be taken into consideration during any decision-making process about your care but this is not legally binding.

It is a good idea to discuss your advance healthcare directive with a medical professional or a member of your healthcare team.

An AHD provides direction to healthcare professionals to care for you under your specified wishes.

IMPORTANT: An AHD only comes into force should you lose your capacity to make your own decisions or become ill in specified circumstances, and be unable to communicate for yourself.

To complete an AHD you must be:

- 18 years or older
- Have capacity at the time the AHD is being made
- Have two witnesses over the age of 18, one of whom is not a member of your immediate family
- The Irish Hospice Foundations Think Ahead form includes a legally valid AHD form in line with the 2015 Assisted Decision Making (Capacity) Act

Finally, as Public Engagement officer with the Irish Hospice Foundation, I encourage everyone to read the excellent book 'Being Mortal' by Atul Gawande. What is noteworthy in the book is that planning ahead is paramount to ensure our wishes are heard and understood.

Tell

Gawande advocates for the difficult conversations, to talk about what you want for yourself, if your care is an issue, or what your parent/friend/spouse/relation wants well before we find ourselves in a crisis situation. It may be uncomfortable, but it is important.

'Being Mortal' not only offers sage advice on planning for outcomes that we all face sooner or later, but Gawande manages these topics with humour and transparency that is refreshing and useful.

In his own words;

> *"We think our job is to ensure health and survival. But really it is larger than that. It is to enable well-being. And well-being is about the reasons one wishes to be alive. Those reasons matter not just at the end of life, or when debility comes, but all along the way. Whenever serious sickness or injury strikes and your body or mind breaks down, the vital questions are the same: What is your understanding of the situation and its potential outcomes? What are your fears and what are your hopes? What are the trade-offs you are willing to make and not willing to make? And what is the course of action that best serves this understanding?"*

Atul Gawande, Being Mortal: Medicine and What Matters in the End

For more information on Think Ahead – visit our website **www.hospicefoundation.ie/thinkahead**

Record

To get further information about having a think ahead session in your community please contact Rebecca at **Rebecca.Lloyd@hospicefoundation.ie**

The Irish Hospice Foundation is the national charity concerned with all matters relating to dying, death and bereavement in Ireland.

Review

Caring for someone with Motor Neurone Disease By Norah Murphy

My husband Vincent was diagnosed with Motor Neurone Disease in 2016, by Professor Orla Hardiman. From diagnosis we have had a very positive relationship with Dr. Hardiman's team. Especially Dr. Eoin Finnegan and our assigned link nurse Katie Kinsella who have been a constant source of help and support.

His diagnosis was the biggest shock of my life and I responded to it by spending every day trying to keep upbeat in front of him, motivating him to carry on to do as much as he could for himself and trying to keep everything normal for everyone else, including our adult children, their families and our friends. All the while I was lying awake at night trying to process his diagnosis and new information and imagining our changed future together. At that time the outlook was terrifying for me.

Vincent handled things differently to me. In the beginning he didn't seem to take the diagnosis too seriously for about a year and neither of us knew anyone who had it, except from the late Colm Murray, the RTE sports presenter, who passed away in 2013, from seeing him on television.

As the disease progressed, I noticed changes in him. After the first year I noticed he was getting very down in himself and there were lots of days he wouldn't speak to me at all, but if someone came into the house he would brighten up, but that would be short lived. Other days he would get up in the morning and then go back to bed and stay there all day and that was very worrying.

I didn't know what to do so one day I told our GP, AnneMarie O'Brien, in her surgery how bad things were. She could see how the whole thing was impacting on me. I was at my wits end back then so she made an appointment for Vincent and I to see a psychiatrist, Dr. Gormley. It was Dr. Gormley who referred us to St Brigid's Care Centre, a place I had heard of but though it was only for wheelchair users. He started attending on 8th of September 2017.

Our district health nurse, Ann Young, of Taghmon, organised for him to go there and when I offered to drive him I was told firmly but kindly that going on the bus was part of Vincent's therapy. As I waved him off on the bus that day my heart was breaking. It was one of the lowest points I had and I remember spending the rest of the day in the house crying. I now know I was also grieving for the life I thought we might have had together, having raised our children and imagining a nice normal life together. That day I also felt so guilty like I was putting him away and I kept thinking that at any moment a phone call would come to say that I should come and get him. But to my big surprise when he arrived home that evening he almost galloped into the house, telling me all about what he had been up to and what a lovely day he had and all that went on, plenty of chat and laughs including some singing and the overall care he had experienced from everyone, including the bus drivers and helpers.

At first he went there two days a week. That gave me a bit of time to myself and I hadn't realised how much I needed that. It helped us both so much. When I plucked up the courage to go on holiday by myself I also encouraged him to avail of another day just to break up the week for him when I was away. At first he didn't see any reason to do so but eventually he came around to the idea and loved it.

When I came back from my short holiday he had loads to tell me and he began going for a third day and when an appointment clashed with his days in St. Brigid's a week later I had to cancel it and reschedule as he wasn't going to miss a day there. He was so happy and it was great to see him so positive and upbeat, thank God. For the first time in a long time I felt more positive about his diagnosis.

I am so thankful as well for all the people in our lives who come in and out of our home to help Vincent. We could never manage without them. They are so kind and caring, all of them and they help Vincent every day by continuing to motivate him to do as much for himself as he can.

Recently he celebrated his 84th birthday and as well as his wonderful family birthday in a local hotel, the staff of St. Brigid's arranged a party for him and it even made the local paper. I will treasure that photograph forever.

I have to admit that I could never have imagined how the St. Brigit's Centre has positively influenced both our wellbeings and it frightens me sometimes to think about all we would have missed out on if we hadn't engaged with this wonderful service.

Battle Hard By Andy Minogue

"The words cover most of how I have coped over the difficult past few years. I hope these words can help others, as they have helped me," Andy Minogue – living with MND

B is for Busy. Keep yourself occupied in some way or other particularly if you had to leave work
A is for Acceptance. Once you accept the illness, you can move on with your life
T is for Targets. Give yourself something to complete or achieve
T is for Treats. Treat yourself! Go to that show or buy new clothes or whatever it is you want
L is for Letting Go. Let go of what you can no longer do but do not look back in anger
E is for Exercise. Do whatever you can do for as long as you can

H is for Headspace. Get your head right in order to face this battle, seek professional advice
A is for Adjustment. Make adjustments, which make your life easier and less stressful
R is for Rest. Take time out for a lie down every afternoon or evening - you will need it!
D is for Diet. A good healthy and nutritious diet is important for anyone with illness

Non-Invasive Ventilation Explained

You might have heard the term Non-Invasive Ventilation discussed or mentioned at an appointment or come across the term online. Bernie Corr, is the MND Nurse Specialist in Beaumont Hospital and a face many will recognise. Below she discusses these terms and their implications.

Non Invasive Ventilation by Bernie Corr

Motor Neurone Disease is a progressive neurological condition that attacks the motor neurons in the brain and spinal cord. This means messages gradually stop reaching the muscles, which leads to weakness and wasting of the muscles. The respiratory muscles used for breathing are also affected.

Breathing:

Breathing is the process of moving air into and out of the lungs to facilitate gas exchange by bringing in oxygen and breathing out carbon dioxide.

The lungs are springy and elastic so your muscles need to work to expand your chest and draw air into your lungs. Signals from your brain travel down nerves to your diaphragm and other respiratory muscles. The diaphragm is pulled down flat, pushing out the lower rib cage and abdomen. At the same time, the muscles between your ribs, (the intercostal muscles), pull your rib cage up and out. This expands the chest and draws air into the lungs. The air is pulled in through your nose and/or mouth, and into you windpipe (trachea). The windpipe divides into airways supplying the right and left lung.

Breathing out is mostly a passive process. After you breathe in the muscles relax and the lungs push the air out. The system works so that you breathe in and out comfortably, you may not be conscious of your breathing when relaxing and notice that during exercise you take in bigger breathes and breathe faster.

Beaumont Hospital MND Clinic:

When you attend the MND multidisciplinary clinic in Beaumont hospital, we routinely measure your breathing function. Regular monitoring allows breathing muscle weakness to be identified early and strategies such as Non-invasive ventilation (NIV) can be offered before an emergency situation occurs. As the presence of weakness in the muscles for breathing may be subtle we need to check if you are experiencing any of the symptoms we know are caused by respiratory insufficiency. The symptoms may include: Poor sleep, nightmares, fatigue, morning headaches, daytime sleepiness, poor concentration, voice becoming faint, difficulty breathing when lying flat, breathlessness on exertion.

Non-invasive ventilation:

Non-invasive ventilation (NIV) or Non-invasive positive pressure ventilation (NIPPV) refers to a method of providing breathing support to a person without placing an artificial airway into the windpipe, (trachea). This is usually achieved by fitting a mask specifically selected to fit your face, covering the nose, or covering the nose and mouth which is connected to a machine that helps with breathing by tubing. The ventilator settings are prescribed by the Consultant Neurologist or Respiratory Consultant.

Those with MND who attend the specialist clinic in Beaumont are regularly assessed for problems with breathing. If changes in breathing are identified, we offer an outreach service that provides non invasive ventilation in a home setting, this is performed by myself. Once we have established that the person is likely to benefit from NIV, I along with an expert representative from one of the companies that supplies breathing machines will arrange a time that is suitable to commence a trial of NIV at home. During the visit, the person with MND is shown how to use the NIV and how to maintain the machine.

The cost of renting the machine is covered by your Medical card or the drug refund scheme.

A very close working relationship has developed between the MND team, the pulmonary function department in Beaumont hospital and the company who provide the non-invasive ventilator. This collaboration ensures that people are fast tracked for trial of NIV and receive training in the comfort of their own home, with plenty of time for questions and the opportunity to try different types of face masks. The company also provides a phone advisory service, twenty four hour back up and a home visiting service if required to identify and resolve any issues that may arise.

You will be issued with:

NIV Machine (with a power lead): Mask (with headset): Tubing, Filters and a Carry Bag. The NIV machine has an inbuilt battery. The NIV should be kept plugged in at all times to keep the battery charged. The NIV can run off the battery for five to six hours.

Using the NIV Machine:

The prescribed settings are set and locked into the machine. Put the mask on first, then to turn on the machine press the power button once and to turn it off press the power button twice.

To clean the machine and mask: Wipe the mask before use with a damp cloth, do not use wipes. Weekly wash the mask in warm water and towel dry. The tubing is also washed weekly, rinse warm water through the tube and hang over a shower or door to dry. Masks and tubing should be dried fully before use. Change the filter once a month. To clean the machine, wipe with a clean damp cloth and then dry with a soft cloth. Do not use any cleaning agents and do not immerse the machine in water. As masks and machines may differ ensure to follow specific instructions given by your Respi Care technicians.

For some people initially it can be a little challenging to tolerate the NIV for long periods or throughout the night. We recommend using it for short periods during the day, perhaps while watching TV or listening to the radio to get used to it and build confidence. Sometimes we may prescribe medication to help relax the person when commencing on NIV.

Factors that adversely affect the ability to tolerate NIV include the presence of bulbar symptoms, the ability to manually adjust the mask and the presence of cognitive impairment.

Common problems associated with using NIV include:

Mask seal problems: A leak may occur around the mask or into the eyes which may be problematic. You can adjust the headset or try a different mask, there are many to choose from.

Soreness on the bridge of the nose: Soreness on the bridge of the nose is often an indication that the mask is too tight at the top. The mask can be refitted or changed. A specific very thin dressing can be put on the bridge of the nose to help relieve the pressure.

Mouth Dryness: A dry mouth is very common, especially if tolerating NIV through the night. We can provide a humidification chamber which can be attached to the NIV machine.

Aerophagia, this is a condition in which the patient may feel gastrointestinal discomfort, a feeling of being full of wind with the tummy feeling bloated. This problem usually disappears after a few weeks of starting NIV. If the discomfort continues we can prescribe medication to reduce the symptoms.

Palliative Care:

Everyone's experience of MND is different. Therefore the management of MND is an individualised symptomatic palliative approach from the time of diagnosis through the course of the illness. Many people think that palliative care is only available to people who are soon to die. However, the aim of palliative care is to maximise the quality of life of people with life limiting progressive conditions and their families, by relieving symptoms, promoting comfort and providing emotional and psychological support. If community palliative care services are not in place when setting up NIV we will request that the GP makes a referral.

Planning for the future:

The setting up of NIV at home can often facilitate an opportunity to determine a person's wishes regarding their ongoing future care. It can be very difficult for people with MND and their families to discuss what may happen in the future. Although it can be difficult to plan in advance for ones end of life care, if we don't have these difficult discussions we may never know the person's wishes. Everyone's experience of MND is different and so are their needs. It is extremely important for people to understand what treatment options are available to them and for their choices to be heard by those who provide their care. It may help to have a discussion, make a plan and then get on with living with MND. The Irish Hospice Foundation developed a Think Ahead Form. The purpose of the Think Ahead Form is to help members of the public talk about and record their preference in the event of emergency, serious illness or death. This form can be down loaded at www.hospicefoundation.ie.

Non Invasive ventilation has been shown to improve symptoms caused by respiratory weakness, increase quality of life and prolong survival, particularly in people who are compliant in using NIV for over five hours at night, during sleep. Research has shown that it is best to introduce a trial of NIV early to enable the person develop confidence and feel comfortable while on the machine.

If you would like more information regarding NIV or would like to see if you would be suitable for a trial of NIV please contact me:

Bernie Corr, Motor Neurone Disease Clinical Nurse Specialist,
Beaumont Hospital
Call 087-2110663

Nippy Ventilator by Respicare

RespiCare

Positive pressure ventilation is a process of assisting a patient's respiratory effort by introducing a positive pressure (blowing) into the airway. The simplest form of positive pressure ventilation is Continuous Positive Airway Pressure (CPAP) which is used simply to support the airway during normal breathing. For some respiratory disorders, a greater level of support is required and this is normally achieved by providing a higher pressure when inhaling and a lower pressure to support the airway when exhaling. This is known as intermittent positive pressure ventilation.

In an intensive care unit, critical care ventilation is often provided by introducing a tube into the patient's airway. This is known as invasive ventilation. When ventilation is provided without introducing an artificial airway (eg using a mask) it is referred to as non-invasive ventilation (NIV).

The first Nippy Ventilator was introduced in the early 1990's and was simple called Nippy (now known as Nippy 1). The name was taken from the type of ventilation provided Non Invasive Intermittent Positive Pressure Ventilation. Wherever you see the name displayed on the device or on any of the manufacturer's literature, you will notice that it is actually NIPPV with the 'V' made into a 'Y'. This first model simply provided positive pressure when inhaling and no pressure when exhaling.

In 1996, the Nippy 2 was introduced and provided two pressures – a higher pressure when inhaling and a lower pressure when exhaling.

In 2003, the Nippy 3 was developed and was followed in 2007 by the current model – Nippy 3+. This new device is quieter, lighter, offers more modes and features but essentially the therapy principal has remained the same.

RespiCare Ltd

RespiCare was established in June 1998 and began operating as a Home Service Provider to patients using non invasive ventilation in Ireland and Northern Ireland The range of equipment, devices and accessories we provide has expanded over the past 20 years but our main product has always been our home service to clients with respiratory and neuromuscular diseases.

Our first involvement with the IMNDA and with Bernie Corr was in September 1999 when a patient was discharged from hospital using a Nippy 2 Ventilator. We have been working closely with Professor Orla Hardiman, Bernie Corr, the IMNDA and the staff at Beaumont Hospital for many years now. In recent years, our service has expanded to include the Clearway Cough Assist device for secretion clearance which we see as an extension to NIV therapy

We are delighted to be a small part of the excellent service provided by the MND team and hope that we can continue to do so in the future.

My Journey with Motor Neurone Disease by Mairead Coleman

Sometimes Silence Speaks Volumes

Imagine an hour…a day….a week without speech. Imagine not being able to say 'I love you' on 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**. Mairéad Coleman bravely fronted the campaign for us. Here is her story.

My name is Mairéad Coleman, from near Roundfort, Co. Mayo. I'm married to Michael and we have two children, Cian and Hannah. Our son Cian passed away in February 2013 aged 16 years after a two-year battle with cancer, Osteosarcoma. Our daughter Hannah is now aged 20 years and is doing Health & Social care in Letterkenny.

I was diagnosed with Bulbar Palsy, Motor Neurone Disease in August 2017 by Dr. Michael Hennessy, Galway.

My first indication that something was not quite right with my health was one evening at a Fundraising event for the Mayo Roscommon Hospice, I was chatting and suddenly I began to slur my words. I was so embarrassed as I only had one glass of Prosecco and knew it couldn't be that!! That was December 2016. Prior to this, I had a couple of nasty colds and chest infections since September 2016 which I would never have had before. I was always well with the usual colds and flu's everyone gets. I was also extremely tired all the time but put that down to working too hard and so kept going.

In December 2016, my husband suggested I go to my doctor as he was beginning to notice an occasional slurring of words and knew I wasn't myself. So I had a visit with my doctor and described my symptoms and history of my health since September. She decided to put me on a round of antibiotics and sent a request for a chest x-ray, which I had done in the first week of January 2017. I returned to my doctor as I was still not feeling well and I was told I had old Pneumonia in my left lung, which needed to be treated.

And so it began, three rounds of antibiotics, bloods taken and my speech still slurring, I suggested to my doctor that maybe there was something neurological going on!! I had no idea what that meant or why I even suggested it, but in my own head I thought maybe I was suffering from delayed Post Traumatic Stress, as a result of my son Cian's illness and death and I thought that it may be effecting my speech. When my doctor suggested making an appointment with Dr. Hennessy Neurologist, I agreed hoping that I would be sorted in no time. Whilst waiting for an appointment, my doctor also suggested that I have a lung function test, sleep apnoea test and a blood test to rule out myasthenia gravis which was done in the Galway Clinic in April 2017. The results at that time were negative of myasthenia gravis and no fasciculation's noted. My appointment to see Dr. Hennessy was set for August 2017 and between April and August, I was in reasonably good health but my speech was becoming more noticeably slurred and I was having episodes of shortness of breath and fatigue.

I went to see Dr. Hennessy in August 2017 and he carried out a Nerve Conduction study which I understand was normal at that time. He also carried out some visual test, looking into my mouth where he saw some fasciculation of my tongue. He decided to treat me for myasthenia gravis just to rule it out fully and called me back to see him in September. At this visit Dr. Hennessy confirmed that myasthenia gravis was not an issue as the medication prescribed had no effect on my symptoms. It was at this consultation that Dr. Hennessy began to suspect Bulbar Palsy MND and so recommended I attend his clinic for MND patients. I was still holding out hope that I was just suffering from PTS although I was told that my symptoms were not typical of PTS.

In October of 2017 I attended my first MND clinic where my diagnosis was indeed confirmed and so I was introduced to various support networks such as Speech Therapist, Physiotherapist, Dr. Rutherford Respiratory consultant, Teresa my liaison nurse and of course Dr. Hennessy. I was immediately put on Riluzole the only known medication to work at suppressing the nervous system and hopefully slow progression.

That day was very, very difficult. I attended the clinic alone even though Michael, my husband really wanted to come with me but I wanted to protect him and told him I wouldn't be told anything bad even though in my heart I knew. I called Michael immediately after clinic and arranged to meet him for lunch where I gave him the dreaded news. He was inconsolable!! He couldn't believe that this was happening again to our family. For me, whilst I was shocked and very disappointed with the diagnosis, the worst had already happened to my family, the loss of our son Cian. He only had 16years on this earth while I have had 50years so far. I didn't feel sorry for myself but I was heartbroken for my husband Michael and my daughter Hannah. Numerous things were running through my head!! How will Michael and Hannah cope with this again? Will I see Hannah get married and meet her children, my grandchildren? Our small family of four will become two. It's so unfair on Michael and Hannah. They were my first thoughts.

Michael and I decided to tell Hannah when we got home and decided not to tell any other family members until we grieved the diagnosis. We talked it out, cried it out and then after a couple of weeks told our families and close friends. Everyone was in shock and couldn't believe what our family had to face for a second time. For me it was important that I received positive support rather than sympathy. I am a very active, positive person who tries to enjoy life; even after all we have been through already. So once the news got out into the community, I insisted on telling everyone that whilst I have received a diagnosis of MND, I'm still me and I'm going to continue doing what I do until I can't, end of!!

Everyone has a bucket list, some of it we get around to doing and some of it we don't. I was told that because I have Bulbar Palsy MND, it primarily affects my lungs, swallowing, breathing and fatigue so I decided to put a plan in place to do some of things I wanted to do. I continued to work my part-time day job and my therapy work as a Reflexologist and Bio-Energy therapist from home. Our first adventure was to go to our friends wedding in Italy, then Dubai in the December 2017. Thankfully I was well for these trips and just paced myself and rested when I needed to. Once I came home from Dubai, I got a nasty chest infection and had to have a few rounds of antibiotics and steroids. This set me back a lot and it took a lot out of me and for the first time I had to take a step back from work as my speech was pretty poor and I was really fatigued. This was the first time that I really felt the effects of my conditions and reality kicked in. I realised that I needed to start looking after myself and allow my body to recover from the shock of my diagnosis and start to build up my immune system and rest. This was one of the hardest decisions I had to make, giving up my day job and my therapy work. My therapy work was the hardest decision I had to make as I absolutely loved working with my clients and all from the comfort of my own home. It was only when I stepped back that I realised how tired and run down I was so it was a necessary that I stepped back from my work not only for myself but for Michael and Hannah. I want to be here for as long as I possibly can and more importantly, I want to be here for Michael and Hannah.

In February 2018, we were given the opportunity to travel to Cape Town, South Africa with family and in April we travelled to New Zealand to see my sister. I was lucky that I was well enough to do these trips when I did because I have deteriorated a little over the year to a point where I was put on a Nippy machine at night, which gives my lungs a rest at night and allows me to have a restful night's sleep. This started in June 2018.

In September 2018, I got another bad chest infection which took over four weeks to clear with the help of antibiotics and steroids and because of this I was also given a cough assist machine with a suction pump which helps clear my lungs. I also had to have a hospital bed put into my bedroom as I find it difficult to breathe on a flat bed even with two pillows. This had a huge impact on Michael and I as this was the first time I had to sleep on my own and for Michael it was very upsetting. For us it was another step in the wrong direction and another sign of deteriorated. The muscles in my mouth including my tongue are very weak and so I need to use the machines every day, morning and evening to keep my chest clear.

For me all of this takes up a lot of my day when I should be doing other things but it is a necessary evil and these machines help keep me well. Along the way I have had various medications prescribed to help with my breathing and in October 2018 I had a feeding tube inserted. This was decided upon because of the reoccurring chest infections, which indicate that I am silently aspirating which is not good. Thankfully I have maintained my weight throughout my illness and this is very positive and so for the first time in my life I don't have to worry about what calories I'm taking and I can eat what I like. In saying that there are foods I have to avoid like crummy biscuits, brown bread, salads as my tongue doesn't allow me to manipulate food around my mouth which can cause severe coughing and choking so that needs to be avoided of course.

I have had a rough few months battling with chest infections and breathing issues and so this month January 2019 I'm being introduced to peg feed and therefore I will not be eating by mouth for the most part but I can enjoy some foods from time to time.

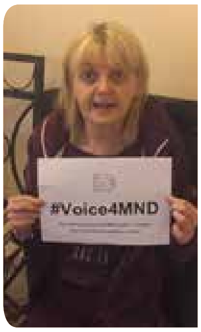
One of the first things that was suggested to me was to register with the MND association, which I did, and within a few days, I received a call from Fidelma the MND Nurse and we arranged a home visit. Fidelma was wonderful answering all my questions, which were flying around my head, and she really put my mind at ease whilst being completely honest with me too. Fidelma is always at the end of the phone and visits me when I need a chat or to organise my medical needs with Galway and Beaumont. She has organised getting all the breathing machines, hospital bed and anything else I need and always within a few days. She is an invaluable resource to have and always has the patient's interest at heart. She is my number one go to person.

As you can see, there is a huge impact on my life having been diagnosed with MND. My choices have been limited, what I eat and drink, travelling abroad by plane is now a past leisure activity with my family. I have to bring my nippy machine and cough assist with me when travelling anywhere overnight. I have to ensure that I always have my medications with me. Letters from my consultant, doctor detailing what I have and the letters from the suppliers of my machines to allow me to bring them with me when travelling abroad. From now on my travelling will be by car or boat. My everyday life is restricted in lots of ways. I have to avoid family, friends and people in general who have colds, flu's or any kind of illness because for me when I get an infection, it escalates my illness, therefore my freedom is restricted. I have to constantly ask everyone that I meet or call to my door if they have an infection of any kind and if they do, I have to turn them away which I find extremely hard to do but for me, it would be unfair to my family if I don't protect myself and reduce the risk of getting an infection that I may not be able to fight.

For now I am doing very well albeit I am susceptible to infection easily but I live my life and treasure my family and friends who support me and surprise me all the time with their constant friendship and understanding. I am very positive when it comes to my illness and embraces the changes it has made to my life. Don't get me wrong, sometimes I have meltdowns like everyone else but for the most part, I'm enjoying my family, my friends, my life so bring it on!!! I'll keep fighting until I can't fight anymore.

From all at the IMNDA, we just want to say a massive heartfelt thank you to Mairéad. Her courage and spirit throughout the campaign was amazing. Her infectious enthusiasm and dedication had not only all of Mayo buttoning the lip but the rest of Ireland followed suit. Mairéad really went above and beyond – the donations are still pouring in.

But Mairéad was 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!!!



"Silence is golden or so the song goes. For those of us with MND, it is one of our woes. But with the help and support of IMNDA we'll still have a voice when our own ceases to be," Angie Byrne, living with Motor Neurone Disease in Blessington, Co Wicklow.

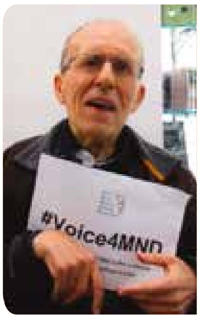
"Losing your voice is like losing your vote. You have things to say but no one to listen," Audrey Purcell in Palmerston, Dublin 20.

"My speech deficit is very frustrating. But your time & patience help me to communicate," Mary Hall in Bishopstown, Co Cork.

"There are those that say I talk too much. I don't think there is anyone who wouldn't like to hear me speak again. Support this appeal for when you will not hear me at ALL," Michael Clancy, living with Motor Neurone Disease in Castletroy, Limerick.

"I was diagnosed with motor neurone disease six years ago. The tone of my voice has completely changed and I worry about losing it all the time. I have already lost my mobility and to lose my voice would make a great change in the quality of my life," Veronica O'Brien in Ferrybank, Co Waterford.

"I was diagnosed in July 2017. I have lost the use of my legs and hands. Soon I will lose my voice. Will you be my voice?" Tom Guckian, Co Leitrim. Since sharing his words with us for the Sponsored Silence #Voice4MND, Tom sadly passed away. His family still wanted his brave story shared. May he rest in peace.



"I decided early on that I was going to fight this disease. Every day I face new challenges. I lost my voice within a year or two. Up to then I took my voice for granted. Initially, much to the frustration of others, I scribbled on pieces of paper. I'm right handed by nature. As a result of a fall I lost dexterity in my right hand. I now use one finger on my left hand to type on an IPad. My IPad goes everywhere with me. I still get frustrated from time to time. There is a delay in my replies. The conversation often runs ahead of me. I type ahead of most anticipated encounters with other humans. It's the only way I keep abreast in conversations. It's tiring at times. Be grateful that you can speak!" Pat Walsh in Rochestown, Co Cork.

Thanks to 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. 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!

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

Still jumping the gun

Our Tea Event Ambassador, **Roy Taylor** is a national treasure. And that's not just because he represented Ireland in Eurovision in 1988 with a great band and a terrific song. It's because he's a force for good. He's a giver, a motivator, an encourager. His infectious positivity isn't just visible in how he talks and connects with loved ones and strangers. It defines him. It's as if his optimism is in his DNA. And it's all the more extraordinary when you learn that just one year ago, he received the stark diagnosis of Motor Neurone Disease.

For Roy and his family, the moment of diagnosis was a catastrophic and terrifying one – as it is for most people with MND. Roy's brother-in-law had died from MND, so there was no hiding from the tough and uncompromising road that lay ahead.

But within a few months, Roy felt he had the measure of the disease – it's like he's now treating MND as a fierce opponent. He knows the tough fight ahead, but Roy is dictating the pace and tactics – and crucially, the number of rounds.

Roy also knows, everyone deals with the condition differently:

"We're all made differently. People have different strengths and different support networks. My family and friends really are amazing. But not everyone has that. It's everyone's right to live with the disease as they see fit. I just try to instill a positive attitude around living the best life we can within whatever limits we have."

Roy's extraordinary wife, Lisa, describes him in a very moving way:

"He is truly an amazing husband, father, friend. He is trying to be brave for everybody – sometimes he seems like the strongest guy in the whole world. But I know he feels the darker moments too. Honestly you could go from here to the end of the world and nobody would say a bad word about him."

Roy is passionate about music. He talks about his busy and successful career:

"I've been a musician for most of my life. As a kid, I worked in an electrical appliance company and one day, I met a friend who suggested I should contact people in the music industry. I went into a phone box outside Dunnes Stores on George's Street and I called a showband agency. I sent in a tape and photo and, low and behold, I was picked. Suddenly – I was a member of the Nevada Show - band."

He had lots of other music projects on the go. He formed the band Jump The Gun with some friends. Then his career took another turning point:

Thanks to Johnny Logan's win in Brussels in 1987, Dublin hosted the following year's Eurovision song contest. 'Take Him Home', performed by Jump The Gun, was chosen to represent Ireland. That meant a higher profile and more touring.

Recently, MND has begun to limit his ability to perform:

"Unfortunately, I had to stop playing bass last October. But I still sing – I sit on a stool because I've respiratory problems."

Roy copes by being Roy. By being active. And advocating for funding. And he says, of course, he has tough moments.

"I worry about not being around for my children and grandchildren. I've one leg and one arm that are much weaker now. And I've problems breathing. Going up stairs is really difficult for me."

Roy's support for Drink Tea For MND means the message for better services and research is reaching more people and he is motivating people all over the country to host an event:

"It's so Irish – to gather around and drink tea. And at those important moments. Crisis, happiness, birthdays, funerals – if the Russians invade us, the first thing the government will do is remind us all to have a cup of tea. I hope lots of people out there host an event. It's so easy and the funding is so crucial."

MND is part of his life now – but only a part. His positivity spreads – just like his generous spirit does – wherever he goes.

"Despite the huge challenge of living with a distressing illness that may end my life early, when I hear of Irish people gathering and having fun over a tea or coffee – to help people like me and our extraordinary caregivers – it brings joy to my heart. You have no idea how much it means to us."

So, Roy continues to live life to the full. He's still immersed in his family. Still advocating for patients and for funding for research and new treatments. He's still active in music. He still drives his car.

In fact, you get the sense from Roy that in spite of Motor Neurone Disease, he'll continue motoring. The neurons can take care of themselves.

FUNDRAISING

Drink Tea for MND!!!

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 at fundraising@Imnda.ie or freefone 1800 403 403.

As we have already mentioned, Roy Taylor 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 Roy. 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. To register and hold a Tea Day simply visit www.imnda.ie – for more info please call Jackie or Gemma on 1800 403 403 or email fundraising@imnda.ie

Let's Drink Tea for MND!!

DRINK TEA FOR MND

JUNE 21

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

IRISH MOTOR NEURONE DISEASE ASSOCIATION

This June 21st, get ready for a cup of something really special!

To register, please fill in your details below and return this form to us in the Freepost envelope enclosed. **Thank you!**

I'M HOLDING A TEA DAY WITH IMNDA!

Contact Name: ....

Organisation Name: ....

Address: ....

....

....

Contact Number: ....

Email Address: ....

Date of Tea Party: ....

Event / Tea Party Location: ....

Tick the options below!

☐ I am happy to hear from you via phone.

☐ I am happy to hear from you via email.

☐ I can't host a 'Drink Tea for MND' event but I want to support IMNDA with a donation of:

☐ **€40** ☐ **€100** ☐ **€250*** ☐ **€500*** ☐ **Other €** ☐

**If you are a taxpayer, a gift of €250 or more in one year could be worth an extra 45% (€112) to IMNDA - at no extra cost to you!*

I enclose a cheque/postal order OR please debit my: **Visa / Visa DEBIT / MasterCard** *(Please circle)*

Card Number ☐☐☐☐ ☐☐☐☐ ☐☐☐☐ ☐☐☐☐

Security Code ☐☐☐ **Expiry Date** ☐☐ / ☐☐

Signature ____________________ **Date** ____________________

You can also register online at www.imnda.ie or call us on 01 873 0422

facebook.com/IrishMND2011 @IMNDA

For information on how we store and use your data please refer to our Privacy Statement on www.imnda.ie

☐ We greatly value your support and would like to keep you informed about our work. Please tick the box if you would prefer not to receive post from IMNDA.

The amazing power of your support ... and a good cup of tea

Last year, Róisín Foley from Drimnagh was our amazing Drink Tea For MND ambassador. This brave single mother of three beautiful girls has been living with Motor Neurone Disease since September 2017. On her 30th birthday, Róisín noticed her hands were weak and she was having difficulty tying her laces. Then, after months of tests, she was diagnosed with MND.

"I was rapidly changing and I could see my family getting worried. My eldest daughter, Rachel, had had to do her younger sisters' hair in the morning and had to unlock the front door for me as I couldn't get a grip of the key," said Róisín.

Last year Róisín decided to share her story about living with this degenerative and debilitating disease in the hope that greater awareness would raise vital funds for those living with this terminal condition.

And, thanks to Róisín's encouragement, over 310 people did just that. They baked and brewed and helped spread the word about MND. We want to thank Róisín and everyone who took part because your support really does change lives.

All over Ireland, from Donegal to Dublin and from Cavan to Cork, people held Drink Tea For MND events and the results were just tea-tastic.

> "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"
>
> – Róisín Foley

You raised an incredible €200,000. Thank you so much.

Thanks to the phenomenal amount raised from Drink Tea for MND last year, we are now able to support the vital role of our primary caregivers through the 'Family Caregiver Support Program 2019' in the following ways:

- Day and night respite
- Counselling – including bereavement counselling
- Funding towards holistic therapies – to give caregivers some much needed 'me time'
- Funding towards essential everyday household duties such as cleaning
- Transport funding for families who may struggle travelling to medical appointments

This year we want you to help us make an even bigger difference for families living with MND.

So let's put the kettle on and make this the biggest and best

DRINK TEA FOR MND ever.

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.

COFFEE MORNINGS

Helen Traynor and Family held a very successful coffee morning in the Scouts Hall in Castleblayney in memory of Helen's Mother, Marie Murphy. There was huge attendance and a very enjoyable day was had. Helen's husband, Philip also took part in the Dublin City Marathon to support their fundraising. Together they raised over €13,000. Amazing stuff! Thank you so much.

Thank you to Minister Joe McHugh who hosted a coffee morning in Letterkenny, it was a lovely afternoon with plenty of treats and chat on offer! They brewed up a fantastic €1,077! The IMNDA would also like to thank Charlie Boyle for attending the event on our behalf.

FUN-RAISING

Every Christmas, employees from Eli Lilly in Kinsale carry out various fundraising events to raise money for charity. The Charity Committee kindly selected the IMNDA as one of the charities to receive a donation from their 2018 fundraising. IMNDA Secretary, Katie Hallisey was delighted to accept a cheque from their fundraising efforts for a truly amazing €5,668.67. Thank you so much to all involved!

Big thanks to Carrigdhoun Comhaltas based in Carrigaline, Co Cork who chose the IMNDA to benefit from their annual Wren Festival on St. Stephens Day. The festival is very popular with the local Cork people who turned out in large numbers to support. The parade included 'Strawboys' in straw suits and Wren Boys who danced and played music with the South Union Hunt who followed behind on horseback. A superb €1,106 was collected on the day! Special thanks to all who supported and the volunteers who generously gave up their time to collect on the day.

Thank you so much to all the staff and students from Monaghan Collegiate School who organised various fundraising events, such as a Christmas jumper day, talent show and choir performance and raised a brilliant €1,520.20!

Well done to Leon Blanche and all from Boylesports and the Evening Herald who raised a fantastic €1,100 from their annual 'Beat the Bookie' event. Super stuff!

Jennifer Mullholland and colleagues from Abbott Diagnostics in Longford organised lots of fundraising activities such as a cycle, table quiz, ice bucket challenge and a monster raffle. They went above and beyond and raised an amazing €12,000! Well done to all involved, we are deeply grateful.

Thank you to the transition year students from Loreto in Clonmel for bringing some festive cheer to the town as they sang beautiful Christmas carols at the Main Guard in the centre of Clonmel. They also held a raffle at their market day and raised a brilliant €400 overall!

The IMNDA would like to say a big thanks to the McMahon Family from Kildare, their support has been incredible. They handed over a cheque for the fantastic amount of €4,578.24 raised from various Church Gate collections. Thank you all so much for your continued support!

DANCES

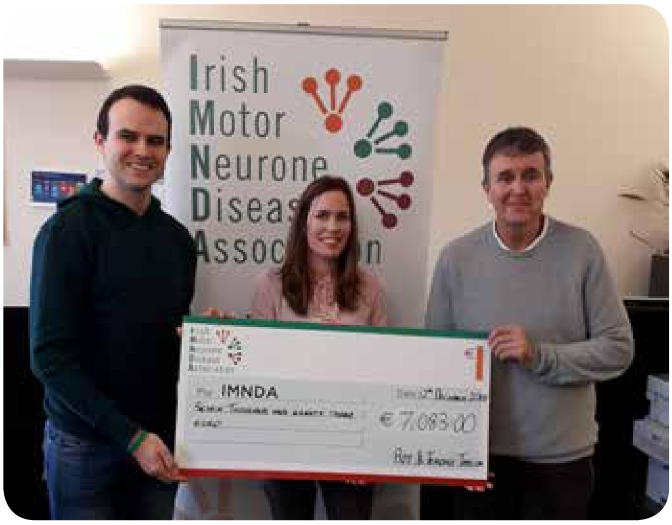
Mary Shannon hosted an 8 hour Line Dance Marathon in The Seven Oaks Hotel in Carlow. It was an energetic night with dancers attending from all around the country. They raised a truly amazing €11,291.50 which they presented to IMNDA Chairman, Dr. Declan Mac Daid. Thanks so much to all involved and a special mention of thanks to Mary's fellow line dancer Patricia Magee for nominating the IMNDA as the chosen charity for 2018.

Huge thanks to Gerry O'Loughlin and family who organised their annual ceili in Cois na hAbhna in Ennis in memory of his wife, Mary. They danced the night away with music from The Shandrum Ceili Band and raised a toe-tapping €4,815. Gerry's daughters Lorraine & Niamh also took part in our Croke Park abseil and landed home with a superb €2,171! Well done ladies!

Susan Dempsey & Peter Connolly who work for ICON plc participated in the companies 'Strictly Come Dancing' competition held in the RDS. They waltzed home with a phenomenal €10,025.50! Thank you so much Peter, Susan and all from ICON!

ROCK FOR MOTOR NEURONE

Huge thanks to Roy & Terence Taylor who organised a fundraising gig at The Stillorgan Orchard, it was a fun, music filled night with performances from Jump The Gun, Hold Up, Big Digger & Alan Sommerville Band. The night drummed up over €7,000 for the IMNDA!



Well done to Barry Jennings who also organised a rock gig for the IMNDA in Garbos of Castlebar, the event sold out and raised a whooping €7,946! So much hard work went into organising this night, from the musicians who played to those who donated spot prizes, worked hard behind the scenes and all who gave generously. Thank you, thank you, thank you!


ROCK FUNDRAISER 2018

SATURDAY
29
DECEMBER 2018
GARBO'S
CASTLEBAR

DOORS AT 7.30PM
ENTRY €10

SOCIAL WELFARE

THE NEW SOCIAL

SPECIAL GUESTS
CIAN MORRIN | JAMES COLEMAN
ALL DONATIONS WELCOME

ALL PROCEEDS GO TOWARDS THE
IRISH MOTOR NEURONE DISEASE ASSOCIATION

IMNDA Irish Motor Neurone Disease Association

BENEFIT NIGHTS

Martin Kirby & Family organised a race night in Clarkes Bar in Mullingar in February. An incredible €8,644.57 was raised for the IMNDA!! Thank you so much to the Kirby family.

A brilliant traditional concert took place in the Radisson Blu Hotel in Cork, organised by Mother & Daughter team, Geradine & Meadhbh Hayes. It was a highly entertaining night which was MC'd by RTE's Tommie Gorman and included music from De Dannan and Two Time Polka, a dancing demonstration from Tom Jive, a raffle and much more! Geradine's family, friends and local community hosted a number of other fundraising events to support her efforts and an overall amount of €28,591 was raised for the IMNDA. Unbelievable! A heartfelt thanks to everyone involved, we are truly blown away by your support!

Andy McGovern kindly asked for donations in lieu of gifts at his 86th birthday bash, he raised an outstanding €6,799! Thank you so much Andy, we are deeply grateful and we hope you had a wonderful birthday.

LEGACIES

Thank you to Rita Doyle & The Griffin Family who very presented our Nurse, Katie Kinsella with a legacy donation for an amazing €7,960.45. Thank you so much!

Thank you also to James O'Reilly who handed over a cheque for €10,000 donated on behalf of his late wife, Ann O'Reilly in memory of Oliver Kavanagh and Vrijlal Mewada. We are so appreciate for this very kind gesture.

Thank You For Getting Active For Your Association

A huge well done to everyone who took part in marathons in Ireland and around the world! A special thanks to Monica Joyce who ran the Dublin City Marathon and also hosted a coffee evening and raised an amazing €3,650! Big thanks to Deborah McArdle who also ran the Dublin City Marathon in memory of her friend Sharon Friel and raised a brilliant €2,326.30 and Elaine Horan who raised a fantastic €1,697.32.

ABSEIL

We would like to say a big thanks to everyone who climbed onto the roof of the Hogan Stand in Croke Park for our 100ft abseil to the pitch. We were blown away by your support and the incredible fundraising efforts you all made. Over €48,000 was raised because of your bravery! THANK YOU!

Huge thanks to Sports & Fitness Ballyfermot who organised a triathlon fundraiser at their centre which included a Try A Tri, sprint triathlon and relay triathlon. They raised an outstanding €7,113

FUN-RAISING

We would like to say a massive thank you to everyone who took part in the Annual Digital Mile organized by Hewlett-Packard Enterprise in Galway, DxC and Microfocus running Clubs. They raised over €1,600 for the IMNDA. We can't thank all the volunteers and runners enough! Well done everyone!

REINDEER RUN

John O'Donoghue's friends and family once again organised the brilliant Reindeer Run in Caherdaniel and the Flaggy Shore over the Christmas. They raised over €5,000! Well done to Aoife, Vivienne, John and all involved. Amazing event! Thanks also to Brian Sweeney from Analog Devices who nominated the Reindeer Run to receive a €1,000 donation from the company, IMNDA Ambassador Michael Clancy was delighted to accept this cheque on our behalf.

PADDY BUTLER MEMORIAL CYCLE

Tom Mahon & fellow members from the Engineer Group of the Defence Forces organised the 'Paddy Butler Memorial Cycle' which took place in February. They really put their foot to the pedal when they took on a 3 stage cycle starting at the Curragh Camp and passing through Athlone, Kilkenny and back to Kildare! They raised a fantastic €4,130. Well done to all involved.

CHRISTMAS DIP

Big thanks to Sally & Dick Lynch and family who organised a swim on Christmas Day at Greystones beach. Well done to everyone who left their cosy homes on Christmas Day and joined them for a chilly dip all for the IMNDA! A brilliant €4,420 was raised on the day. Sadly, Dick has since passed away, the IMNDA would like to extend our sympathies to the Lynch family.

SING OR SWIM FOR NOEL

There was a huge turnout for the fantastic "Sing Or Swim" fundraiser for Noel Shannon which took place at Fountainstown Beach in Cork. The Defence Forces kindly provided tents, food, soup, drinks & cheerful chat as many braved the cold water on the day! The IMNDA would like to say a huge thanks to the National Learning Centre, Noel, his family & friends and everyone who helped out with this event which raised over €13,000. A phenomenal result!

Thank you for Getting Active for your Association

Damien Mannion & friends took on the 2018 Amsterdam Marathon in memory of Damien's cousin, Andrew Calpin. They trained hard and after a number of setbacks, they absolutely smashed it! Here is their story….

In December 2017, my 4 running buds, Caroline McGrath, Ann Egan, Leah Murray, Darren Ruane and myself hatched a plan to run a marathon in some European city in 2018. Amsterdam was picked (the lack of hills was a big help on picking this one!). All that was left to do was the training.

As it was Amsterdam and the fact Andrew lived most of his life in Amsterdam, I decided to organise a fundraiser for the IMNDA, the gang or as now we were called "The A Team" came on board and the training began. We had 10 months and we were determined.

We had long runs, short runs, speed sessions, hill sprints, all part of a marathon training programme. But the warm weather in 2018 and the dreaded injuries, all part of a runners nightmare, our training was curtailed. Caroline had a hip injury, Darren a Calf injury, Leah a thigh injury, Ann was lucky, she escaped any bad injury, and myself…. well, my heart in July decided to take a wobble and I ended up with 2 stints. Safe to say our participation in October in Amsterdam was not looking good.

But, with persistence, numerous trips to physios, and 3 brilliant nurses in the Cardiac Rehabilitation unit, Amsterdam was back on. Caroline, Leah and myself decided to complete the Half Marathon (after getting clearance from Cardiac Rehab), Ann and Darren, the full Marathon. We hit the fundraising really hard at this stage and thankfully we exceeded our expectations with the final figure collected.

On the 21st of October, 5 athletes from Ballina AC in various condition fitness wise, hit the start line in Amsterdam, my immediate and extended family in tow to support us in their IMNDA T-Shirts. They also had the task of supplying Ann and Darren with the pick me ups badly needed when you run 26 miles, flat Coke, energy bars, bananas. They got trams, cars and nearly bicycles to be at the pre agreed meeting spots about the root.

Ann and Darren completed the Full Marathon, Caroline the Half Marathon and 12 weeks and a day after my heart attack and 7 weeks in to rehab, Leah and myself crossed the line in the Olympic Stadium to complete our Half Marathon. Personally it was an amazing journey, supported by my family, Andrew's family, and all at Ballina AC, especially my running buds, it was a great moment to cross the finish line. It was great to remember Andrew who was one of life's gents and true characters. I know he was with us every step of the way, and we definitely toasted him later that day.

The IMNDA would like to say a huge well done to the 'The A Team'. They raised a phenomenal €4,388. Overcoming illness and injury to take part, truly inspirational stuff! We know it can't have been easy and we cannot thank you enough!!

Get Active for Your Association

VHI Women's Mini Marathon 2019
Calling all you active ladies – we need you!!!!! Please 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 Sunday 2nd June**. You can register by completing the entry form in the Herald newspaper or online at: www.vhiwomensminimarathon.ie. The minimum age to participate is 14.

Vhi Women's Mini Marathon

Whether you walk, jog or run the 10k on the day we would love to hear from you! Once you have your place on the race, call Gemma or Jackie on freefone 1800 403 403 or email fundraising@imnda.ie and get your sponsorship pack which includes sponsorship cards and a green IMNDA t-shirt. You can fundraise online at www.idonate.ie / www.everydayhero.ie or you can even set up a Facebook Fundraiser page attached to your own profile and select the IMNDA as your charity of choice.

The mini marathon starts at **2pm on Sunday 2nd June on Fitzwilliam Street Upper** and finishes on Lower Baggot Street. The IMNDA's base on the day is near the finish line in the upstairs function room of Toner's Pub (139 Lower Baggot Street, Dublin 2) where we will be from approximately 12:30pm.

You can leave your belongings in the lounge safe and securely during the race and water, crisps and chocolate will be provided afterwards in Toner's. See you then!!!

The IMNDA is thrilled to announce that the world renowned Riverdance is our new charity partner. We are ecstatic at being chosen and we are dancing with joy in anticipation of the fantastic events they have lined up for us.

The key day in our dancing diary is Thursday 20th June when there will be a live 12-hour danceAthon outside the Gaiety Theatre from 10am - 10pm. This will feature dancers from schools right across Ireland as well as the world famous Irish dancers themselves.

Volunteers Needed - During the danceAthon we will be collecting on the street for its duration. We need as many volunteers to help us so if you have an hour or two free that day and would like to get involved – please call Jackie or Gemma on **1800 403 403** or email **fundriasing@imnda.ie**

It will be a fantastic day and you may recognise some famous faces who will be on hand lending their support! It also falls during our National Month of MND Awareness – what better way to mark the occasion, have a jig and a cuppa for Motor Neurone Disease!

HOPE STARTS WITH ONE STEP
CHANGE HAPPENS WITH MANY

WALK WHILE YOU 5K CAN sept 14

Hope starts with one step. Change happens with many.

WALK WHILE YOU CAN 2019

Never one to be struck down by adversity, in July 2018 just a short few months after his diagnosis of Motor Neurone Disease Fr Tony Coote and his incredible team walked over 550Km from Donegal to Cork. Thanks to Fr Tony and his unbelievable crew, they managed to raise a truly incredible €600,000 for Motor Neurone Disease. The proceeds were equally divided between the IMNDA and Research Motor Neurone. From these miraculous funds, we were able to employ a fourth nurse.

This year, to honour Tony's incredible achievement we are going to Walk While We Can once more. However, this year the format will be different. The IMNDA is organising 5K walks in various locations nationwide on Saturday 14th September. We want people from all over Ireland to join us and help keep the pilgrimage alive. We want to continue the fundraising fight that Tony started!!

The first event to be announced is the **Phoenix Park** on **Sat 14th Sept** but more to follow!

Please check out **wwyc.ie** and our social media channels for more information on our WWYC 2019 events!

To find out how you can get involved or to organise your own walk please email **fundraising@imnda.ie** or call Jackie or Gemma on **1800 403 403**.

10 year anniversary Croke Park Abseil!

2019 marks the 10th Anniversary of the IMNDA's Croke Park Abseil fundraising event! Over the last 9 years the event has gone from strength to strength with hundreds of brave people climbing up onto the roof of Croker's Hogan Stand and braving the 100 foot drop. Since 2009 a staggering €400,000 has been raised from the abseils alone!!

We were not only the first charity to abseil off the famous roof but our participants back in October 2009 were the first ever people to take on this challenge! An accolade we will always be proud of.

Now it's your turn to join the lucky few hundred and sign up to this very exciting anniversary event taking place on **Sunday 20th October**. Just contact Gemma or Jackie in the office on 01 873 0422 or email fundraising@imnda.ie and we can email you an application form.

A non-refundable €100 deposit is required to secure your place on the abseil and cover our costs. We then ask each abseiler to commit to raising a minimum of €200 which is to be lodged prior to 20th October; these funds will go straight to providing services to people affected by Motor Neurone Disease. As soon as your deposit is paid we'll send you sponsorship cards and you can start your fundraising, the more time you have the better! We also recommend setting up a fundraising page at www.idonate.ie or **www.everydayhero.ie**

Participants must be over 18 and no abseiling experience is required. This event is run in conjunction with **www.adventure.ie** who will provide full training on the day.

Please note, if the weather is unsuitable on 20th (e.g. high winds) the abseils will be rescheduled.

Church Gate Collections

Thanks to the massive support of local communities, the IMNDA's Church Gate Collections raise thousands of euro each year. Money raised supports our vital services. We are seen as an invaluable part of their community and YOU are an invaluable part of ours. We urgently need more local Church Gate Collectors to join us for our Church Gate Collections and would love to hear from interested volunteers.

What do I need?

We supply you with everything you need for the Collection. We will send you a Volunteer Collectors Pack which consists of a Thank You Letter, Bank Giro (to lodge funds following the collection), Permit, branded posters, buckets and bibs! We even arrange the permit so all you have to do is turn up!

If you are willing to do a Church Gate Collection, please get in touch and chat to Marie **mreavey@imnda.ie 01 873 0422** who'd be delighted to have you on board.

IMNDA Ambassadors

In 2016 the IMNDA launched its Charity Ambassador Programme. This proved to be extremely popular and we have number of fantastic Ambassadors that do fantastic work representing the IMNDA. As we are a very small team it is not possible for one of us to attend every event as much as we would love to.

We are always looking for volunteers to join our team of community ambassadors through the country. We need people who are friends and supporters of the IMNDA and who can be the face of the IMNDA in their community.

Full training will be given.

Ways you can get involved

- Inspiring your family, friends, colleagues and online networks to support the IMNDA
- Attending cheque presentations and thanking our supporters face-to-face.
- Volunteering and helping at events.

Join our team today!

Find out more about becoming an ambassador by contacting Marie mreavey@imnda.ie / 01 873 0422.

Christy Lehane & Kerry Friends of Motor Neurone

One of our long standing ambassadors is Christy Lehane. He got involved way back in 2011 fundraising for the IMNDA. He set up a regional committee called Kerry Friends of Motor Neurone. Here is his account of all their marvellous activities and achievements over the past 8 years.

Since we were formed, Kerry Friends of Motor Neurone have worked tirelessly to raise much needed funding and awareness for the Irish Motor Neurone Disease Association. The Irish Motor Neurone Disease Association hosted an open meeting on the 15th January 2011 in the Park Hotel Killarney. This meeting was well attended and was our introduction to understanding Motor Neurone Disease.

In April 2011 we held a coffee morning in Mac's Ice Cream Parlour Killarney where John Reidy and his many friends got together for a coffee and a chat. Johnny, as we knew him was instrumental in setting up Kerry Friends of Motor Neurone. Johnny had MND at the time. While he never wanted all this promotion work to be associated with him, he gave unselfishly of himself travelling to IMNDA Information evenings and participating in both television and local radio programmes to raise awareness of MND and the impact it had on him, his family and his community. On the 11 May 2011 Kerry Friends of Motor Neurone was launched in Darby O 'Gills House Hotel and so our fundraising began.

Our first fundraising effort back in 2011 was a sponsored walk around Lissivigeen which raised a huge €45,000. Our events and their success grew from there. In 2012 we held a High Nelly cycle in 1950's period dress and it went from strength to strength. One of our biggest success stories was hosting the Ring of Kerry Charity Cycle in 2014. Being selected was a huge challenge for our small committee based mostly in East Kerry. We had to get the required number of cyclists to cycle the Ring for Kerry Friends of Motor Neurone, not to mention all the other associated work that goes into running this huge event. It was an incredible privilege to be involved in such a prestigious event – the awareness and funds raised were phenomenal.
The following years 2015 to 2018 Kerry Friends of Motor Neurone held their annual flag days in Killarney Town and supermarkets. There were céilí dances, golf classics, bag packs, coffee mornings, runs, Christmas draws and much much more. Countless events and countless people across the years have really gotten behind us – we cannot thank the community enough!

On Wednesday 20 February 2019, Kerry Friends of Motor Neurone made a cheque presentation of €26,500 to Marie Reavey from the IMNDA. This brings the total amount presented by Kerry Friends of Motor Neurone to the IMNDA to date to almost **€280,000**!

To all the people who organised these many events and the loyal volunteers who come on board with us every year to fundraise, I as Chairman of Kerry Friends of Motor Neurone and proud IMNDA Ambassador, want to sincerely thank you all for coming on this road with us and I can say that all monies donated will be put to good use and as the IMNDA remind us that 83% of its annual budget is reliant on fundraising.

The main aim of Kerry Friends of Motor Neurone is to create awareness of MND and to ensure that those living with Motor Neurone Disease are at the heart of all our focus. It is sad that Motor Neurone Disease does not go away and fundraising does not get any easier but Kerry Friends of Motor Neurone will continue to participate in fundraising in the hope that in the not too distant future, medical science may find a cure for this awful disease.

For further information on all the items mentioned above please see our website Kerry Friends of Motor Neurone **www.kfmn.ie**

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.**

Jill Armstrong
Frank Barry
John Barry
Orla Batt
Jim Benson
Mary Bentham
Roland Besler
Bobby Brady
Hugh Brady
Joseph Butler
Derrick Byrne
Niall Callan
Iris Carnegie
Ann Carson
Edward Casey
Mary Cassidy
Maisie Concannon
James Cooke
Desmond Creighton
James Daly
John Delaney
Ellen Doheny
Austin Donohue
Mary Doran
Declan Dorrian
Kathleen Drumgoole
Christopher Dunne
Joseph Fallon
Mary Ferguson
Eamonn Flynn
Emer Foley
Thomas Gallagher
William Gibbons
Tom Guckian
Mary Halpin
Liam Haran
James Harte
Ellen Heavey
Fergus Hennessy
Noel Kelleher
Angela Kelly
Bernadette Kenny King
Sean Laherty
Tony Leahy
Dick Lynch
Thomas Lyons
Mary Mackey
Marie Maloney
Eugene Mannion
Christy McCarthy
Ingrid McDonald
Dorothy McGloin
John McKenna
Seamus Meade
Catherine Mullaney
John Murnaghan
Anthea O'Donoghue
Seamus O'Hagan
Tobias O'Meara
Bridie O'Neill
Michael O'Neill
Kevin O'Sullivan
John Power
Catherine Quinn
John Reid
John Rezin
John Roche
David Ryall
Josephine Sheridan
Teresa Smullen
Malcolm Smyth
Tony Swann
Michael Wilson
Robert A Wilson

Staff Update

We have had a few changes in the IMNDA this year and unfortunately we sadly had to say goodbye to Hamufari Mtamiri. Hamu looked after our accounts and joined the IMNDA in June 2014. She was an integral cog in the IMNDA team and we can't thank her enough for all she has done for us. 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 Hamu!!

But it wasn't all sad fair wells. We also welcomed two new additions. We are delighted to introduce you to our new financial accountant Maria Hill. She has an unusual CV and trained as both a Certified Chartered Accountant and as a Research Molecular Neuroscientist. Eventually though, in 2006, she fell in love with the Not-for-Profit and Charity Sector and she has been working and volunteering there as an Accountant and Finance officer ever since. In 2015 she took part in the first ever Certificate in Charity Law and Governance run by the Law Society and The Wheel and is a big advocate for proper Governance in Charities. She has a wealth of experience and we are thrilled to have her on board.

It is with great excitement to introduce you to our new IMNDA nurse Louise Hennessy. We were able to employ Louise thanks to the fantastic fundraising achieved by Fr. Tony Coote and Walk While You Can. Louise started in April. As our fourth nurse she will be looking after Dublin and some surrounding counties.

Louise started her nurse training in collaboration with Beaumont hospital and DCU in 2007. She qualified in 2011 and began working in St. Brigid's Neurology Ward, Beaumont Hospital where she worked for 6 years. She has a vast amount of experience within neurology and especially within the area of MND.

"I am very excited to join the IMNDA team and looking forward to working alongside both primary and secondary care to offer support to people and their families," said Louise.

Corporate Update

A huge thank you to all our corporate supporters – your incredible support means we can continue to provide much-needed services to all our MND clients and families.

2018 was a fantastic year for the IMNDA and our corporate partners. Everyone went above and beyond and we really can't thank them enough for their outstanding commitment to the Association.

Firstly want to thank all the staff in Irish life for not only nominating us but for all your immense fundraising this year. A special thank you to the **Irish Life Charities Committee** for their hard work especially **Cormac Donnelly** who was our liaison. There were some great events ran by Irish Life during 2018. From Hell & Back to bike tours. We cannot thank each one of you enough for all you have done! We are completely blown away by the final figure of **€182, 094!!**

A huge thanks to **DAA Charities Committee** and a very special thanks to **Christina Byrne and Denise Dowling** for lobbying tirelessly for the IMNDA to be one of the three chosen charities. Events ran by the DAA included sponsored silence, Runamuck, Cycles and marathons to name but a few. They raised a whopping **€103K** for the IMNDA!

The Central Bank support different charities each year through corporate donations. Following the passing of a colleague's brother the Central Bank choose the IMNDA as one of their 2018-2019 Charity Partners. The partnership started in July 2018 and to date has raised **€29,022.40** for which we are extremely grateful. This partnership continues on until the end of June 2019.

Thanks so much to everyone from **FFH Management Services** for supporting the IMNDA and raising **€5,000** through various fundraising events including 'Drink Tea for MND and a very generous donation of €2,000 to our Walk to D-Feet campaign. The partnership commenced in April 2018 and ended in March 2019. It was our absolute pleasure to work with such a lovely team.

Once again, thank you, thank you, and thank you for your amazing support!

Get Your Company Involved

The IMNDA acts as a lifeline to people living with MND. Often we are the only available support they have access to. We would be delighted to be considered as your charity of the year and we would love to work with your charity committee to help you develop a programme of fundraising for the year ahead. We know different companies like to do things in different ways. A member of our team are on hand to develop a tailored calendar of activities and provide you with a range of fundraising materials, support and motivation along the way. There are a number of ways to get your company involved to make a difference to people living with MND. Some of the most popular methods of giving are... **Charity of the Year Partnerships, Sponsorships & Donations, Pay Roll Giving, Volunteering, Matched and Tax Effective Giving.**

If you have an idea that's not listed and would like to talk through your idea please don't hesitate to contact Marie mreavey@imnda.ie / 01 8286615.

Legacies

Do something amazing… leave a legacy and make life more manageable for someone with Motor Neurone Disease.

You don't need to be wealthy to give a significant gift to people affected by MND and you can make a substantial contribution that costs nothing during your lifetime.

A legacy left to a charity is exempt from tax. By leaving a legacy to the IMNDA you are reducing the overall tax bill on your estate and getting more value from your gift.

Some people leave their entire estates, but most leave a modest sum. However much you choose to leave is up to you but please be assured that every legacy counts, no matter how large or small.

Once you have made provisions for your nearest and dearest you might choose to leave the remainder, or part of the remainder of your estate to one or more preferred charities.

Making Your Will: Questions and Answers

1. Why is making my will so important? Making a Will is the only way for you to limit inheritance taxes, say how you want your assets and belongings distributed after you pass, and outline any legacy you want to leave behind. Without a Will to give your final instructions, those decisions will be made for you by others. Getting started is as easy as a phone call: Will-making is a basic service almost every solicitor provides.

2. Could my estate be impacted by inheritance taxes? Yes. Inheritance tax rates have jumped from 20 to 33%. Because of these significant changes even modest estates will suffer the taxman's share, shrinking your estate and creating needless tax bills, especially for children. A proper Will helps protect you from this.

3. I want to remember people affected by Motor Neurone Disease in my Will. Do you have wording I can bring to my solicitor? We certainly do. Most people choose what's called a residuary legacy. This looks after your loved ones first, then leaves the remainder of your estate – or the portion you decide – as your legacy, after debts have been paid. Here is the ready-made wording:

"I give, devise and bequeath all (or a fraction or a percentage) of the residue of my estate of whatsoever nature and wheresoever situate to the Irish Motor Neurone Disease Association, registered charity number CHY 8510 (Ireland), and I direct that the receipt of the Treasurer or other proper officer for the time being of the said Association can be relied upon as proof of full discharge of same".

4. Must I notify you once I've set aside a gift in my will to the IMNDA? We would love you too but it's your decision. Informing us that you've included the IMNDA in your will lets you direct your legacy to a part of our work that's closest to your heart, which may add meaning for you. It also lets us thank you, in your lifetime…

If you are considering remembering the IMNDA in your Will and would like to let us know or need further information to bring to your Solicitor please call Gemma on 01 828 6614 or email gwatts@imnda.ie.

More information can also be found at www.mylegacy.ie

Nobody Knows MND By Hayley Reddy

My name is Hayley Reddy. My Mam Geraldine has MND and has had it now for about four years. It started as drop foot and progressed from there. She is now permanently in a wheelchair as the disease takes hold of her more each day. My Mam is one of the strongest, kindest and most caring people I know. She is a glamorous lady who always takes great care and pride in her appearance. It is part of what makes her - her. She continues to do so now, despite how difficult it is to do her hair or make up, get dressed etc.

But she has found that because she continues to keep herself looking well, people dismiss her disease and don't realise how difficult life is for her because on the outside she still looks like she always did. They don't see her unable to dress herself alone or struggle to feed herself. All people say when they ask how she is, is sure you look great but that does not mean she feels great.

In the supermarket one day a lady looked at my Mam and said I should be in a wheelchair because I'm killed with my sciatica almost implying that because my Mam looked well she shouldn't be in a wheelchair. My Mam was completely taken aback by this lady and felt if only sciatica was all she had to worry about. Little did that lady know the real struggle my Mam's life had become.

Based on all the times this or something similar has happened my Mam's reply to myself or my father would be nobody knows what it's like! Nobody knows how bad she feels and how hard life has become because she puts a brave face on, soldiers through and smiles to the outside world.

I wrote a poem called "Nobody Knows MND" for her and about what living with MND means to her and many other people with the disease.

Nobody Knows MND

Nobody knows what I'm feeling inside
Nobody knows what I'm trying to hide
They see me and tell me that I look great
Would they say different if I looked a state!

Nobody knows the struggle life is
Nobody knows the trouble this gives
A rotten disease that goes right to your core
A difficult battle that makes everything a chore

Nobody knows how I really feel
Nobody knows it's such an ordeal
Simple tasks that once I could do
Now a distant memory can't even tie my shoe

Nobody knows when I sit in this chair
Nobody knows, do they really care?
A difficult battle I face everyday
Sometimes I tell them, they don't know what to say

Nobody knows the pain in my heart
Nobody knows how could they even start
Losing control when you tell your body what to do
So many people they haven't a clue!

Nobody knows what MND is
Nobody knows, they'd cry if they did!

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!

Irish
Motor
Neurone
Disease
Association

To Contact Us:

Irish Motor Neurone Disease Association (IMNDA)
Coleraine House
Coleraine Street
Dublin 7

Freefone: 1800 403 403
Email: info@imnda.ie
Web: www.imnda.ie

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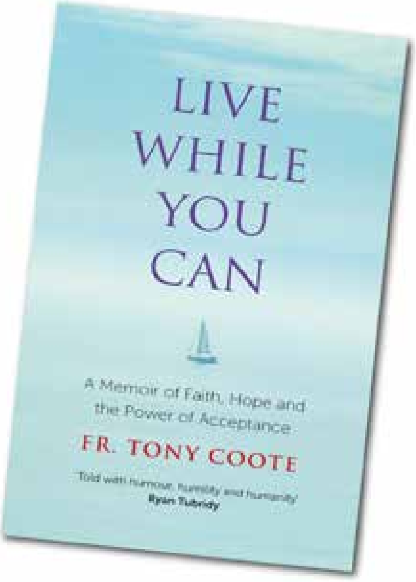

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Irish
Motor
Neurone
Disease
Association

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!

SUNDAY 20TH OCTOBER 2019

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

Are you game?

Then 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 ran 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