Irish
Motor
Neurone
Disease
Association

CONNECT

ISSUE
20

Autumn 2018

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- LIVING WITH MND
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A NOTE FROM OUR CEO

It was such a pleasure to meet many of you at our recent Annual Conference and Patient and Carer weekend in Wexford. On a personal note, I couldn't have asked for a better induction into IMNDA and the community we serve. It was an honour to be able to talk to many of you face to face and hear your personal stories as it really drove home the impact we have as an organisation and the responsibility we have to you, our members and also your families and carers. I am really looking forward to working on your behalf and putting your needs first and foremost in everything that we do.

We have had a really busy summer this year. Our Drink Tea for MND campaign reached a record high with €195,000 being raised throughout the country thanks to Roisin Foley fronting the campaign. We were also fortunate to have been part of Fr. Tony Coote's epic fundraising campaign Walk While You Can which has raised more than €450,000 to date for both IMNDA and Research Motor Neurone. This campaign not only raised much needed vital funds for both organisations but it also raised our profile nationwide and highlighted our ever growing needs in terms of resources and funding as new figures suggest that one person is diagnosed with ALS/MND every second day in Ireland.

As we enter the final few months of 2018, I would like to take this opportunity to thank everyone who has supported us throughout the year – our vital corporate partners, individual and community fundraisers and our IMNDA ambassadors and volunteers. Every act of kindness and every cent raised goes a long way to helping us achieve our vital mission. And it is only with your support that we can continue to provide specialist equipment, fund counselling and extra home care hours and sustain our vital nursing service.

I would also like to extend my sincere thanks and appreciation to all our families and also the IMNDA staff and Board for their unwavering dedication and inspiring commitment to the organisation.

Roisin Duffy, Chief Executive

Diary Dates –
Do Something Special in 2018

Croke Park Abseils
Hogan Stand, Croke Park Stadium, Dublin
13th October 2018

Sing While You Can
Church of St. Therese, Mount Merrion, Dublin 4
25th October 2018
www.eventbrite.ie/e/sing-while-you-can-tickets-49885462762

Dublin City Marathon
Dublin City
28th October 2018
www.sseairtricitydublinmarathon.ie

Rock for Motor Neurone
The Stillorgan Orchard, Dublin
3rd November 2018
https://imnda.ie/shop/

Annual Memorial Service
Capuchin Friary, Church Street, Dublin 7
24th November 2018 @ 12pm

Annual Grand Raffle Draw & Christmas Coffee Morning
Richmond Room, Carmichael House, North Brunswick St, Dublin 7
Tuesday 11th December @ 11:30am

Reindeer Run
In Your local area
Saturday 22nd December 2018

Rock Fundraiser
Garbo's, Castlebar, Co Mayo
29th December 2018

Irish
Motor
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OUR HIGHLIGHTS FOR 2017

8,314
Nursing Support Calls

€1,757,886
Raised

46
Professional Education & Information Sessions Held

524
Clients & Families Supported

€485,407
Spent on specialised equipment

10,566
Health Care Professionals Accessed our Service

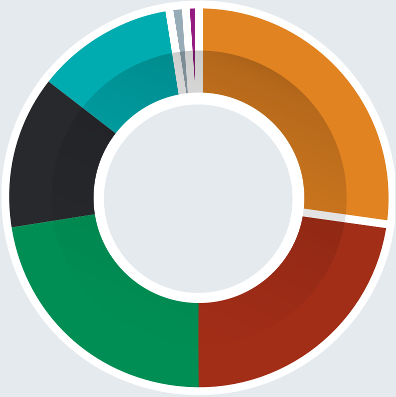
654
Home Visits

83%
income raised from Fundraising

17,000+
Home Care Hours Funded

HOW WE MANAGE OUR FINANCES

WHERE THE MONEY CAME FROM…



2017 INCOME:

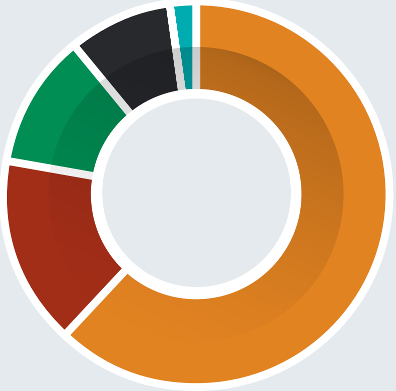
€1,757,886

21%	General Fundraising
20%	Sporting Events
20%	IMNDA Events
16%	Donations
16%	HSE
6%	Corporate
1%	Restricted Funds

As this graph shows the Irish Motor Neurone Disease Association is heavily reliant on donations and fundraising , based on how little public funding is available.

The IMNDA would like to sincerely thank all of our loyal supporters and fundraisers for all their efforts, contributions and support as the IMNDA would not be able to do its invaluable work without them

…AND HOW WE SPENT IT



2017 EXPENDITURE:

€1,773,586

60%	Services
18%	Dedicated Nurse Service
12%	Fundraising
8%	Governance & Communication
2%	Research

In 2017 the IMNDA spent the money you raised in the following way:

- **60%** went directly on the services we provide to families living with MND
- **18%** was spent on our vital nursing service
- **12%** was spent on Fundraising to ensure we have a steady income flow to fund our services
- For every **€1** spent on fundraising **€7** euro is raised
- **78 cent** of every **€1** raised goes directly towards services
- **8%** was spent on governance and communications to ensure your money is spent correctly and we comply with all charity regulator laws
- **2%** went towards research

AGM / Patient & Carer Weekend

In September of this year, the IMNDA's AGM, Annual Conference and Patient & Carer weekend took place in White's Clayton Hotel in Wexford. The event was well attended with over 120 delegates coming along. The business part of the weekend took place on Friday morning where the IMNDA's Board of Directors reviewed the operations and financial performance of the organisation in 2017. Two new board members were also introduced.

Following the formalities of the AGM, we were then treated to a very interesting conference MC'd by the IMNDA's board member and radio presenter Jonathan Healy which featured a variety of speakers.

First up Jonathan welcomed everyone to the conference and thanked people for their generosity and support throughout the year. We then had an in-depth presentation on voice banking with MND by Lesley Doyle. Lesley is the Senior Speech & Language Therapist in Neurology in Beaumont Hospital Dublin.

She started by explaining how MND affects your voice. Dysarthria is difficulty with movement of the muscles used to produce speech. These muscles control respiration, how you articulate and pronounce words, it can affect the tone, resonance, stress, and rhythm of your speech. To compensate for this communication aids are often recommended. These communication devices vary from tablets, handwriting, eyegaze technology, Say It Sam and Lightwriters.

Electronic devices are commonly used for their text-to-speech functions and nowadays there are lots of apps available on phones and tablets. When you type the message an electronic voice 'speaks' it. These apps can be handy to pre-save messages that you frequently use and don't want to type out every time.

She explained that there are different types of recording:

- Message banking
- Voice recording
- Voice repair
- Legacy recording

Message banking is the digital process of recording words, phrases, sentences, personal meaningful sounds and/or stories using your natural voice, intonation and refection. This is done when your speech is still quite clear for potential future use. It helps maintain your identity as a communicator. It allows you to preserve some of your own 'trademark messages' such as a frequently used joke or affectionate name for a friend or a unique greeting and your own personal delivery of those messages.

The main purpose of message banking is to capture your personality in the form of pre-saved voice messages that can be used on an electronic device to enable social closeness and convey messages of love or needs and wants.

You start by choosing phrases or messages, recording them, save them, organise them and use them. Straightforward right? There can be a few hiccups to overcome. Some people do find it tricky getting started and it can be hard drawing up a list and knowing what to record. It can help to involve family as they will have an awareness of phrases that you use. However if you are still having difficulty choosing what to record, your Speech and Language Therapist (SLT) can provide you with a list to get you started.

Once you have a list, then comes the recording. The most recommended recording device is called a Zoom H1 Handy Recorder. It is small and portable, easy to use and easy to transfer files. You can purchase this online or it is available to borrow from the IMNDA. If you don't have access to a Zoom recorder then there is a list of apps that also work but again consult your SLT on this and they should be able to point you in the right direction.

Your SLT will be able to discuss this process with you and set a timeframe. Help you decide if this is for you or if it might not suit. They can help source the equipment and review the quality of the messages.

This form of recording may be suitable for you if:

- Your speech is intelligible
- You are satisfied with your current speech quality
- You want to maintain elements of your own voice

- You see it as a positive project
- You want to be pro-active
- Like to plan ahead
- Feel empowered by creating a future choice

This may not be for you if:
- Your speech is difficult to understand
- You don't like how your speech sounds
- You feel upset by the idea
- You are not ready to learn about alternative communication
- Prefer to focus on current symptoms only
- Feel pressured or stressed by the idea
- Likely to use writing if you needed to use a communication aid

Lesley then moved on to explain about Voice Banking. Voice banking involves creating a personalised computer-generated voice that is a digital representation of your own unique voice. This is a more lengthy process and involves reading a large inventory of your speech while reading setlines of text to capture different speech sounds. This is done by using services through the internet and will never sound completely like natural speech as it is electronic.

Voice banking requires a lot of forethought and preplanning. If you are not comfortable with computers, it could be overwhelming and needs to be done with no or very mild speech changes. If there is moderate or severe speech difficulty, voice banking might not be suitable for you but you could also consider nominating a family member or friend to use their voice instead. With voice banking, the voice quality outcomes can be variable. It is always good to be aware that the resulting voice will always sound robotic, as it is electronic.

In order to bank your voice you will need a computer with audio, an email account and you have to sign up to an online voice banking service that will require a payment. You will also need a microphone headset with a USB, not headphone jack, computer connection and a quiet space without background noise. The best online voice banking options are ModelTalker and CereVoice Me. Again ask your SLT for more advice on these.

The next topic that Lesley touched on was Voice Repair. This is a way of creating a personalised voice for a person whose speech may already be experiencing damage, by use of a donor voice. It is possible to 'repair' the voice by patching damaged elements with voice segments from a donor voice. You can choose from a bank of healthy voices in various different accents. This process can be costly however and again it is advisable to get further advice on this. For more on Voice Repair, Lesley recommended using Vocal ID. See www.vocalid.co/bespoke

The last topic Lesley covered was Legacy Messages. This is where you want to capture your voice and unique style of communication but don't plan on using recordings for direct communication. She mentioned how some people record videos or sound recordings capturing stories and memories. Some people record storybooks for children or grandchildren. You can record stories through story apps such as Story Corp or RecordMeNow.

To close Lesley just briefly summarised that there are numerous different ways you can record your voice and if it is not for you, there are several communication options available. She stressed that it does not suit everyone and some people can find it upsetting. If you feel it is something you would like to explore then the sooner the better. Talk to your SLT or if you have any further questions email lesleydoyle@beaumont.ie

We then had the pleasure of listening to our new IMNDA team member Johanna McDonagh introduce herself and her new role. Johanna is the Information and Support Officer and she will be working on our services team providing information and advice on advocacy services. She will also liaise with our MND Nurses and act in an advisory role to the Multidisciplinary teams. She is available to all our members to write support letters, source information and assist with our Counselling and Homecare grant. To get in touch with Johanna all you have to do is email services@imnda.ie or call 01 871 7800.

Next up on the podium was Joan Fogarty. Joan spoke about the benefits of early intervention in palliative care. Joan recently retired from the Wexford Palliative Care service. She was a nurse with the Homecare team for 19 years and worked with the service in Waterford for six years before this so she has a vast knowledge and experience of Palliative Care services.

Joan started by explaining what Palliative Care is. She explained Palliative Care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems: physical, psychological and spiritual.

She explained that the approach to palliative care has changed drastically over the past twenty years and now the approach is more holistic and more about symptom management and support. The main objective is to optimise quality of life and choice for the patient and their family. It provides person-centered care, focusing on the whole person, to help them live as actively as possible with their illness. It provides relief from pain and other distressing symptoms.

One of the central purposes of palliative care is to offer a support system to the patient and family to help them cope with the illness. A patient is generally referred to their services following a Palliative Needs Assessment by Multi-Disciplinary Team and where a need for specialist support and knowledge has been identified. Once someone is linked in with the service the palliative care nurse will become actively involved with the person and the family. They are there to provide advice, information and support to patients and their families. To help with symptom control and will also assist the family by linking with primary care team and other disciplines. Palliative Care recognises that illness affects the whole family, and in return, family's response to illness affects the patient. Most of the patient's time is spent at home so the majority of care falls to families and each family is unique, with their own history, relationships and coping skills. Illness can impact each person and family member very differently so it's always important to be mindful of this and to try to reassure families how well they are doing. Joan spoke of different coping strategies and stressed that their duty of care was to the patient but this does not mean relatives wishes are not respected. She finished with a lovely quote from Robert Frost,

> **Hope does not lie in a way out**
> **but in a way through……**

For more on palliative care or if you wish to receive Joan's slides please email info@imnda.ie

Jim Connolly from Goodbody stockbrokers was up next and given that he was speaking about financial planning – the amount of laughs he received was surprising! In his presentation, Jim covered some of the financial do's and don'ts that everyone should really be heedful of. His first recommendation was to seek the advice of a qualified financial planner but to be aware of people who say they can do everything. Always important to get advice from the right people because it could leave you with less rather than more.

He stressed the importance of creating a will. Having a will simplifies probate and speeds up the process. It gives clarity and certainty to your wishes and can provide for your children. It protects your Estate from being contested and reduces inheritance tax.

He then turned his attention to Capital Acquisitions Tax which according to Jim is CAT by name and by nature. If you receive an inheritance then you must pay 33% tax on it but Jim had a few manoeuvres to lighten the blow. He suggested to use up the thresholds and spread your assets over multiple beneficiaries. If you move shares into the name of the person who is ill, you avoid Capital Gains Tax as the shares are revalued on death. Sometimes it is advisable to move assets into joint names but be very careful on this because this could affect allowances that are subject to means testing. Another tool is to bequeath gifts as you can gift €3,000pa to anyone without any tax issues. Another avenue to look into is placing specific assets in Trust, this allows you to pass assets to nominated beneficiaries without waiting for Probate.

Another area to look into is State Assistance. A lot of information on carers allowance and the drug repayment scheme can be found on www.citizensinformation.ie. Jim also mentioned how it might be possible to employ a career credit, which can result in relief of up to €75,000 being made available to you.

The other main area for discussion was pensions and the perks and pitfalls. Any money in a pension fund belongs to you or your Estate. The tax treatment of payments differs enormously

- On death
- On illness
- On death before retirement
- On death after retirement

The rules also differ according to the type of pension structure so it is critical that you take advice. There are often more options available to you than you may be aware of. Some of these include taking early retirement, going on long-term sick leave, leave employment and take a transfer value. It is worth weighing up each option and unlocking what is the best financial outcome for you. It is essential that you know the terms and conditions of your pension plan and know what benefits your employer may offer. To summarise Jim left us with a short do's and don'ts list:

- Don't believe everything you're told
- Don't try and sort out things yourself
- Do take advice (from the right sources)
- Don't make short term decisions
- Do review all of your contracts and do pay someone to do it properly
- Don't assume that you can't do something e.g. don't assume you have to wait until age 65 to access your pension (if you are over age 50 you can access all of your old pensions)
- Do interview your adviser – ask them what their specialities are, get references, look them up on LinkedIn, FinancialBroker.ie

Our final presentation was from Dr. Eoin Finegan who is a part of Prof Orla Hardiman's research team and who some of you may be familiar with from the Beaumont Clinic. He started by giving a brief outline of the challenges that he and his colleagues are faced with in the field of MND research. One of the main difficulties with MND is how the condition hugely differs between individuals. No two cases are the same and this makes finding a universal treatment extremely difficult.

The geneticists are discovering that MND is not caused by one gene (monogenetic), which is also another reason why finding treatments have proved elusive. They are now realising that several genes could be involved and certain changes to the genetic code may be more important than others. More on this can be found at www.projectmine.com

There is also extensive cognitive research being undertaken as it has been discovered that some people with MND may exhibit severe thinking changes while others experience none. Another area of interest for the research team in Trinity is the Patient and Caregiver journey in MND. The importance of the caregiver is invaluable in the MND journey and it is paramount that their needs are also considered and monitored. Carers can inform clinicians on the important day-to-day functions that a patient may have. This affects medication and therapies.

The next section that is showing positive progress is the area of MRI. This research is conducted in St. James's Hospital as they have a very specialised scanner that can pick up very subtle changes in the brain. This allows the team to track and measure which parts of the brain are affected and to what extent. It allows them to map out which pathways are affected.

They found that subtle changes in part of the brain that controls voluntary movement correlate sensitively with the extent of physical disability. They also found that parts of the brain that were previously considered unaffected by the disease may play an important role in the disease process. From these scans it is their intention to develop sensitive diagnostic protocols and learn more about how MND affects various parts of the brain which ultimately will lead to more accurate clinical trials being established.

After the conference talks were over, Róisín presented the Silver Pin Recognition Awards to people who contributed to the IMNDA over the last year. The association could not function without the fantastic support received from so many people across the country. Each year at our AGM we like to select a small percentage of the people we feel dedicate their time and effort to our organisation. We like to acknowledge this by presenting them with an IMNDA Silver "Thumbs Up" pin and were delighted that so many of the recipients could attend and accept their award in person. Pins were awarded to Joan White, Lilian Carroll, Kate Attride, Tomás Kavanagh, Emma Burke, Michael McMahon Snr, Róisín Foley, Patricia Sweeney, Sharon Barry, Fr Tony Coote, Mary Shaughnessy, Christina Byrne, Eileen and Joan Boland. Thanks again to all our silver pin awardees. These people truly went above and beyond for the IMNDA in 2018.

A light lunch followed where our guests got the chance to mingle and chat to fellow clients, IMNDA staff, board members and speakers. Hopefully everyone had a relaxing afternoon.

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

Thanks to everyone for making it such a memorable weekend. We hope you enjoyed it, see you next year!

2018 Research Update

Orla Hardiman BSc MD FRCPI FTCD MRIA
Professor of Neurology TCD, Consultant Neurologist, Beaumont Hospital.
Leader, Irish ALS/MND Research Group,

Amyotrophic Lateral Sclerosis (ALS), also known as Motor Neurone Disease (MND) is a neurodegenerative disease that strikes in midlife. One person is diagnosed with ALS/MND every 2 days in Ireland, and we now know that ALS overlaps with other more common brain conditions including dementia and schizophrenia.

At present there is no effective treatment for ALS/MND, but this does not mean that we should not lose hope. Over the years, there has been a big investment in animal models of ALS /MND, but to date we have not been able to translate these successful treatments to humans. This is because recent research has shown that human ALS /MND is more than one condition, and our animal models are too restrictive. Because our clinical trials have been drawn from animal research where human genes have been inserted into mice to make the disease, drug development for ALS/MND has focussed on specific pathways that are important in the laboratory form of the disease but may not be as important in the human forms.

It is now time to move to a new human precision-medicine based approach towards treatment. We know that ALS/MND is a human disease, and does not occur naturally in animals. This poses a challenge, and most successful treatments are first developed in animal models. We need a radical change in how we engage in research to find these new and more effective treatments For ALS/MND we must take a slightly different approach. While laboratory research is still important, we must shift some of the focus from animal research to human research. We will not find new treatments without working together as scientists, and also investing in the study of people with the disease.

We in Ireland are part of a group of European ALS/MND Centres that have recently agreed to join forces to capitalize on our individual strengths, and to build on new and creative approaches that enhance our collective scientific expertise. Centres of ALS/MND research in Ireland, Holland, the UK, France, Belgium and Italy are now working closely together to improve new drug development and drive new clinical trials. Each centre has cutting edge skills and scientific expertise in ALS/MND that will contribute to our goal of a precision medicine-based approach towards new treatments for ALS/MND. It is also very important that we include those who are experiencing the disease first hand.

By working together, we have a better chance of succeeding in our shared goal to find a treatment for ALS/MND.
The objective is to have the right drug in the right dose, for the right patient at the right time.

An important obstacle to finding new treatments for ALS has been our incomplete understanding of genetic factors. Project MinE (www.projectmine.com) was designed to address this. Project MinE is a crowd funded initiative, in which 13 partner countries have raised funds to support genome sequencing of DNA samples from their own population. Project MinE is achieving its goals by analysing the genetic code of 15,000 ALS patients and 7,500 healthy people in exquisite detail to discover every gene that contributes to ALS risk.

Having raised €1.6 million, the Irish arm of Project MinE, based in Trinity College Dublin, has contributed DNA samples of 700 ALS/MND patients and 350 healthy participants to the project. This work is ongoing, under the leadership of Dr.Russell McLaughlin, Ussher Assistant Professor in Genetics at TCD, and the 2018 winner of the European Young Investigator Award for ALS/MND.
Project MinE has already made many important discoveries that are reshaping our understanding of ALS/MND. Our Irish researchers including Dr.McLaughlin, Dr.Kevin Kenna and others, have been major contributors to these discoveries, and have have taught us that there are many subtypes of ALS/MND with distinctive characteristics. Some subtypes of ALS/MND seem to have links with schizophrenia. And each subgroup of patients is likely to require a different treatment.

But Genetics is only part of the story. We also need to focus on how the disease manifests in individual patients. We need to combine our collective clinical studies with our new genetic insights to have a true Precision Medicine approach towards new treatments. Our new European initiative will now combine the genetic information from Project Mine with exciting and innovative approaches towards disease categorization, using shared methods developed by individual partners within the European grouping. These additional cutting-edge methods include novel approaches towards clinical assessment, neuropsychology and behavioural assessment, biochemical measures, MRI, and brain signal analysis and measurements of patient outcome.

Sharing resources include sharing training of young investigators. The Irish ALS/MND research and the Dutch ALS/MND Research group are jointly training a young Neural Engineer (Stefan Dukic) in new ways to analyze brain signals using EEG. The leader of this work is Dr.Bahman Nasseroleslami of the Academic Unit of Neurology in TCD. Bahman will supervise Stefan's work in TCD Dublin and in the University of Utrecht, and will help to share new discoveries across the two centres. Similarly, Dr.Peter Bede, Research Associate Professor in the Academic Unit of Neurology at TCD, who has recently been appointed as a new HRB Emerging Leader, is coordinating brain imaging research in ALS/MND . Dr.Bede, along with his research group in TCD (Dr.Eoghan Finnegan and Dr.Ranga Chipika) will work across centres in Ireland, France, Holland and Canada, and will drive a new and coordinated approach towards understanding the structural changes that occur in the brain as a result of ALS/MND.

Outcome measure are also very important in clinical trials. Dr. Dara Meldrum, and Dr.Deirdre Murray are both academic physiotherapists who have recently joined the ALS/MND Research Group at TCD. They are coordinating an international study that will identify the best way to measure changes in breathing in ALS/MND. They are also working on the best way to measure changes in walking ability (gait) and hand function (dexterity), to establish better outcome measures for clinical trials. This is important because our current way of measurement do not tell us anything about clinical meaningfulness". We have no way of determining the real-life impact of a drug in a clinical trial because we cannot convert the numerical outcome measurement into how functions of everyday life.

Dr. Miriam Galvin, Senior Research Fellow in the Academic Unit of Neurology, and GBHI Fellow at TCD, is working on the concept of "clinical meaningfulness" with colleagues in the Universities of Sheffield, Utrecht, Turin, Leuven and Kings College London, so that future outcome measure will also tell us whether people who are affected by the disease and are being treated with a new drug find a meaningful impact of the drug.

By engaging in these types of collaborations, our European initiative will combine approaches to identify new ways for grouping patients into different clusters, develop new and more cost-effective ways of testing new drugs, and will have better outcome measures to determine whether a drug is effective, and whether the effect is meaningful. This will allow us to enroll groups of patients in new clinical trials that are specifically targeted towards their type of disease.

These new initiatives are already well underway. A number of new clinical trials will be taking place over the coming months. Clinical trials have stringent criteria for enrolment, and not all patients are suitable. One of the objectives of the new international consortium will be to loosen the enrolment criteria, so that we can offer clinical trials to everybody with the condition. We are not there yet, but we are confident that we will be able to do this over the coming years as we develop better markers for the condition, and better outcome measures that are meaningful.

In the meantime, the Irish ALS/MND Research Group has already committed to participation in two new industry-sponsored clinical trials, and one trial funded by the European Commission, all commencing enrolment in September -December.

A further three investigator-led trials are currently being discussed at European level. Investigator-led trials mean that there is no pharmaceutical industry sponsorship, and these trials will be funded by each participating centre, using local funding sources. We in the Irish ALS/MND Research group is confident that we will be in a position to participate in all investigator-led studies, and we look forward to working with the Irish ALS/MND community in partnership with the IMNDA to make this happen.

The Irish Hospice Foundation
Striving for the best care at end of life for all

LIVING WITH LOSS

An information evening for the public about bereavement with guest speaker

Niamh Fitzpatrick

(Psychologist, sister of Capt. Dara Fitzpatrick)
Observations on grief from the inside out

November is traditionally a month for remembrance. This Irish Hospice Foundation event aims to provide information about grief and the range of supports available to bereaved people.

Members of the public are invited to attend this free public event:

Thursday, 1st November 2018
5.30pm - 8.00pm
The Alex Hotel, 41-47 Fenian Street
(off Merrion Square), Dublin 2.

Talks
*
Video
*
Information Stands hosted by Volunteer Bereavement Support Services and Professional Therapeutic Services

The evening will open at 5.30pm with a formal introduction. There will also be an opportunity to chat to voluntary bereavement support services about the supports they provide. During the evening Niamh Fitzpatrick will address the gathering and speak on the theme ‘Living with Loss’.

This public event is free to attend. Bookings are not necessary.

If you have any queries or would like further information please contact

Iris Murray, Irish Hospice Foundation,
4th Floor, Morrison Chambers, 32 Nassau Street, Dublin 2.

Telephone: 01 6793188

email: iris.murray@hospicefoundation.ie
website: www.hospicefoundation.ie and www.bereaved.ie

This event is kindly sponsored by Fanagans

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LIVING WITH MND

New collar for people with MND is launched

**This article was kindly given to us from the MND Association UK & Philip Brindle.*

After years of research and development a collar made specifically to help people with MND who are experiencing weakness in their neck has been launched. Here, we explain more about the collar and the research behind it.

FOR Philip Brindle using the HeadUp Collar has been life-changing.

Diagnosed with MND in 2015, Philip soon started experiencing weakness in his neck meaning that everyday tasks such as eating, reading a newspaper or using a computer became almost impossible.

He explained: "My head dropped forward which just meant that life became really difficult. I couldn't even have a face-to-face conversation. It also affected my self-confidence, I just didn't want to go anywhere."

Philip first started using the collar during the trial phase and the affect it has had on his quality of life has been remarkable.

He said: "Using the collar meant that I could keep driving for a while, as before all I could see were the pedals. I don't drive any more because my arms are now too weak, but it gave me my independence which was wonderful. It also meant we could go on holiday and that I didn't feel self-conscious. The collar is very comfortable, I would say that it feels like a scarf and it is also discreet. It can hardly be seen under clothing such as a shirt. The level of support is also variable, you can use different strength struts which come with the collar because the support needed varies depending on what you are doing at the time."
The creation of the HeadUp Collar has been made possible thanks to the efforts of clinicians based at the University of Sheffield, whose work has been supported by the National Institute for Health Research, the Association and Talarmade, the company which produces it.

Professor Christopher McDermott, from the University of Sheffield, was one of the clinicians behind the collar's development.

He explained: "We started from scratch by working collaboratively with people living with MND to identify what the problems were with current neck collars and what features the ideal collar would have.

"The design team listened to everything the user group suggested and went away to make prototypes. There were at least six or seven different types of design solutions being developed and it was the expert users who influenced which ones had merit and went forward into more advanced prototyping."

The final design, which became known as the Head-Up collar, was produced and tested by 150 people living with MND. After wearing it for a month, they were asked to provide feedback and were given the opportunity to keep the collar if they wanted to.

Prof McDermott said: "Eighty percent of participants in the study continued to use the HeadUp Collar after the end of the study, judging it to be better for them in terms of support and comfort compared to other collars they had tried.

"Our hope is that the HeadUp Collar will be something that, rather than being abandoned under the stairs or in the cupboard, people will actually use and we hope they can experience an improved quality of life."

If you think this collar would work for you please consult your OT or talk to our team by calling Freephone 1800403403. For more email services@imnda.ie

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Dublin Bus

Travel assistance Scheme

Dublin Bus offers a free Travel Assistance Scheme for people aged 18 or over. If you are unfamiliar with using Dublin Bus or are now using it for the first time using mobility aids this scheme can provide you with an assistant who will accompany you for the first few times you travel. The assistant can also give you advice on planning a journey using Dublin Bus, the Dart or the Luas. This will enable you to become familiar with using public transport in the greater Dublin Area with the aid of the assistant and then hopefully you will gain the confidence and experience to use it on your own. This service is available Monday- Friday between 8am and 6pm. To find out more call 01 703 3204, email travelassist@dublinbus.ie or check out their website at www.dublinbus.ie.

Passengers using Wheelchairs

With Dublin Bus all buses will stop if there is a wheelchair user at the bus stop. There is one space available for a wheelchair user on each of the low floor buses and wheelchairs can be accommodated up to a size of 70cm wide and 120cm long. When boarding a bus there are a few tips that Dublin Bus offer to customers such as keeping clear of the bus until the ramp has been lowered onto the footpath. The best way to board the bus is facing forward as this puts you in a better position once on board to proceed to the wheelchair space. They advise you position yourself with your back against the backrest and always apply your brakes. When you are approaching the stop you wish to alight at press the button with the wheelchair symbol which is next to the wheelchair space as this makes a distinct sound which will alert the bus driver that you wish to exit the bus. The front doors should always be used to board and exit the bus as the ramp is only available here. If at any time you are unable to board a bus due to a broken ramp Dublin Bus advises you wait for the next bus and inform the Customer Comment Desk by phoning 01 703 3160 or 01 703 3195.

Mobility Scooter Permit

Any users of a mobility scooter wishing to travel on Dublin Bus must have a permit as some mobility scooters are too big to fit on the buses. To check if your scooter can be accommodated and to arrange a permit you can contact the travel assistance at 01 703 3204 or email customercomment@dublinbus.ie. They can also provide you with some helpful tips on bus travel.

In the Stores with Pat Malone

I am a Kilkenny man, from the home of good hurling and now live in south Carlow. I started working for the IMNDA in 1999, nearly 20 years ago with just one van and my son Patrick to help with the deliveries. That was when the founder of the IMNDA was CEO Eithne Frost. Then as the years went on, it started to get busier and my son Mark started with us and today we have three vans on the road to keep up with the demand for equipment. It is not a job to us. Well not one that everyone gets a chance to do, which is to help others. It is not a 9-to-5 either as most mornings the vans are gone out of the store around 5 or 6 o'clock and they could be in Donegal or Kerry or wherever the equipment is needed and when they come back late at night they empty the van and load for the next day. My job is to make sure all the equipment is working perfect, arrange a time with the client that suits them. We check all the equipment that comes back into stores, order parts if needed, talk to OTs when they need to know about a special piece of equipment and change seat size on wheelchairs, do the paperwork and that is just an ordinary day here.

Sometimes I would have a call from the office that someone needs equipment taking out of his or her home that same day and I would go with my wife Eve to do that no matter what county it is in, or what time we would be back. What do I get out of my Job? Well that is an easy one to answer - knowing that we can help people get out of their house in a wheelchair so they could enjoy meeting their friends. Knowing that when I bring a bed to someone, that it helps him or her to be able to get into it easy and get out of it easy and makes his or her life a little bit easier. The same goes for a simple thing like a ramp. We never would think that a ramp could be the difference between a person being able to get in or out of their homes with a wheelchair. Not until you see the delight on a person's face. To know that now I can go to the shop in my wheelchair without being stuck in the house all day just things like this makes my job worth it.

To finish off this now, the one thing that I have to say is that the team in the IMNDA are just one of a kind. The whole team looks after each other. For example, I had a call one day from a person whose husband had just passed away that day and they wanted the equipment out to bring him home. It was a hard phone call to take and you would be drained after it, and all the girls know what I am talking about as they do this every day, but sometimes there is one call that will just get you and always there will be someone from the IMNDA office that will phone and ask are you ok.

Now this is what I mean by that the team are one of a kind and I class all in the IMNDA as my friends not as just people who work in the office in Dublin. I am proud to be here for so long and hope to last another few years! Before I sign off, I would like to thank all of you in the office for the last 19/20 years. For helping us through bad times and good times and whenever the day comes to stop doing this job (I hate calling it a job as its just normal to us now) I will be sad to say goodbye to such good friends.

Thanks now, that's it

Pat

Putting one foot in front of the other

By Andy Minogue

Fair play to you for running with a broken arm or is that a special Japanese technique that you are using? These are just some of the reactions that I got when people saw me running with my self-engineered slings for the first time. Another person told me that I must be very stubborn! (I cannot argue with that as I don't believe that many people would even try running if they had no power in their arms). These reactions are of course totally understandable and I just politely set the people straight. I cannot hold my arms up due to muscle atrophy from a condition called Flail Arm Syndrome (a rare variant of MND with a better prognosis). Indeed, I cannot run at all now without my slings. Luckily, only my arms have been affected after 3 and a half years since onset of the illness. It is very true to say that there are always people who are much worse off than yourself. Indeed, I have met other MND patients and they are courageous and dignified people. So, what I have been trying to do is accept it, make adjustments, put on the runners and keep putting one foot in front of the other!

The people at Parkrun (a weekly timed 5K running event) at Clarisford Park, Killaloe are well used to me at this stage and they just treat me like any other runner. Indeed, there are one or two of them who would, and do, gladly pip me at the line on any given Saturday! Everyone at Clarisford has been so supportive of me and you would not meet a friendlier bunch anywhere. The fact that my wife, Clare and my two sons Eoin and James run with me almost every Saturday makes it all the more special and enjoyable. Of course, they always help me to tog out in the first place as I need assistance. While many people at Parkrun are monitoring their progress, I am seeing my times getting slower due to the progressive nature of my condition. However, I am working very hard to keep that decline as gradual as possible and that has been the case so far. The bottom line is that I am just happy to be running at all.

Having spoken to other Parkrunners, I have learned that there is great diversity among the field. Many seem to have a story to tell, whether it is recovering from a physical or mental illness or other life trauma. The general feeling I get is that the people at Parkrun really appreciate how good running and walking are for your mental health and general well-being. I could not agree more and having Parkrun milestones to target and basically accumulate as many Parkruns as I can, has made my difficult journey easier over this past few years. When I achieved 50 Parkruns last year I was pleasantly surprised, relieved and even delighted. As I approach the 100 milestone I can scarcely believe how truly blessed I am. I really hope that my battle will continue in a pair of runners among some great friends.

Living with MND By Gerardine Hayes

It is now almost 10 months since I was diagnosed with MND and my life has changed dramatically. After the initial shock and disbelief, I made a decision (with the help of some very positive people) to "make the best" of life!

For the past 30 years, I worked as a Pharmaceutical Sales Representative covering all therapeutic areas within the Republic of Ireland and attended conferences all around the globe. My last role was working in Oncology, where millions of dollars are invested in research and where outcomes are generally improving for people with Cancer.

To get a diagnosis of MND was shocking enough but to learn that very few treatment options exist was devastating! It was difficult to cope with, knowing that medicine had NOT progressed in the MND area.

I was diagnosed in Nov 2017, then in Jan 2018 I spent three weeks in CUH with pneumonia and needed to use a Rollater after my hospitalisation. Initially it was my legs were affected but I was determined to keep walking with my Rollater for as long as possible. Unfortunately, I now need to use my scooter for getting around and I am using the Rollater less and less.

Thankfully, though my upper body is still reasonably good. I go swimming three times per week with the assistance of the IWA and play traditional Irish music on my fiddle as often as possible. I purchased a wheelchair car, which has hand controls on it, and that has given me huge independence.

The first adjustment for me is my pace of life now and my inability to do activities. When I worked, I drove 70,000km annually, I ran on the sand dunes close to my house and used the gym - all of this is now a thing of the past. The second adjustment was not being able to do personal and house chores - now these are done for me!

While all these changes might sound defeatist, I have been blessed with meeting some wonderful people in the HSE, Home Help scheme, IWA and IMNDA - who are all incredibly supportive. As I live in a rural area, the local community is great and I go to the pub weekly to play and listen to music.

Like everyone else with MND, I don't know how this will progress but I hope for a good quality of life. I hope that a breakthrough will come sooner rather than later for us patients but in the meantime I will try to remain as positive as possible!!

Eating and Drinking with Motor Neurone Disease (MND):

Information, Tips and Easy-Swallow Recipes

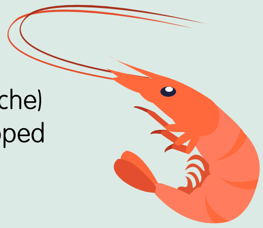
The Motor Neurone Disease Association UK has recently released a guide to Eating and Drinking with Motor Neurone Disease (MND): Information, Tips and Easy-Swallow Recipes. To access the guide you can request a copy from their helpline MND Connect by calling them direct on 0808 802 6262 or e-mail them at: mndconnect@mndassociation.org or alternatively you can view their guide at www.mndassociation.org

Below are two sample recipes to show you what they have to offer:

Fish Pie

A traditional family favourite, but soft fish is also easy to swallow, especially with the sauce. Lovely served with peas that have been puréed with mint, butter and a little cream.

Ingredients
- 600g cod fillet (or a mix of cod, salmon and smoked haddock)
- 50g shelled prawns
- 2 hard boiled eggs, sliced
- 150ml white sauce (or crème fraîche)
- 300g potatoes, peeled and chopped
- Grated cheese



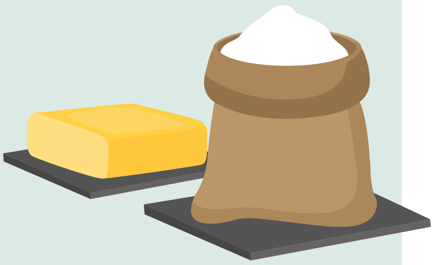
Method
1. Cook the cod or fish (can be poached in milk or lightly fried with shallots and capers for extra flavour).
2. Flake the fish into a casserole dish, taking care to remove any bones and the skin.
3. Add the prawns and sliced egg, then cover with the sauce or crème fraîche. You can blend these ingredients if required, but you may need to add more sauce, crème fraîche or a little milk.
4. Boil the potatoes until soft, then mash. You can add butter and milk when mashing to soften and add richness.
5. Add the potato as the top layer to the dish and sprinkle with the grated cheese.
6. Cook in a fairly hot oven (200o C, 180o C fan oven, gas mark 6) for 35 minutes.

Preparation time: **25 minutes**
Cooking time: **Under 1 hour**
Serves: **2 – 4**

Meat and Potato Cake

A layered dish that can be easily adapted to different swallowing needs.

Ingredients
- 400g meat, minced
- 800g potatoes, peeled and thinly sliced
- 200g onions, sliced
- 400g tin chopped tomatoes or tomato passata
- 1 egg
- 150ml milk
- 15g butter
- 15g plain flour
- 25g grated cheese
- Chopped parsley
- Salt and pepper



Method
1. Place the meat, onions and parsley in a pan with ½ cup of water. Simmer until all the water is absorbed.
2. Add the butter and continue cooking gently, then add the chopped tomatoes and season with salt and pepper to taste. Cook for 20 minutes until the meat and onions are tender.
3. Grease a cake tin and arrange a layer of potatoes at the bottom. Cover with a layer of the meat mix, then potatoes again and so on, finishing with a layer of potato.
4. Gently melt the butter in a pan, then mix in the flour. Gradually whisk in the milk and keep whisking until the sauce thickens. Continue stirring the white sauce for another couple of minutes.
5. Remove the sauce from the heat and beat in the egg and cheese. Pour over the top layer of potatoes.
6. Bake for about 1 hour in a moderate oven (180o C, 160o C fan oven, gas mark 4).
7. Serve with a vegetable side dish. If you need the whole dish to be smoother, blend the meat mix and add to the bottom of the baking dish. Then add a layer of mashed potato on top and pour over the sauce.

Preparation time: **15 minutes**
Cooking time: **1 hour 25 minutes**
Serves: **2 – 4**

How the Family Carers of Ireland Can Help You

Family Carers Ireland is Ireland's national voluntary organisation for and of family carers in the home. Family carers provide high levels of care to a range of people including frail older people, people with severe disabilities, the terminally ill and children with special needs.

Family Carers Ireland provide family carers with emotional and practical supports including:

- In Home Respite Service
- Information on Rights and Entitlements
- Promote the interests of family carers and those receiving care in the home
- Lobby and advocate in an effort to gain recognition and social justice for carers' invaluable contribution to Irish society
- Work in partnership with other organisations to further the interests and welfare of family carers

Family Carers Ireland's national office is based in Tullamore, Co. Offaly. All of the organisation's 25 Resource Centres provide a range of information and support to family carers.

Personal Advocacy

It can be difficult to negotiate the system of health and social services in Ireland; often, individuals feel uninformed, inexperienced or otherwise unequipped for engagement with it. It is not uncommon for them to feel intimidated in dealing with that system, and unwilling or unable to challenge or question its representatives. Family Carers Ireland offers a free personal advocacy service to family carers.

A member of our organisation can accompany you and assist you in dealing with enquiries, appeals and other appointments with health or social service professionals. If you feel you would benefit from this service, please contact Marian Mahon, our Carers Support and Advocacy Manager, at mmahon@familycarers.ie.

Please note that this service is subject to funding limitations, but we will do our utmost to support carers wherever we can.

Below are some of the payments that you or a family member may be entitled to:

Carer's Allowance is a payment for people who are caring on a full-time basis for someone who requires full-time care and attention and will require it for at least 12 months. You must satisfy a means test and the habitual residency condition. If you get Carer's Allowance you are entitled to a Free Travel Pass and may be eligible for the Household Benefits Package (only if they are living with the person they are caring for or the cared for person may be eligible in their own right) which includes Free Electricity or Natural Gas Allowance and Free TV Licence. You will also be entitled to the annual Carers Support Grant of €1,700.00 (which is paid on the 1st Thursday of June each year).

Carer's Benefit is a payment made to insured people who leave the workforce to care for a person(s) in need of full-time care and attention. You can get Carer's Benefit for a total period of 104 weeks for each person being cared for. This may be claimed as a single continuous period or in any number of separate periods up to a total of 104 weeks. However, if you claim Carer's Benefit for less than six consecutive weeks in any given period you must wait for a further six weeks before you can claim

Carer's Benefit to care for the same person again. If you are caring for more than one person, you may receive payment for each care recipient for 104 weeks. This may result in the care periods overlapping or running concurrently.

The Carer's Support Grant is an annual payment made to carers by the Department of Social Protection. Carers can use the grant in whatever way they wish. You can use the grant to pay for respite care if you wish, but you do not have to do so. In June of each year (usually on the first Thursday of the month), the Department of Social Protection pays the grant automatically to carers getting Carer's Allowance, Carer's Benefit, Domiciliary Care Allowance or Prescribed Relative's Allowance from the Department. Only one Carer's Support Grant can be paid for each person receiving care. The grant is €1,700.00.

If you require any more information on any of the above please do not hesitate to contact our: National Freephone Careline: 1800 24 07 24 Website: www.familycarers.ie Charity Number: CHY 10962

FUNDRAISING

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.

Keith Kerwick organised a beautiful memorial event in memory of his father. The Kerwick family and supporters released lanterns into the sky at Ballylynch Remembrance Garden and raised an amazing €1,760.09. Thank you so much to Keith & all involved.

The IMNDA would just like to say a special thank you to the Andrew Lydon Trust Fund committee. As per Andrew's wishes, an incredible contribution of over €8,500 was bequeathed to the IMNDA. This sizeable donation will enable the IMNDA to fund much needed services for people living with MND. Thank you to Andrew, his family and the Trust Fund Committee for their amazing generosity.

CARD TRICKS

Big thanks to Ellen Simmons who organised her annual card drive which raised a superb €2,215!

Thanks also to Carmel Niland & all from Galway Education Centre Bridge Society who donated €500 to the IMNDA from their charity bridge game.

Isobel Brooker and all from St Clare's Bridge Club in Carlow also played a bridge night for the IMNDA and raised a brilliant €150. Thanks to all involved!

Thank you so much to everyone from Naas Trumps Bridge Club for taking the time to organise a bridge night in memory of John McGaley, which raised a truly fantastic €700.

EGG-STRA EGG-STRA!

We just want to say THANK YOU to everyone who took an Easter Hamper this year and raffled it off in local bars, cafes, shops & workplaces across the country. The campaign was a huge success once again and it is thanks to you! Another egg-citing year with an egg-cellent €25,784 raised!

FUN-RAISING

The IMNDA would like to say a big thank you Peggy & Elizabeth Kelleher for organising another very successful Ceili in Fossa Community Centre in Killarney which raised a superb €2,150. Well done ladies!

Big thanks to Jean & Erica O'Brien & Joan Kelly who opened their beautiful garden in Cahir and raised an amazing €1,234. Thanks also to Mary Phelan & Sharon Nugent who held a Plant & Bake Sale in Dungarvan which raised a fantastic €1,225.10.

Big thanks to all from Woodcock Hunting Ireland and Streete Wildlife Club who organised 2 clay pigeon shoot fundraisers in memory of Luke Kiernan and raised a phenomenal €3,077.

Car lovers & families flocked to the Grand Hotel in Malahide for the Malahide Lions Club 7th annual Classic & Vintage Motor Show which was supporting the IMNDA this year. A fantastic day was had by all and they revved up a whopping €3,000 for the IMNDA

Nursing Service. Well done to all involved!!
Thank you to all from Naas Country Market who held a fundraising day for the IMNDA and raised €620.

Marian Callaghan Coyne once again put together the fantastic annual 'Hot to Trot' Pony Drive in Frenchpark, Roscommon. There was a great turn out on the day which was followed by a brilliant night's entertainment and refreshments in Farrell's Public House in Frenchpark. The ponies trotted home with a fantastic €1,020, which local IMNDA Ambassador's Pauline Breslin Lynch & Thomas Lynch kindly accepted on our behalf. Thanks so much to Marian, Seamus and everybody who contributed to the event so generously.

SCHOOLS

Killina Presentation Secondary School in Tullamore performed a Lip Sync battle and raised an amazing €1,614. We can't thank the staff and students enough! Special thanks to IMNDA Ambassador Emma Kinsella who represented the IMNDA on the day.

The CSPE and LCVP students along with their teacher Ms Coffey in Marist College, Athlone organised various fundraising events including fancy dress and a cake sale raising an amazing €1,154.95! Well done to all involved.

Thank you so much to everyone from Moate Community School for kindly donating the fantastic proceeds of €200 raised from a non-uniform day at the school.

We would like to say a massive thanks to all the 5th & 6th class pupils from Lisdoonan National School in Carickmacross who chose the IMNDA to benefit from their business project in conjunction with the Local Enterprise Board. The children got crafty and decided to make and sell thread bracelets raising a brilliant €443.04. Well done all!
Big thanks to all the students from The Kemmy Business School at the University of Limerick who chose the IMNDA to benefit to from their Charity Ball. They raised an outstanding €1,212.26. Thanks also to Michael Clancy who kindly accepted the cheque on our behalf.

Thank you so much to everyone from Cashel Community College who organised various fundraising activities as part of AIB's Build a Bank project, such as a makeup masterclass, a table quiz and a bake sale which collectively raised a fantastic €250!

COFFEE TIME!

The ever popular coffee mornings proved once again to be a timeless treat. Stacks pharmacy in Lusk treated their customers to some coffee & cake and raised a lovely €158. Thanks also to KPMG who held a coffee morning and raised a fantastic €125.60 and McGreals Group Pharmacies who held coffee mornings in Baltinglass & Blessington and brewed up a superb €1,700. A special mention to Margaret & John Delaney for all their tea & coffee mornings down through the years. They held another incredible event this year - super work guys!

TRACTOR RUNS

Michael O'Mahony had more than horse power on his side when he organised the annual Baltimore Tractor Run. They raised an outstanding €4,700. Well done to all involved.

Thanks also to Teresa King, The Colgan Family and all from the Fivealley Inn, Birr who organised a tractor run and auction, which raised a super €6,170! Streete Parish Park Vintage Committee raised a fantastic €1,000 from their Philip Moran Tractor Run. Amazing!

JUNE POLO IN THE PARK

The garden party of the summer 'Polo in the Park' took place in the Phoenix Park on June 9th. Attendees were treated to gourmet food, bubbly, live music and a six team Polo

Competition for their viewing pleasure. This glamorous affair organised by the June Ball Committee was once again a huge success raising an amazing €14,250. Thank you so much to all involved.

BENEFIT NIGHTS

We want to say a massive thank you to Joy Buchanan & all the members of Donegal Presbyterian Choir who held a charity concert for the IMNDA. Their beautiful songs gathered an amazing €1,571. Special word of thanks also to local IMNDA Ambassador Charlie Boyle who represented the IMNDA on the night.

Irish philanthropist organisation 'FiftyTwoWords' hosted their third event, titled 'Hope', at 'The Liberty Hall Theatre in Dublin on the 29th of June. This inspiring evening explored the meaning of the word 'Hope' through personal stories, perspectives and talks. A fantastic €515 was raised on the night. We would like to thank John Murphy & Diarmuid O'Flynn for organising this event and all the speakers and people who supported it.

Huge thank you to Irene Cafferky who organised a very successful ladies maxi dress fundraiser in the Fourways, Kilmovee. An amazing €1020.00 was raised on the night for the IMNDA. Special thanks to all the ladies who came in their lovely maxis and helped out on the night, Kieran Regan for nominating the IMNDA, Brian Duffy of the Fourways, Kilmovee for providing the venue, music and food, those who donated spot prizes and especially to everyone who gave so generously on the night. The IMNDA would also like to thank Gemma Coleman who kindly accepted the cheque on our behalf.

A huge thank you to Willie Wolfe and all from St. Kieran's Dance Club in Cloughjordan who held their annual social dance, which raised a toe-tapping €1,425!

The documentary 'The Window in Heaven's Gable' was made by Ed O'Connor to honour the late Kieran Gleeson, a keeper of the flame of cinema in North Kerry for thirty years until he sadly passed away from MND. The fantastic proceeds of €2,260 from the screening of the documentary in Kieran's cinema, The Classic in Listowel, were donated to us by Kieran's fantastic wife Teresa and children Alice and Ciaran. We can't thank them all enough.

A fun evening of BBQ & 80's Music took place in aid of the IMNDA in the National Yacht Club in Dun Laoghaire. The event was organised by Margaret Ryan and raised a sizzling €5,470! Margaret also organised a Drink Tea for MND event in Benitos Restaurant in Dalkey and raised a superb €890. Thank you so much to Margaret and all who supported these wonderful events. We would like to say a huge thanks to the Munster Association of Referees for choosing the IMNDA to benefit from their 2018 Presidents Dinner. A fantastic €1,000 was raised. A special mention to IMNDA Ambassador Michael Clancy for representing the IMNDA on the night.

CELEBRATIONS!

Love was in the air when Frank & Una Cassidy celebrated their 50th wedding anniversary in the Conyngham Arms Hotel in Slane. They kindly asked for donations in lieu of gifts and raised a whopping €2,030! Thanks also to Anna Cosgrave & her husband who collected a fantastic €1,500 for the IMNDA at their 40th Wedding Anniversary Party. Congratulations from all at the IMNDA!

Thank you to Patsy & Paul Garland who asked for donations in lieu of gifts for their 70th birthday celebrations raising a fantastic €1,845 in memory of Sharon Friel. Laura Tully also raised a brilliant €1,360 in memory of Jan Battles during her 40th birthday party.

Big thanks to everyone who included the IMNDA in their birthday celebrations this year, through parties and Facebook birthday fundraisers, you are a very generous bunch and we hope you all had wonderful birthdays. Hip-Hip-Hooray!

MOCK WEDDING

The official cheque presentation took place in September with our board member Jonathan Healy and the key players from from February's tremendous Mock Wedding which raised an HUMONGOUS €126,195.00!!! We would just like to express our gratitude to Eileen, Tom, Bernie, Joan and all the Boland and O'Connor families as well O'Connor Utilities Ltd for their unbelievable generosity. Thank you to the many companies who donated and everyone in the local community who supported the event and attended.

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

Corporate Partnerships

Goodbody

At the beginning of 2017, Goodbody Stockbrokers took a more focussed view on their charitable contributions and selected one charity to work with over a two-year period. We were the lucky chosen charity!

As this hugely fruitful 2 year partnership draws to a close Goodbody have raised a tremendous €85,000 for the IMNDA through fundraising events such as white collar boxing, 6-a-side football, staff cycles, 'Ton of Cash' initiative, a fire and ice walk, raffles and Drink Tea for MND events. Aside from the monetary contribution, Goodbody used their expertise in various areas to help us develop a good corporate structure; they donated raffle prizes, provided volunteers for events, attended our AGM to give invaluable financial advice to our clients and helped us to become GDPR compliant.

They were also the key sponsor for the Good Run in St Anne's Park, Raheny in 2017 and 2018.

The IMNDA expresses a huge thank you to all in Goodbody for the last 2 years and we hope this isn't really goodbye!

DAA

Cristīona Ò Broin is a brilliant ambassador for the IMNDA within the DAA who have been taking part in various events throughout the year including cycles, Run-a-muck, Hell & Back, a World Cup tournament & family day and raffles! The DAA has also helped to spread awareness by generously giving the IMNDA free advertising space in the airport. Cristīona, please keep up the great work – we are proud to have you as our charity champion!

Central Bank

In July we got the wonderful news that we had been chosen as one of Central Banks 5 charity partners for 2 years! The charity committee kindly invited us into the Central Bank to present to staff members. It was a great opportunity to tell the employees a little bit about the work we do and how they might be able to support us over the next 2 years. We look forward to working with you.

Irish Life

Our Irish Life partnership continues and the employees have been very busy raising funds for their two charity partners, the IMNDA and Remember Us. Many employees took part in Hell and Back and the Great Dublin Bike Ride and a number of other smaller events have been taking place in the workplace.

Payroll Giving continues to be a huge source of income for the charity partners and we are very thankful to everyone who donates every month.

Irish Life have also helped the IMNDA to make an awareness video and will be volunteering their time to help us out during the busy periods leading up to Christmas. Thank you!!

Customer research in Gas Networks Ireland raised over €13k for charities in 2017

Gas
Networks
Ireland

The IMNDA is delighted to announce that we are one of the lucky charities to benefit from Gas Networks Ireland's support in 2018 along with Aware, Simon Community, Irish Cancer Society. Every time a Gas Networks Ireland customer fills out a customer experience survey, Gas Networks Ireland give us a donation.

"We are delighted that our process aimed at driving continuous improvement for our customers also generates some much needed funding for hugely important services," said Marie Lyster, Customer Experience Manager, Gas Networks Ireland. "While our customers are generally willing to provide honest and constructive feedback we find that the opportunity to play a part in generating funds for charity is welcomed and appreciated. It's a nominal amount per customer but it all adds up for the charities".

Marie added: "On a year to year basis we assess which charities our customers would like us to support via this process so in effect, they select the charities. In fact, our decision to include IMNDA for 2018 came about following a particular piece of research with a GNI business customer who had been diagnosed with Motor Neurone Disease and who contributed to our process to enable us to identify improvements. So, when he asked if we could consider supporting IMNDA, we didn't hesitate to make this possible".

Please keep the IMNDA in mind if you (or somebody you know) works for or has links with a company that choose a charity to partner with or support in some way. We would love to have the opportunity to apply and/or present to the Charity Committee. The IMNDA has developed close corporate relationships over the years and has vast experience with a broad range of companies, small and large. Thank you.

Solid Joys Lasting Treasure - a wonderful and memorable evening!

Kilbride Community Centre, Fourmilehouse, Co Roscommon was transformed from sports hall to concert venue and filled to capacity (500+) on Friday 18 May to celebrate the life and ministry of Canon Liz McElhinney.

The evening was based on the reading of Canon Liz's poetry, by renowned actor, Ian McElhinney -written following her diagnosis of Motor Neurone Disease. This was complemented with beautiful singing by local choirs, Cór Comáin and the Convent of Mercy Chamber Choir and soloist, Nicola Browne from Lurgan, Co Armagh and with traditional Irish music by Sean Hanily Music Group, (Sean is a Roscommon native.) Organist Carl McCambley, also from Lurgan accompanied the above as required and also the hymns that were sung by all in the hall.

Compere for the evening was Bishop Ken Clarke and the opening welcome was given by Fr Raymond Browne, Parish Priest of Kilbride and the final blessing was given by Bishop Ferran Glenfield.

The poems were accompanied by well-chosen visual images, displayed on screens and three video clips were also shown – 'The story behind Liz's poetry collection' by Dr Sharon Heron; 'IMNDA – Care and Research' and 'Faith and Hope in the midst of MND' – a clip recorded for YouTube by Liz herself.

There was also a brief interview with the son-in-law of Lanesborough man, Joe Farrell who also suffered from MND but who had developed a friendship with Canon Liz before either of them were struck by the disease.

Whilst the mood throughout the evening was one of celebration and a joyful occasion, as befitted Canon Liz, there were, nevertheless lumps in throats and tears in corners of eyes as the reality of the terrible disease that is MND was poignantly highlighted at times, particularly by people who knew Canon Liz and Joe Farrell but there were many people present who, whilst knowing neither of the above people, were touched by the emotion in the video clips and interview and the overall atmosphere.

Each person present received a copy of the booklet of poems written by Canon Liz on admission and further copies on the booklet and CDs of Ian McElhinney reading the entire collection were available to buy afterwards.

Sponsors, to whom we are very grateful, covered all the expenses of the night. A fantastic €6,000 was raised on the night.

The IMNDA would just like to say a huge thank you to Susan Compton, Cyril McElhinney and all involved with organising this wonderful event, you really went above and beyond and we are so grateful for all your hard work. Well done!

Global Awareness 2018 & Drink Tea for MND

"My children are slowly becoming my hands. For now, I can still make a cup of tea and give them a hug," said Róisín Foley

Róisín Foley from Drimnagh bravely fronted our National Awareness campaign this year in June. The single mother of three beautiful girls noticed her hands were weak and she was having difficulty tying her laces on her 30th birthday. After months of tests, in September 2017 she was diagnosed with Motor Neurone Disease.

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

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

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

The campaign ran throughout the month of June to mark Global MND/ALS Day on June 21st. Róisín appealed to people to Drink Tea for MND and to organise Tea Days in their homes, communities and work places. Róisín featured on a radio advert that ran on the National airwaves, she did countless interviews and even made an appearance on TV3's Ireland AM.

Thanks to Róisín's encouragement, over 310 people did just that, they baked and brewed and helped spread the word about MND. We can't thank Róisín and everyone enough for their support and want you to know it truly has made an impact.

A special mention to our sponsors SuperValu who provided the teabags and chocolate bars and also held tea events in many of their stores – thank you!

Tea days took place right across the country, from Donegal to Dublin, in Cavan and Cork! We had the whole of Ireland drinking our SuperValu tea bags and we raised over a teatastic €195,000!!! This phenomenal amount is all thanks to Róisín and you!! We cannot thank everyone enough for the incredible support.

Thank you for Getting Active for your Association

ON YOUR MARKS!

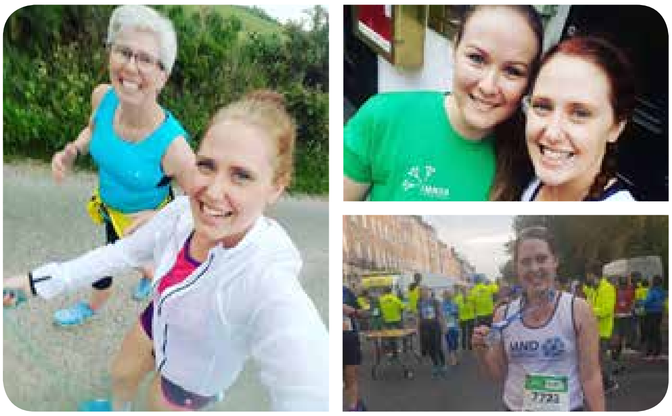
A massive thank you to everyone who put their trainers on and ran, jogged or walked for the IMNDA. We appreciate you all beyond words!

To all the fabulous women who took part in the VHI Women's Mini Marathon, every year you blow us away with your support. Together this year, you raised over €44,000, amazing! Thank you to each and every one of you! Special mention to Linda Garvey, Rosh Farrell O'Donovan, Jude Bromley, Catherine Meere, Sonia & Clodagh O'Donoghue, Kathleen Walsh, Joan White, Marie Gallagher, Lea Moore, Mary, Eleanor & Marilyn McGrath, Sandra Rothwell & Rita Morley, Sharon Barry, Jane Reilly & the girls from Team Sonny, Catherine Slevin & friend Patricia, Orna O'Beirne, Clare Kavanagh & friends Mary & Jane.

Huge thank you to everyone who completed the Cork City Marathon, we had some absolutely amazing participants this year, your hard work and stamina certainly paid off raising a combined total of €12,283 for the IMNDA! Special thanks to Julie Egan, Amy Byrne, Cliodhna Carroll, Rory O'Connor & Mark McColgan. You should all be very proud of yourselves!

Massive thank you to Padraig Leddy, Mark Matthews and all of 'Team Petes' who took on and smashed the Drogheda 10K in memory of Peter O'Keeffe. They crossed the finish line with an amazing €5,224.28 for the IMNDA. Well done to you all!

Claire Kelly is a marathon runner and fundraiser from Aberdeenshire, North East Scotland. Claire took on the ultimate challenge when she decided to run 12 marathons in 12 days while raising funds for MND Scotland and for the IMNDA! Her adventure started in Scotland, crossing to Belfast and then taking her down to County Laois. She raised an impressive €887.80 for the IMNDA. Thank you so much Claire! We know how much hard work you put into training, you are a true inspiration!



A BIG thank you to Olivia Sexton & family and all who helped organise 'The Good Run 2018'. They raised an incredible €17,000 from this year's run in St.Anne's Park for the Irish Motor Neurone Disease Association and Project MinE Ireland. Fantastic amount!! It was a brilliant event and we are already looking forward to next year! Well done guys!

Thanks to everyone who took part in half and full marathons this year - Caroline Farrelly smashed the London Marathon. Roisin Gilroy & Erica Balfour completed the Connemarathon. Joseph Gallagher completed the Edinburgh Marathon. Well done to you all!

PEDAL POWER

Gerry Barnes & fellow members from Hillbillies Cycling Group organised a cycle and walk in memory of former member, John Ryan who sadly passed away. The event was aptly called Cycle & Walk for John. 50 cyclists and 30

Thank you for getting active for your Association!

walkers took part on the day and together they raised an amazing €6,661.81

John's family were blown away by the amount of people who got involved and for their generosity. As were we! We cannot thank them all for their unbelievable support. The event was such a success that on Saturday 13th July 2019 they plan on doing it again and everyone is welcome to join. Keep your eyes out for more info on this via our website and Facebook page. Here are a few lines that Ciara Ryan wrote about their Dad John:

'Our Dad was a man of few words. I remember asking him on New Year's Eve for a list of 'What I should do?' in a range of different situations and scenarios – along the lines of something you'd read about in Tuesdays with Morrie, because I knew his days were numbered. He said "Live a good life. Live a happy life." It wasn't the answer I wanted, but as always, Dad was right. Nobody is promised tomorrow. We only get one draft at life, so it's important to make it a good one while we can.

Last July (2017), I tried to organise a party for Dad's 58th birthday. Having reserved a venue, and sent a save the date… his response was "Sounds great, but just to let you know I won't be going". Our Dad touched on so many lives, but he hated being the centre of attention. If the tables were turned, Dad would have always been the first to sign up for a cycle or walk for his own family, friends and acquaintances, without fail. Our Dad was a gentle and loveable person who was there for everyone. We were lucky to have had him in our lives for as long as we did, and to have made such memorable moments with him, which will always fill our hearts.

Thank you to all you joined us as we cycled and walked in memory of our Dad on his birthday weekend. I know he was with us in spirit, guiding us every step of the way.
I hope that the moneys raised will help other patients and their families live a good and happy life, as best they can, following their MND diagnosis. The IMNDA provided us with so much support and kindness during Dad's short illness. Your continuous commitment and dedication goes above and beyond the call of duty. We are forever grateful to you all'

Huge thanks to John Hynes and Panda Power for organising the annual East Meath Cycle which took place on the 12th of August. There was a super turnout at Stamullen GAA where participants took on a cycle of 45k, 70k or 100k through the beautiful Boyne Valley and together raised a fantastic €5,450. Well done to all involved. Special mention of thanks to Peter Devine for accepting the cheque on our behalf.

The D2K cycle first started in 2001 and over its 6 years raised over €250,000 for the IMNDA and Paul's Fight for Life during this time. This was the final and biggest year yet. Over 150 cyclists took to the road from Dunleer to Ballinasloe and wheeled in the kilometers with the euros. On their Last Hurrah the cycle collected an incredible €96,000!!! Paul Lannon and Sandra Fox you have outdone yourselves!! Well done to absolutely everyone who made this possible - from sponsors, local businesses, cyclists and of course Paul and Sandra. Amazing guys!! Sandra and Paul, you always go above and beyond. We are eternally grateful for all the effort you have put in down through the years. Thank you, thank you, thank you!

WALK TO D-FEET

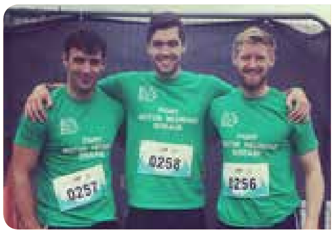
This year our annual 'Walk to D-Feet MND' took place in the Phoenix Park, Dublin on July 21st. We had a great turnout on the day, even some deer joined in the fun! The family fun event raised a smashing €9,000. Thank you so much to everyone who came along!

GOLF

Thanks to the Liam Maher Golf Society who raised a brilliant €1,100 from their annual golf outing. Big thanks also to everyone from Tramore Golf Club who held a charity night and raised a smashing €400.

FUN-RAISING

Alan Gould, Michael O'Connor & Frank Melody took on Tough Mudder in Co Meath and absolutely smashed it, bringing home a fantastic €1,663.50 for the IMNDA. Well done lads!



Westbourne Community Group in Clondalkin organised a 5K fun run. A great day was had by all and a superb €1,233 was raised! Thanks to all involved!

CLIMBS

We would like to say a huge thank you to John Kelly and all who organised and participated in another very successful 'Sunrise Up Croagh Patrick' climb to benefit the Irish Motor Neurone Disease Association, Young Parkinson's Ireland and Huntington's Disease Association of Ireland. Over 150 people joined them on the day including IMNDA Nurse, Eithne Cawley. A Special mention of thanks to Fergal O'Neill who went above and beyond when he completed a marathon across the Sahara desert to support this event! Overall a phenomenal €4,346 was raised. Thanks to all involved!

Thanks also to Elizabeth Dardis who climbed Croagh Patrick and raised a fantastic €250. Julie Reilly & family also climbed Croagh Patrick and raised an impressive €1,406 in memory of Tony Dean. Well done!

Killian McCarthy took on the challenge of a lifetime when he climbed Mount Kilimanjaro for the IMNDA. He arrived back home with an outstanding €1,398. Well done Killian!

Christina Byrne 50 5ks in 50 days!

In July 2017, my Mam Joan was diagnosed with MND. It started with a slur in speech and now she can no longer speak, eat or swallow. When I found out - I cannot explain all the thoughts and feelings I felt at that time and what was going through my head felt like the world was crashing down on top of us. To be honest to this day, it is hard for all of us to accept but we take each day at a time and I treasure every minute I have with my Mam, as does she with the grandkids and us.

I work in the search unit in Dublin airport. Every year the DAA pick three charities and fundraises throughout the year to the three charities. Last year they made €300,000 for the charities. I planned from September 2017 to get in touch with the IMNDA and tell them I would do whatever I could to get the charity voted in for 2018. Myself and my partner in crime who also works in the DAA, Denise got our team of canvassers together and worked tirelessly to get IMNDA voted in which was a success.

We have had book sales, raffles, race nights, breakfast mornings, and our sponsored silence in February and many more events planned. We are doing fantastic!

It is great organising all these events but I thought I could be doing something outside work as well. A personal challenge, something that would keep my mind going, and something I have not done before. So I set myself the challenge of 50 5Ks in 50 days. Not an easy task for me let me tell ya!! And this coming from a person who hates running!!

I was extremely nervous about this challenge as I was not confident on whether or not I could complete it and didn't want to let people down, my family the most, especially Mam. I went into the challenge with no training what so ever, which was not very clever of me.

My first week I died every day in that heat. I started in July - all that good weather we were getting was amazing but not for running in ha!! I was struggling one or two kilometres in but I kept going as long as it took to get to the 5k. I think my first one was about 45 mins. My second week I ran on my night shifts in work on break. That was fun running around the airport at night ha.

I fitted the runs in when I could, whatever times they were they had to be done. There were days I really struggled getting out especially when I was on shift but once I did, I forgot all about that, I just had to keep thinking of the reason why I was doing it and of course the support from my family and friends kept me going.

I met up with people along the way – friends, teammates and family ran with me, which made it easier. Moreover, all the support from people on social media was a boost. I have some great pictures to keep. I finished up on the 27 of August. My last run couple of running buddies came along to support. I thought I never would make it to 50 but I did it!! I had all my family and friends waiting at the finish line and of course my Mam, who everyday was my inspiration for this challenge.

Living with MND is hard. It is so hard to see the person who you love the most in this world be affected so much by this disease. We are a strong knitted family. We are blessed in that sense and a great support for each other. The IMNDA are brilliant. Eithne, my Mams nurse, is a wonderful lady who is always just a phone call away. We take the simple things for granted so much. Eating, drinking, telling your family how you feel.

That was taken away from my Mam. Life can change so quickly. It is hard to accept but you have to learn how to and my Mam is a fantastic example of a fighter who won't ever give up. I get that strength from my Mam. I see how amazing and strong she is, her unbelievable bravery. I am so proud to call her Mam. Despite everything, that has happened these past couple of years, she keeps going no matter what is in front of her and so together, we are fighting against MND and will continue to do so. Thank you all for your continued support and of course all your donations you guys are all amazing x x

OATLANDS

OCT 25

iMNDA CARE AND RESEARCH | Irish Motor Neurone Disease Association

rmn Research Motor Neurone

OATLANDS COLLEGE *presents*

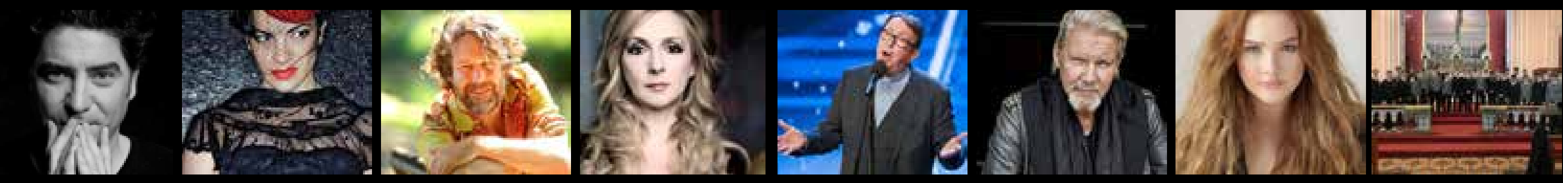
#SINGWHILEYOUCAN

LIVE CONCERT

In support of Fr. Tony Coote fundraising for Irish Motor Neurone Disease Association & Research Motor Neurone

BRIAN KENNEDY
CAMILLE O'SULLIVAN
LIAM O'MAONLAÍ
MOYA BRENNAN
FR. RAY KELLY
JOHNNY LOGAN
ZENA DONNELLY

featuring Special Guests &
Oatlands College Choir conducted by Sinéad Rodger



Tickets €30 | 7.30pm | Oct 25 | **Church of St. Therese Mount Merrion Dublin 4**

TICKETS AVAILABLE FROM EVENTBRITE

https://www.eventbrite.ie/e/sing-while-you-can-tickets-49885462762

WALK WHILE YOU CAN DONATE & GET INVOLVED WWYC.ie Twitter @oatlandscoll Facebook

Walk While You Can

"Tony Coote is my name. On the Wednesday of the beginning of the recent snow in Ireland, I was told I had Motor Neurone Disease. Like others who have received such news, I was terrified and my body went into shock. Around this time someone asked me to remember that, 'the diagnosis is not the prognosis'. I have repeated that in my head as a mantra every day. I have also committed myself to living each day, looking to the future and choosing to live rather than exist.

I am a priest in the Dublin Diocese working in Kilmacud and Mount Merrion parishes. I used to play squash twice a week and was always on the go thinking of the next plan and idea. This illness has slowed me up and for the first time since I was a child I fall over easily and have to watch the ground as I walk.

Since I was diagnosed I realised the only medication is 24 years old and that the Motor Neurone Disease Association can only provide three nurses for the whole country with just over 400 people living with this illness. Their salaries are paid for through fundraising.

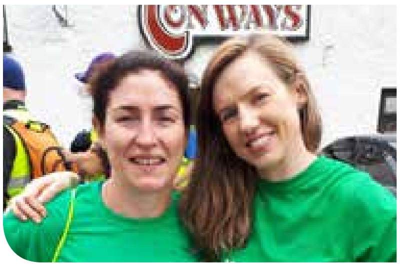
Rather than just complaining about these facts I want to use my time and my voice to do something about it"

Never one to be struck down by adversity, Tony decided to walk the length of Ireland to raise funds and help highlight the need for further funding in this area.
Fr Tony Coote and his incredible team walked over 550Km from Donegal to Cork from 10th July to 6th August. Courageous, inspirational and extraordinary are only some of the words we can use to describe Tony and his Team. They walked all the way from Letterkenny to Ballydehob and let nothing stand in their way. Over 500km marched in all sorts of weather with countless helpers shaking buckets, supporters and walkers - everyone involved deserves a huge shout out including the people in the small towns who opened up their homes, community centres, pubs and kept the Walk While You Can gang fed and watered along the way.
We cannot thank you all enough!!!

So far an absolutely enormous €450,000 has been raised for the IMNDA and Research Motor Neurone.

Thank you, thank you, thank you to everyone who got involved along the way!

There is still time to get involved and support Team Tony and his fundraising endeavours. Visit www.wwyc.ie for more information



Following on from the huge success of last year's Reindeer Runs which took place in various locations and raised a total of €45,000 – the IMNDA is looking for people to get on board this year and organise your very own Reindeer Run.

Christmas is a time for getting together with friends and family so why not round yours up on Saturday 22nd December in your local community and walk or run 5k before the Christmas indulgence really gets going! It might just be a handful of you or you could invite your entire village. It's up to you. Contact the IMNDA to register your Reindeer Run and we can send out t-shirts. Thank you! **fundraising@imnda.ie**

IN AID OF THE IRISH MOTOR NEURONE DISEASE ASSOCIATION

STILLORGAN ORCHARD

FEATURING
JUMP THE GUN
HOLD UP
BIG DIGGER
ALAN SOMMERVILLE BAND
PLUS GUESTS, DOORS 9PM

ALL PROCEEDS GO TO THE IRISH MOTOR NEURONE DISEASE ASSOCIATION (IMNDA)
TICKETS €20 AVAILABLE ONLINE AT WWW.IMNDA.IE/SHOP

ROCK
FOR MOTOR NEURONE

SATURDAY 3RD NOVEMBER

Irish
Motor
Neurone
Disease
Association

Sometimes Silence Speaks Volumes

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

This February we are asking you to take on a sponsored silence to experience what life is like for someone living with MND. How would you cope not being able to communicate? Just pick a day, time and location where you will take on your sponsored silence and then contact us on fundraising@imnda.ie or 1800403403 for your Silence Sponsor pack.

Spread the word on social media by using #Voice4MND and text MND to 50300 to donate €2 (100% of text goes to IMNDA across most network providers. Some providers apply VAT which means a minimum of €1.63 will go to IMNDA. Service Provider: LIKECHARITY. Helpline 076 6805278).

Nominate friends and families to join you. Sometimes silence can speak volumes. Take on our challenge this February. Don't let someone with MND suffer in silence; don't let them live without a voice.

We just want to make a special mention to Paul and Lilian Carroll. They fronted last year's campaign, which was our biggest silence yet. Sadly, Paul lost his fight against MND in June. Paul was an incredible character and he will be greatly missed. We cannot thank Lilian and Paul enough for all they did for us and to highlight awareness of MND. Rest in peace Paul.

Irish
Motor
Neurone
Disease
Association

Support the Irish Motor Neurone Disease Association this Easter

Easter Sunday
Sunday 21st April 2019

Easter Weekend is approaching & the IMNDA is offering beautiful Easter hampers (containing Butler's chocolate eggs, bar, bunny & a chick!) for you to display and raffle in your local pub/shop/club/ workplace etc. the busier the location, the better!!

Raffle sheets will be provided for each hamper, lines are to be sold at **€2 each.**

To order your hamper/s & arrange delivery please contact the office: **1800 403 403** or email **fundraising@imnda.ie**

Thank you for your support!

Closing date for orders is
12th April 2019

Please remember the IMNDA incurs a cost for each hamper delivered so please only commit to the raffle if you are confident of selling the lines.

IMNDA, Coleraine House,
Coleraine Street, Dublin 7
Freefone: 1800 403 403
www.imnda.ie
CHY 8510

ROCK FUNDRAISER 2018

SATURDAY

29

DECEMBER 2018

GARBO'S CASTLEBAR

SOCIAL WELFARE

DOORS AT 7.30PM

ENTRY €10

THE NEW SOCIAL

SPECIAL GUESTS

CIAN MORRIN | JAMES COLEMAN

ALL DONATIONS WELCOME

ALL PROCEEDS GO TOWARDS THE

IRISH MOTOR NEURONE DISEASE ASSOCIATION

iMNDA CARE AND RESEARCH | Irish Motor Neurone Disease Association

EDITORS DESK

In Remembrance

Those we love remain with us

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

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

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

Jan Battles
Teresa Berry
Josephine Bradley
Bobby Brady
William Burchill
May Burns
Joseph Carey
Paul Carroll
Eileen Concannon-Burke
Hugh Conroy
Fergus Corcoran
Olive Costello
Francis Cray
Daniel Dowd
Declan Downes
Patricia Doyle
Helena Duffy
Mary Duggan
Frankie Farrelly
Mary Fleming
Olive Friel
Thomas Gibson
Barbara Haynes
Tony Healy
Esther Healy
Colin Hodgins
Seán Holland
Ellen Jeffrey
Jimmy Johnston
Evelyn Kinsella
Jean Lacey Kerr
Elizabeth Lydon
Eimear Lynch Rowe
Joe Martin
Martin McGinnity
Mini McKenna
Patrick McMahon
Mary McNamara
Carmel McTeague
Bernie Nolan
Fr. Ailbe O'Bric
Sharon O'Brien
Brendan O'Brien
John O'Connor
Kathleen O'Donovan
Eoin O'Duffy
Anne O'Sullivan
Marie O'Sullivan
Tony Reumerman
Pauline Reynolds
Zdzislay Stolowski
Matthew Sweeney
James Sweeney
Bob Thomas
Gerard Tunn
Sheila Tyrrell
Donal Walsh

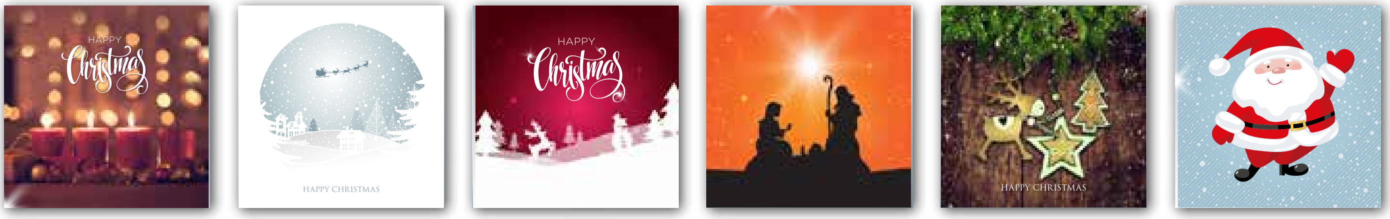
Annual Memorial Service

On Saturday 24th November we would like to invite everybody whose lives have been touched by Motor Neurone Disease to come together with family and friends and join us in remembering those we have sadly lost to MND. Our Memorial Service will be taking place at 12pm in the Capuchin Friary, Church Street, Dublin 7. Guests will have the opportunity to light candles to remember their loved one on the day. Music will be performed by St. Fergal's Gospel Choir. After the service, everyone will then be invited for some refreshments. To attend this commemorative event please email **info@imnda**.ie or call **01-8730422**.

Christmas Shop

Christmas Cards

Pack A



Pack B

Spread a little bit of IMNDA festive spirit this Christmas by purchasing a pack of our charming Christmas cards! The cards are €10 per pack of 12 cards (including postage) and each pack has 6 different designs (2 of each design). This year you will be spoilt for choice as we have 2 different sets of design for you to choose from.

Buying a pack and sending our cards is a simple and effective way for you to help us raise awareness. Please fill in the order form enclosed with your newsletter and return to the IMNDA or freefone **1800 403 403**.

Hang a Star

Our special Irish wooden stars are a small token to hang up during the festive period in memory of someone special or to hang in support of a relative or friend. We chose the star as the light of a star continues to shine long after the star itself is gone. Our stars can be purchased from the IMNDA online shop or by completing the order form included in the Newsletter. Each star is €10 and this includes postage.

Have a Cuppa & a Mince Pie with the IMNDA!

Everyone is welcome to our Christmas Coffee Morning where our Grand Raffle Draw will take place on Tuesday 11th of December at 11.30am in the Richmond Room, Carmichael House, North Brunswick Street, Dublin 7. We'd love to see you there and you might even win a prize! Please RSVP by emailing **fundraising@imnda.ie** or call **01 8730422**.

Awareness Video Appeal

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

To highlight the support that is required to keep people living at home, we are hoping to film with someone living with MND. It would require a few hours of recording in your own home. If you feel this is something that you would like to get involved with – we would love to hear from you! All you have to do to register your interest is email **pr@imnda.ie** or call Maeve on **01-8286617**

Thank you!

Staff Update

We have had a few changes in the IMNDA and are delighted to welcome three new members of staff.

Róisin Duffy our new CEO started in July and brings more than 20 years' experience in leadership, fundraising and communications. Róisín is responsible for the day-to-day financial management of the organisation and for delivering on its long-term strategic objectives. She is committed to advocating on behalf of people living with MND, their families and carers to ensure that they have access to the very best support services available. A strategic and innovative thinker, Róisín is also committed to diversifying the IMNDA's income streams to ensure a sustainable income model is in place to support the on-going and evolving needs of the organisation. We are thrilled to be working with her and look forward to the next few years under her tutelage.

Johanna McDonagh is our new Information and Support Officer. She started in May and her role revolves around providing information, advice and advocacy services to people with Motor Neurone Disease, their families and carers. Johanna will be liaising closely with the MND specialist nurses and acting in an advisory capacity to the multidisciplinary team involved with the motor neurone disease community. Johanna will be on hand to write Support Letters for applications for the Medical Card and Housing Grants, to source information on issues such as Benefits and Allowances and the Fair Deal Scheme. To get in touch with Johanna all you have to do is email jmcdonagh@imnda.ie or call the office on Freephone 180003403.

Finally yet importantly, Paula McNally-Krenn is our new Office Administrator. She is the third staff member to be sponsored by Arthur Cox as the Loretto Dempsey Placement. Paula will be a point of contact for those with MND and their families. She will be liaising with our MND Nurses, healthcare professionals and our Stores Manager concerning provision of services to clients.

ARTHUR COX

To Róisín, Paula and Johanna – welcome to the team!!!

IMNDA Board Update

We are delighted to welcome two new members to our board.

The first being Norman Hughes. Norman Hughes is a Qualified Financial Advisor and Consultant with more than 20 years experience within the Financial Services Industry. Norman left his position as Head of Change in Permanent TSB bank to set up his own consultancy practice in 2013. Living in Dublin, married to Siobhan and father to 3 great children, Norman is a keen rugby supporter and a member of St Mary's College RFC where he coaches the underage teams.

Having lost his brother Karl to Motor Neurone Disease in late 2016 and having witnessed first-hand the services provided by the IMNDA, Norman joined the Board of IMNDA in December 2017 to honour Karl and 'give something back'.

Lillian McGovern also joined Norman on the IMNDA Board this year. She has worked at a senior level in the voluntary sector for the last twenty years. From 1998 to 2004 she held the role of Chief Executive Officer with Victim Support in supporting victims of crime nationally by building a national network of support services. Having completed an MSc in Organisational Behaviour from Trinity College, Lillian took over the role of Chief Executive with the Marie Keating Foundation in 2006 and held this role for a further seven years.

Since 2015 Lillian has worked with the National Children's Hospital Foundation, based at Tallaght University Hospital where she is responsible for managing the affairs of the Foundation to support the work of the hospital. Lillian will be a great addition to the board and we look forward to learning from her expertise.

Leave your gift for the future, leave a legacy

Irish
Motor
Neurone
Disease
Association

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

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

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

My Legacy Week is taking place from 29th October to 4th November 2018. For more information visit www.mylegacy.ie

Thank you for considering leaving a gift to the IMNDA.

You've been so generous, now it's the taxman's turn

We at the IMNDA are continuously so grateful for the generosity of people like you, our donors, who keep our vital services going. You allow us to provide care and support for families with Motor Neurone Disease.

Charities in Ireland, like the IMNDA, can reclaim tax on donations that equate to at least €250 during one calendar year as long as the donation is made by an individual (i.e. not raised from a fundraising event or through a collection). The donation doesn't have to have been made in one go so if you have a standing order set up and give €21 a month or more then we can reclaim tax.

If you are PAYE Tax Payer and kindly donated €250 or more in any one year please help us make your donation go further, without spending any more money. By reclaiming the tax you have paid on this donation your donation could be worth a further 40%!

This is how it works (based on a €250 donation):

Higher Rate Taxpayer – 40%

You donate €250 (thank you!)
We apply to the Revenue
The IMNDA receives a further €174 from Revenue
Total amount received by the IMNDA thanks to you: €424

Standard Rate Taxpayer – 20%

You donate €250 (thank you!)
We apply to the Revenue
The IMNDA receives a further €62.50 from Revenue
Total amount received by the IMNDA thanks to you: €312.50

All you need to do is complete, sign and date a CHY3 Enduring Certificate and return it to:
IMNDA, Coleraine House, Coleraine Street, Dublin 7 - we will do the rest.

To get a form posted to you please call Gemma or Jackie in the IMNDA on freefone 1800 403 403 or you can download one on the Revenue website **www.revenue.ie/en/companies-and-charities/documents/charities/chy3-enduring-certificate.pdf**

Due to changes to the tax reclaim system for charities you can opt to complete one tax back form (CHY3) which is now valid for five years – so if you choose to continue to donate over the next five years you do not need to complete another form.

Thank you!

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Neurone
Disease
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Registering your Fundraising Event

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

To register and receive promo items / lodgement slip etc:

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

Thank you for your support and co-operation.

Irish Motor Neurone Disease Association
Coleraine House, Coleraine St, Dublin 7

Freefone: 1800 403 403 **Fax:** 01 8731409
Email: info@imnda.ie

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Contributions to the next edition of Connect:

If you would like to submit a story, photo or there is something else you would like to share please email pr@imnda.ie

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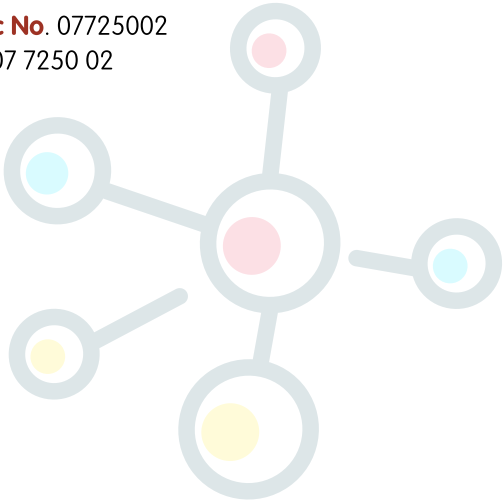
AIB, Capel Street
Sort Code: 93-13-14 **Acc No**. 07725002
IBAN: IE32 AIBK 9313 1407 7250 02
BIC/SWIFT: AIBKIE2D



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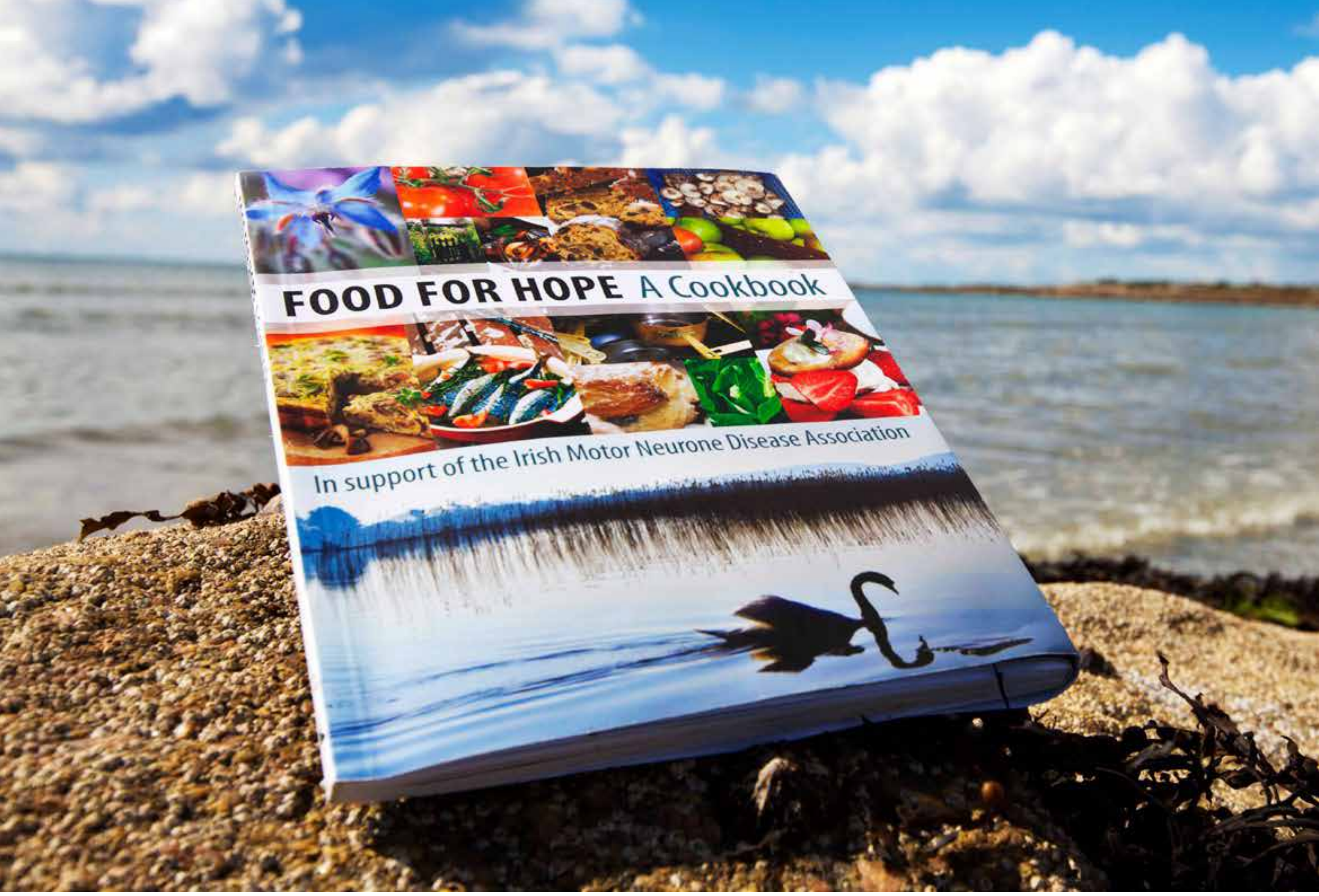
Support People with Motor Neurone Disease by purchasing the IMNDA Charity Cookbook for just €10

FOOD FOR HOPE A Cookbook

A collection of more than 60 recipes from a host of Irish Celebrities

All proceeds go to the Irish Motor Neurone Disease Association



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