IMNDA
CARE AND RESEARCH

CONNECT

ISSUE
18

Autumn 2017

"Farewell to our Patron Jimmy Magee"

IN THIS ISSUE...

- AGM & PATIENT AND CARER WEEKEND DUNDALK 2017
- LIVING WITH LOSS SEMINAR
- ANDREW BRENNAN'S STORY
- CHRISTMAS SHOP

CONTENTS

CONTRIBUTIONS TO THE NEXT EDITION OF CONNECT:
If you would like to submit a story, photo or anything else you would like to share please email pr@imnda.ie / info@imnda.ie or Freefone 1800 403 403.

A NOTE FROM OUR CEO

On behalf of the IMNDA, I would like to welcome you to the last Edition of the Connect Magazine for 2017. It has been a busy year once again for us in the IMNDA and we have had many high-points but a few low too. Unfortunately we sadly lost our friend and patron at the end of September, the legend that was Jimmy Magee. Gemma, has written a beautiful tribute to our dear friend, we echo the nation of Ireland when we say we will miss him greatly. Rest in Peace Jimmy. Any good organisation plans constantly. We are thrilled to once again launch our 2017 – 2020 Strategic Plan. This plan involved many people being consulted, surveyed and asked for their views on what we are doing and how we could change, improve and do better. We consulted a large number of clients and their families and carers, along with our staff and Board members. Three key Strategic Priorities have been identified in an analysis of the data gathered from the 199 questionnaires that were sent to our families.

Strategic Priority One – Support people with living with MND
Strategic Priority Two – Connect and Communicate about MND
Strategic Priority Three – Strengthen our Organisational Presence and Capacity

It is the intention of the Board to adopt and subscribe fully to these three Strategic Priorities and it is the intention of our staff to implement them fully. Further details of the individual aims and actions within each priority will be launched with the plan in the immediate future. Another good piece of news is that the IMNDA is now one of only 50 charities in Ireland to achieve the Triple Lock status that is awarded through the Charities Institute of Ireland which works very closely with the Charities Regulator. Its triple lock standard is a stamp of transparent reporting, best practice in fundraising and good governance. You can find out more details about this on our website.

A sincere thank you to all of our families and supporters, as always we could not do this without you. As we enter a new phase with our new strategic plan I feel that the IMNDA is stronger than ever to provide the essential services that are required by our MND families.

Aisling Farrell

Aisling Farrell
CEO

DIARY DATES DO SOMETHING SPECIAL IN 2017

07th OCT

CROKE PARK ABSEILS
Hogan Stand, Croke Park Stadium, Dublin
7th October 2017

29th OCT

DUBLIN CITY MARATHON
Dublin City - 29th October 2017
www.sseairtricitydublinmarathon.ie

29th OCT

LIMERICK WOMEN'S MINI MARATHON
Limerick City - 29th October 2017
www.limerickminimarathon.ie

25th NOV

MEMORIAL SERVICE
Capuchin Friary, Church Street, Dublin 7
25th November 2017 @ 12pm

13th DEC

ANNUAL GRAND RAFFLE DRAW & CHRISTMAS COFFEE MORNING
Richmond Room, Carmichael House, North Brunswick Street, Dublin 7
Wednesday 13th December @ 11:30am

Registering your Fundraising Event

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

To register and receive promo items / lodgement slip etc:

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

Thank you for your support and co-operation.

iMNDA
CARE AND RESEARCH
Irish Motor Neurone Disease Association
Coleraine House, Coleraine St, Dublin 7.

Freefone: 1800 403 403 **Fax:** 01 873 1409
Email: info@imnda.ie

www.facebook.com/irishmnd2011

@IMNDA

IMNDA Bank Account details:

'Motor Neurone Disease Association'
AIB, Capel Street, Dublin 1
Sort Code: 93-13-14 **Acc No.** 07725002
IBAN: IE32 AIBK 9313 1407 7250 02
BIC/SWIFT: AIBKIE2D

Disclaimer

This newsletter provides information only. The authors have no medical qualification whatsoever unless otherwise stated. No responsibility for any loss whatsoever caused to any person acting or refraining from action as a result of any material in this publication or any advice given can be accepted by the IMNDA. Medical advice should be obtained on any specific matter.
MEDICAL PATRON Dr. Aisling Ryan MB, PhD, FRCPI, Consultant Neurologist
PATRONS: Arthur McGuinness
DIRECTORS: Declan MacDaid (Chairperson), Alison Gray (Hon Treasurer)
Bernie Conolly, Katie Hallissey, Jonathan Healy, Angela Hogan, Orla Clayton

iMNDA
CARE AND RESEARCH

OUR HIGHLIGHTS FOR 2016

5827
Nursing Support Calls

€1,754,827
Raised

43
Professional Education & Information Sessions Held

456
Clients & Families Supported

€524,459
spent on specialised equipment

6,646
Health Care Professionals Accessed our Nursing Service

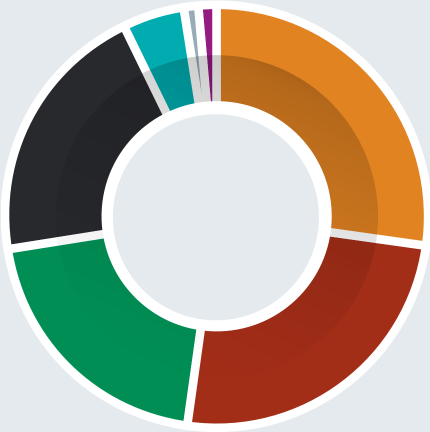
598
Nurse Home Visits

82%
income raised from Fundraising

13,000+
Home Care Hours Funded

HOW WE MANAGE OUR FINANCES

WHERE THE MONEY CAME FROM...



2016 INCOME:

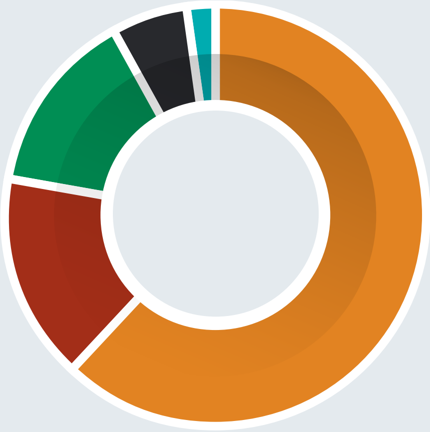
€1,754,827

23%	IMNDA Events
21%	General Fundraising
17%	HSE
17%	Sporting Events
4%	Corporate
1%	Restricted Nurse
1%	SSNO

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



2016 EXPENDITURE:

€1,770,503

62%	Services
16%	Dedicated Nurse Service
14%	Fundraising
6%	Governance & Communication
2%	Research

In 2016 the IMNDA spent the money you raised in the following way:

- **62%** went directly on the services we provide to families living with MND
- **16%** was spent on our vital nursing service
- **14%** was spent on Fundraising to ensure we have a steady income flow to fund our services
- **78 cent** of every **€1** raised goes directly towards services
- **6%** 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

NEWS & RESEARCH

AGM / Patient & Carer Weekend Dundalk

In September of this year, the IMNDA's AGM, Annual Conference and Patient & Carer weekend took place in the Crowne Plaza in Dundalk. The event was well attended with over 110 delegates coming along. The business part of the weekend took place on Saturday morning where the IMNDA's Board of Directors reviewed the operations and financial performance of the organisation in 2016.

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 was Aisling Farrell, the IMNDA's CEO. She welcomed everyone to the conference and thanked people for their generosity and support throughout the year.

We were then treated to a thorough outline of the importance of neuropsychology in MND by Dr. Tom Burke. He explained that Neuropsychology is a specialism within the field of psychology and clinical psychology concerned with the cognitive, behavioural and emotional impact resulting from damage to, or disease of, the brain. Very often there is cognitive dysfunction associated with a diagnosis of MND. Neuropsychologists would use cognitive and psychological tests to examine changes in a person's cognitive and behavioural functions.

Tom explained that the most common cognitive domain affected in ALS is what they call the Executive Function, the part of the brain that controls ones attention and can impede a person's ability to plan, think and problem solve. It can also affect emotions, behavioural control and personality

Language can also be impaired in ALS/MND, especially in the form of word-finding difficulties, and difficulties with comprehension. Patients may present with memory and speech difficulties, where they find it linguistically difficult to express themselves or find it hard to process information. The most prominent behavioural symptom reported in ALS however is apathy, which is defined as loss of motivation, initiative or interest.

Another symptom is disinhibition and this can manifest as a loss of manners or a new onset of socially inappropriate behaviour. A person may display reduced awareness or a broad lack of insight and this may be reflected in poor judgment.

Neuropsychologists can provide diagnostic/therapeutic intervention for changes experienced by patients and can assist in therapeutic supports and supply family members with information to help them cope. Currently there is ongoing research to try and further unearth the complex nature of cognitive/behavioural change, and the psychological impact it can have. Clinical interventions are being trialled to investigate efficacy and effectiveness of treatments and therapies.

After Tom, another member of the research team in Trinity College took the podium. Dr Marie Ryan is a Neurology Registrar and she spoke about how to find the best treatments that work for MND. She went through past trials of MND and looked at why they had failed and what the future of drug trials look like in Ireland.

MND is a complex disease that affects everyone very differently, now rather than trying to find one single treatment they are looking at designing specific treatments to target patient subgroups. She explained this as the tailoring of medical treatment to the individual characteristics of each patient, based on the ability to classify individuals into sub-populations that differ in their susceptibility to a particular disease, in the biology and/or prognosis of those diseases they may develop, or in their response to a specific treatments.

In order to create precision drugs, they first need to define and discover the subgroups of MND patients. Researchers are constantly learning more and more each day about MND, they now know that MND and some psychiatric conditions are casually linked. Treatments are likely to come from unlocking the genetic makeup of MND and by finding causative genes it is hoped that this will provide the key in understanding why some people develop MND and some people develop psychiatric conditions. This may help us prescribe drugs to help target these particular subgroups.

However, we are dealing with very complex population genetics. Currently scientists are studying different populations to try and see if people from different ancestral origins have different disease susceptibilities. The hope is that by unearthing how certain genes interact and the role they play in someone's genetic makeup they will understand the biological pathways that cause /protect against diseases. If they can find and understand these pathways, they can develop new drugs (or re-purpose old ones).

They now know that most MND is caused by interaction between genes and environment. The work that is being carried out in genetics and in neuropsychology is really helping to define patient subgroups. For example some patients may exhibit cognitive and behavioural impairment whereas others may not. So far they have 3 classes of subgroups:

1. No thinking problem
2. Mild changes in thinking
3. Severe changes in thinking

Using all that they have learned thus far it is hoped that the development of new drugs to target these subgroups will lead to more fruitful drug trials. Coming up in 2018 there will be four drug trials ready to start. This is very promising, the more trials they have, the more they will learn and hopefully this will translate into better treatments.

After Dr Marie, our CEO Aisling then spoke about the Government's upcoming Public Consultation on Home Care Services. This is a great opportunity to inform the Minister on the current state of home care in this country. The Minister is looking for submissions from everyone so we are urging people to take this opportunity to inform the future of health care in this country very seriously. Aisling took the time to take everyone through the submission form step by step. Submissions can still be made by completing the consultation online at **http://health.gov.ie/consultations.**

Then it was the presentation that everyone had been waiting for – it was the man of the moment, Michael Clancy chatting with Jonathan Healy on his experience of the IMNDA National Awareness & Drink Tea Campaign. For once Mr. Healy didn't get a word in edgewise as Michael spoke of his life since diagnosis and how he found sharing his story with a nation. Michael spoke and we were all left enthralled. A compassionate and cheeky hero who had Ireland drinking tea like it was going out of fashion! You will read more about Michael and the campaign later on in the newsletter.

Next up Maeve Leahy spoke about changes to our logo from Jan 2018. More will be discussed on this in the Editors Desk Section. After hearing Michael Clancy speak, Maeve spoke about the need to share our family's stories and how impactful real life stories can be and encouraged people to get involved with raising awareness. Whether it was fronting an IMNDA awareness campaign like Drink Tea or the Sponsored Silence or whether it was submitting an article to the newsletter – we are always open to hearing from everyone who has been impacted by a diagnosis of MND. Another way of engaging with creating awareness is to volunteer for the filming of a new promo video for the association. At the moment we are currently looking for people who wouldn't mind getting filmed for an awareness video that we are hoping to do. It would not entail too much but it would involve someone coming into your house and filming you doing a few daily tasks. We want to highlight the impact of MND and the supports that are required. We are looking for involvement from carers and people living with MND so please let Maeve know if you would be interested in taking part by emailing pr@imnda.ie or calling 1800403403.

Marie Reavey then took control of the microphone as she explained about our recently launched initiative, the IMNDA ambassador programme. IMNDA Ambassadors play a vital role in representing the IMNDA at local events and functions, attending cheque presentations and giving talks on the IMNDA and MND. We have ambassadors in several counties across Ireland but we are always looking for more – to find out how you can become an ambassador please email mreavey@imnda.ie or call the office on 01-8730422.

After the conference talks were over, Gemma Watts presented the Silver Pin Recognition Awards to people who contributed to the IMNDA over the last year. The association couldn't 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 Sheila Mantle, Natalie Mason, John Hynes, David Treacy, Olivia Sexton, Tom Dalton, Michael Clancy, Bernie Reynolds, Deborah McArdle, Martina Moran, David Bergin, Jean Maxwell-Greaney and Geraldine Collins. A very special award was given to our miniature hero Senan Friel. Senan is 9 years old and our youngest Ambassador. He even got his first official interview with Jonathan. Well done Senan and thanks again to all our silver pin awardees. These people truly went above and beyond for the IMNDA in 2017.

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!

Research Update by Mark Heverin

Featured Update

The Irish MND Research Group has been busy in the last number of months. We have shown for the first time that MND and schizophrenia may have a shared genetic origin as was mentioned briefly in the last edition of this newsletter. This work, which was led by Dr. Russell McLaughlin and Prof. Hardiman and was published in the prestigious journal Nature Communications was conducted in partnership with the Project MinE consortium. The purpose of this international group is to find the genetic causes of MND.

Project MinE is achieving its goals by analysing the genetic code of 15,000 MND patients and 7,500 healthy people in exquisite detail to discover every gene that contributes to MND. In Ireland, we plan to contribute 700 MND patients and 350 healthy participants to this project along with several key team members and all of the expertise and resources at our disposal. This has already resulted in several important discoveries that are reshaping our understanding of MND genetics:

1. The identification of NEK1 as a major MND gene that contributes to around 3% of cases;
2. The identification of three further key genes (C21orf2, MOBP and SCFD1) that clearly play an important role in modulating risk for MND;
3. A clear picture of how much "background" genetic variation contributes to MND risk;
4. A new understanding of the relationship with other major diseases – as mentioned above the "background" genetic variation that adds to MND risk also increases risk for schizophrenia, which is a crucial finding for our understanding of brain connectivity and its role in MND.

These findings represent the early successes of a project that is gaining momentum and is drawing on resources from research groups across the planet. The important next steps of Project MinE will be to continue to add participants (the project is currently over one third of its way towards completion) and to study all data generated from new and existing perspectives so that our understanding of the genetics of MND is completed. As this continues towards completion, a platform of knowledge and understanding is being laid down upon which drug development will build, which will bring us closer to a cure. This project has been supported by SFI (Science Foundation Ireland) and we are engaged in ongoing fundraising to ensure that we meet our target. More information on Project MinE and how to donate can be found online at **www.projectmine.com/country/ireland/).**

Brief Updates

- MND is less prevalent in Latin American countries. Figuring out why this is the case will help to find new ways of treating MND. For this reason, we have set up a new epidemiology net-work for MND in South America (Uruguay, Chile and Cuba) (funded by the American Center for Disease Control).
- MND presents and progresses in vastly differing forms. Understanding why some people have very fast forms of MND with thinking and behavioural changes, while others have very slow progression is very important. Prof. Hardiman recently received a grant from SFI to look for new ways to understand the different subtypes of MND.
- Dr. Peter Bede was recently awarded a prestigious Health Research Board Emerging Investiga-tor Award to study brain imaging (MRI) in MND.
- PhD candidate with the Irish MND Group at Trinity College Dublin Roisin McMackin received an Irish Research Council award to study EEG patterns in MND.
- New collaborations include a proof of concept study with the Bioengineering Department at TCD (Dr.Bruce Murphy) and the Physiotherapy Dept at RCSI (Dr. Dara Meldrum) in the devel-opment of wearable devices for patients with MND. Finbarr Conroy, medical student supervised by Dr. Deirdre Murray spent 8 weeks this summer on a research placement supported by RMN. The exploratory research was done in partnership with TCD engineering researchers on using sensors to measure breathing and hand movement. This cutting edge research may allow much more sensitive assessment of people with MND in the future. Sensitive measurement will allow researchers to identify effective treatments more reliably.

- MND is also featured in the new Science Foundation Ireland Centre award (FutureNeuro) which is based at RCSI, with Prof. Hardiman's group in TCD as partners.
- Prof. Hardiman, along with Dr. Dara Meldrum and Dr. Deirdre Murray are also coordinating a large European study that measures changes in breathing in people with MND. Enrolment for this study will commence in late 2017.
- Data collection continues on the largest family history project undertaken by the group to date under the coordination of PhD candidate Dr. Marie Ryan. This involves collecting blood samples and detailed family history and neuropsychological measures on MND patients and as many of their close relatives as possible as well as collecting the same information for healthy controls and their families for comparison. Also working on this project is PhD candidate Emmet Costello and for the duration of the summer Marie and Emmet were joined by HRB Summer Scholar Katie Nolan.
- And finally, Prof. Hardiman's group at TCD is a partner on a H2020 funded award to conduct a new clinical trial of a drug (TUDCA) for people with MND which will commence in early 2018. Further details about this trial and how it will be conducted will be available later this year.

Clinical Trials in Ireland by Liz Fogarty

The MND research team here in Beaumont Hospital for the Clinical Trials is based in the Royal College of Surgeons Building on the Beaumont campus. Professor Hardiman, Dr Sinead Maguire, Dr Amina Coffey and Dr Eoin Finegan along with Clinical Research Nurses Liz Fogarty and Siobhan Lee complete the Clinical Trials team. Many of you will already familiar with the Doctors from the clinic setting in Beaumont Hospital.

Currently we have 2 trials on-going for MND patients, one a Phase III with a drug called Tirasemtiv and the other does not involve any investigational drug. These are both closed to recruitment. We are anticipating the results for Tirasemtiv at the end of this year.

There are 2 new trials for MND in the offing. One is funded by the European Commission under the H2020 programme. The trial is to test the use tauroursodeoxycholic acid (TUDCA) as add-on treatment in patients affected by amyotrophic lateral sclerosis (ALS). We anticipate that this will begin later this year or early in 2018. The second trial is for the drug Masitinib. A recent trial suggested benefit, but a second larger study will be required to confirm the finding- probably commencing in early 2018.

Recently we have had a number of patients enquiring on a drug called Edaverone which has now become licensed in the United States of America since 5 May 2017 with the trade name of Radicava. This drug underwent a trial in Japan with a positive effect. It received FDA approval in the US, but the European Regulatory agency has not granted approval. According to the article on Edaverone published in The Lancet in May 201, Professor Orla Hardiman and Professor Leonard van den Berg noted that the effect in the Japanese study was in a very small group of patients with early onset and rapidly progressive disease. Looking at the Irish population with ALS, we think that less than 6% of patients would meet the eligibility criteria.

The European Network for Cure of ALS (ENCALS) has issued a statement and guidelines about the use of Edaravone in Europe. We do not think that the drug should be prescribed in Europe at present. The consensus view of the ENCALS Neurologists is that an extended clinical trial with at least 12 months follow up is required. There is a need to ensure that appropriately selected patients with MND have maximum opportunities to avail of a potentially beneficial therapeutic agent.

The full statement can be found on this link: **https://www.encals.eu/encals-statement-edaravone/**

We pride ourselves on being the centre for clinical trials for MND for Ireland and look forward to developing new and better drugs for people with MND.

On a final note the team would like to acknowledge and thank patients with MND and their families for their help, participation and continued support to the clinical trials.

– Liz Fogarty, Clinical Research Nurse

Response to Consultation on a Statutory Scheme for Home Care 2017

The Department of Health is carrying out a public consultation plan to develop plans for a new statutory scheme for home care services. This is an important opportunity to raise our concerns as all of our families need home help at some point during their MND journey.

The IMNDA are highlighting three main concerns and asks:

Currently home care funding is inconsistent throughout the country.

The IMNDA are asking for a single standardised assessment tool to be used in all health offices. At present, the lack of a single standardised assessment tool means that there are geographical inconsistencies in the nature, type and extent of the supports provided.

The use of a single tool would also make it easier to put in place transparent appeals processes where someone is dissatisfied with the level of care and support that they are being offered.

Currently the main priority for home care packages is for older people (aged 65+)

43% of our clients are under the age of 65. The IMNDA is asking that a centralised, ring fenced fund for intensive home care packages for people of ALL ages who require high levels of support to have their needs met in the home and in the community.

The dividing of services based on age needs to be discontinued. If a person requires supports then there should be a single application and application process that they can follow regardless of age. The current system is discriminatory and confusing for families.

Currently there is a lack of flexibility and lack of engagement with families around the provision of home care services.

Packages should be designed with people with MND and family members as equal partners in the process.

There needs to be more flexibility regarding the way home care is delivered – people with MND and their families need to have more control of when home care workers visit. As needs change weekly/monthly.

Trinity College Research Appeal

Are you the family carer of a person who has been diagnosed with MND?

Do you provide any assistance to a loved one to help with eating and drinking?

Are you interested in taking part in a study exploring your experience of eating, drinking and swallowing difficulties (dysphagia)?

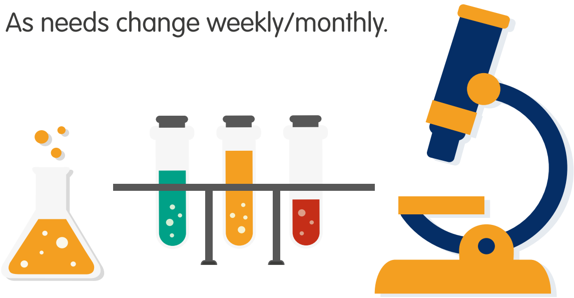
What does the study involve?

Participation in one of the following:

An interview which will take place on one occasion only

OR

Completing written journal entries outlining you thoughts after a meal, on a quarterly basis



OR

Video-recording a meal shared by you and your family member who has been diagnosed with MND, on a quarterly basis

Why do this study?

This study aims to highlight factors that lead to both negative and positive experiences for family carers. It will help confirm successful strategies Healthcare Professionals use in dysphagia management and enhance the way dysphagia care is delivered for people with MND and their families in future.

For more information about participating in this study please contact: Ms. Stacey Daly, Principal Investigator
Department of Clinical Speech and Language Studies
sdaly9@tcd.ie
087 228 9927

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*

Laura Kennedy

*(Columnist with The Irish Times,
freelance writer, journalist and
author of the personal reflection column
'Leavetaking')*

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, 2nd November 2017
5.30pm - 8.00pm
Alexander 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 Laura Kennedy 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 Fax: 01 6730040

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

** Tea/Coffee will be served throughout the evening*

*This event is kindly
sponsored by Fanagans*

FANAGANS
EXCELLENCE IN FUNERAL CARE

LIVING WITH MND

Living with MND by Tim Shanahan

In August 2014, I had the honour of having my President's Prize in Cahir Park Golf Club. And as soon as the presentation of prizes was completed, my fellow Officers – Captain and Lady Captain – and I took part in the 'Ice Bucket Challenge', which was doing the rounds at that time. Although I was aware that this was for charity, I had no idea of what charity it was in aid of.

“Twelve months later, I visited my local GP complaining of a weakness in my left hand, neck pains and a slurring in my speech. After extensive tests, some 6 months later, I was diagnosed with Motor Neurone Disease. It was shortly after this that I realised that the Ice Bucket Challenge was actually raising funds for Motor Neurone Disease (MND). Ironic, wasn't it!!!

At the time of my diagnosis, I was advised by the Neurologist that MND was a progressive, incurable and terminal disease, where most patients die within a 3 to 5 year period. Ouch!!

I was advised that there were Clinical Trials happening at that time aimed at finding out the cause for the disease, and also geared towards finding a cure. I was invited to test to participate on these trials, but it was also clarified that even if or when a cure would be found that any symptoms that had occurred in me would be irreversible. Despite this, I signed up for Clinical Trials. Although it was highly unlikely that something would be found during my life time that would cure me, I went ahead with the trials on the basis that it would give my life a purpose, and in the knowledge that I could perhaps help some other families going through the heartache and suffering that my family are currently going through.

Here I am now, some 20 months after my first symptoms, and although the progression has been relatively slow so far – thank God – life has become much more difficult. First to go was my regular weekend Golf – a small sacrifice in the overall context of things. I hadn't the strength in my arms to lift a club, never mind hit a ball any distance. As a matter of fact, now, I have difficulty in even lifting a cup of tea, or a pint of beer. My hands are becoming more and more useless as using cutlery has become a real burden, putting more and more pressure on my wife, who acts as my helper.

So far, I have maintained my independence when it comes to showering and drying myself. But after showering, I am absolutely exhausted and fit for bed, indicating that before long, my wife will also have to help me with this as well. Fortunately so far, there has little effect on my legs, although my daily walk with our dog is limited to about 20 minutes per day and 4/5 days per week. So I presume it is only a matter of time before this gets worse. All of this deterioration has forced me to give up work since September last.

Despite the level of deterioration that I have experienced, I am quite grateful as I know that there are plenty of others that are considerably worse than me.”

Online support for Family Carers

Are you a Family carer? Family carers need support and now there is a new online support group that you might find helpful.

From September onwards turn2me.org will be hosting a dedicated Online Support Group for Carers with their professional Team.

Their Online Support Groups are completely free but they require booking. The online support groups are run by qualified professionals who ensure every member is respected and heard. To join one of the groups, simply select a group from the schedule on their website **https://turn2me.org/group-supports**

One of their Counsellors will then approve your registration for the group and you will receive an email confirmation. Once the group is scheduled to start, simply logon to Turn2me and the chat window will appear on the site. Members are not permitted to book multiple groups on different topics, so please only select the group that is suitable for your current needs.

For more on this online support forum please see **https://turn2me.org/group-supports**

A Better World for Wheels

Anyone with mobility problems or with friends and family who struggle with mobility concerns know the challenge of getting around. From day to day tasks to day trips out, planning a mobility friendly route can be a struggle without the right information. Fortunately, everyday volunteers can change this with the help of Google Maps.

Better mobility for everyone

Crowd sourcing to improve access information available via Google Maps has been ongoing for a while with volunteers, known as Local Guides, answering access questions about visited locations. Thanks to a petition, Google are now trying to raise even more awareness about this feature. If current Local Guides dedicated time to answer 3 questions a day for just two weeks, there will be nearly 2 billion answers shared on Google Maps. That's 2 billion bits of information for millions of locations that can help the 65 million wheelchair users that need it.

It's not just wheelchair users that benefit from this information either. Anyone with temporary or permanent mobility concerns, or even just mums with strollers, will be able to find more routes and locations suited to their needs. The more awareness raised, the more people may consider access issues when planning a day out, whether it's for a family member or friend.

Become a Local Guide

You can become a Local Guide by joining and making your own contributions to Google Maps and answering the wheelchair accessibility questions available. You can do this:

1. Ensuring Location History is enabled on the Google Maps app on your phone.
2. Go to "Your Contributions".
3. Select "Answer questions about a place" – this can be any place you've been to without wheelchair access information.
4. Answer all the accessibility questions that you can.
5. With Android devices, you can even find places near you that are missing information and make contributions.

You'll find a range of accessibility questions to answer in Google Maps, from wheelchair accessible entrances and restrooms, to seating and elevator facilities.

You can make further contributions by uploading images, focusing on the facilities that matter to wheelchair users and writing a review that highlights the benefits and potential mobility problems. Level 3 Local Guides can also join a meet up or even host one to explore neighbourhoods with others and answer accessibility questions along the way. For more on this please see:

https://www.theramppeople.co.uk/blog/a-better-world-for-wheels

Andrew's Fight Against MND

In 2016 Andrew Brennan fronted the Drink Tea for MND campaign. Now 34 he has started writing a blog – here is how Andrew is getting on;

A few people have asked me to share some of my thoughts, experiences and details on how I deal with the many challenges that I have encountered since my diagnosis. The truth is - all of these often change on a day to day basis but I will do my best to provide some information below and let's see where it goes from there.

~ Andrew

15/02/17 - The Nippy Machine.

The latest member of my treatment aids, a nippy machine or Non-Invasive Ventilation (NIV). My breathing irritates me sometimes; it can take greater effort to inhale mainly when I am lying on my back. So a test was carried out 1 night while I slept to monitor my breathing which showed it dipping at times.

My care team is fantastic and really don't get the credit they deserve. A Motor Neurone Disease nurse and another specialist paid me a home visit to fit me for the nippy and demonstrate it. Basically there's a power unit, a tube and a mask. The theory is it forces air into the lungs when you inhale and holds a small bit of inward pressure to keep my lungs open while I exhale. It won't breathe for me but assist me to give my breathing muscles a rest.

The simplest thing in the world to do, what we all take for granted, the ability to breathe. The single and most important thing that keeps us alive on this earth wants to pick a fight with me. Well I don't think so, I have technology on my side buddy, so ha, be prepared because it's going to be a long fight. I haven't let my girls see me using it yet. I don't want to frighten them so I use it in the evening when they're gone to bed. But they see it and are curious. They ask "what's that?" so we say

"oh that's daddy's mask"

and they seem to be content with that answer. In the near future I hope to introduce them to it some more but for the time being I'm happy to shield them from this nightmare.

22/01/17 - MND stealing my love to drive, my independence, my freedom.

"Driving, one of my favourite things to do is leaving me slowly. I love to drive, the minute I turned 16 I bought a new moped and at 17 my first car. Having invested heavily to get on the road between lessons and insurance I did everything to keep driving, working overtime and part time jobs delivering Chinese food and Pizzas.

My Motor Neuron Disease is trying its best to steal my ability to drive, punishing me every journey as it attempts to defeat me, taking a little energy and restricting my movement more and more every day.

I have a habit of dropping things, the most common being my cars keys. I've dropped them that many times the lock and unlock buttons are no longer in the key; I've lost them, who knows where. When I get them into the ignition it takes all my strength to turn them to start the car, the muscle wastage in both my hands leaving something as simple as turning a key all but impossible. Everything takes huge energy, using the clutch and gear tires me on long journeys."

Identity Crisis by Sharon Friel

“I’m in a constant battle to hold on to my identity these days. I don’t recognise the person looking back at me in the mirror. Practically all the things that made me *me* have departed: I don’t look the same, I don’t sound the same, I don’t move or do things like I used to. Because I’m not the me I used to be.

No longer known as a wife, mother, daughter, sister or colleague; I’ve acquired a new, unique, identity dictated by my poor health. Forever-more I’ll be synonymous with a disease: Sharon + MND = me. That’s the label life has bestowed on me.

It’s practically impossible to hide the impact of a serious disease on your face and body. Regardless of this, I still try. I still like to put on my makeup daily, wear nice clothes, paint my nails and don jewellery. I enjoy my style but most importantly I’m still trying to maintain part of who I was.

Since being diagnosed, I’ve been catapulted on a voyage of self-discovery and I’ve been forced to carve out a new identity for myself. Whilst forging this new identity, I’ve also had to rediscover my purpose and worth in my new altered life. I had lost my self-worth along the way, I was no longer a contributor in life but a taker, or, the worst feeling ever; a burden.

I managed to remain working for two and a half years after my diagnosis, thanks to the support of my work colleagues. For a short time after I retired I still had the energy to do lots and get out and about. It wasn’t until the fatigue hit me that I needed to rest more and therefore didn’t get out as much. That is when my self-worth plummeted. While physically everything has slowed down, a myriad of ideas still swirl around my head. Fortunately writing this blog has given me a new focus and direction for ideas.

My husband said to me recently that

“MND has been the making of me”.

I was shocked at his comment and it took me a while to make sense or perhaps peace with it. This Ted Talk, by writer and psychologist Andrew Solomon helped me understand the uneasy compliment: ‘How the worst moments in our lives make us who we are’.

“You need to take the traumas and make them part of who you’ve come to be and you need to fold the worst events of your life in to a narrative of triumph, evincing a better self in response to things that hurt”.

When a seismic change rocks your life it causes you to re-evaluate everything. While MND has crushed me physically, it has made me stronger mentally. I’m not unique in reacting this way. I know and read about fellow MND patients around the world who have chosen this path too. There’s something about this disease that brings out the fighter in you, maybe it’s the injustice of your body wasting away that spurs on a mental fight like never before.

I haven’t given up on myself yet – I’m determined it will not squash me entirely!”

Sharon x

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.

FUN-RAISING

A massive well done to Kerry Friends of Motor Neurone Disease fundraising group. They have been working tirelessly to fundraise for the IMNDA. They presented us with an unbelievable cheque of over €38,000 from various fundraisers in Kerry! We would just like to say a special thank you to Christy Lehane and all the committee who made this possible.

A big thanks to Catherine O'Connell and the staff at ESB in Aghada who raised a sizzling €178.64 from their Summer BBQ!

Tullow Friends & Tullow Church of Ireland Parish organised a Soup & Lunch Fundraiser and raised a hearty €1,000. Thank you so much!

Well done to Leon Blance and all at Boylesports and the Evening Herald who raised €1,300 from their beat the bookie event. Super stuff!

A huge thanks to Angela Reilly and her Irish dancers who organised a showcase in the Aras Inis Gluaire, Belmullet which raised €300. A great day was had and TD Gerry Coyle presented trophies on the day. Big thanks to all the children who took part and all the local businesses that sponsored the event!

Big thanks to Marian Callaghan Coyne who organised a Pony Drive in Frenchpark, Roscommon and trotted home with €650!

Michael France organised a pool tournament in The Country Club Bar in Limerick which raised a fantastic €1,725. Well done! Massive thanks also to Lisa Fitzgerald and everyone from the Welcome Inn in Buttevant who donated the proceeds from a raffle held at their pool tournament. They had some fantastic prizes and raised an amazing €3,000!

Kilternan Adult Education Committee chose the IMNDA to benefit from the raffle held at their annual art exhibition. The night was a great success and the raffle raised a fantastic €3,800. Thanks to all involved!

Thanks to Peggy Kelleher and all who organised an afternoon Ceili in the Lakehouse in Tousist, Kenmare and for raising the fantastic amount of €3,400!

Well done to Brian Harrison who organised a fundraising night in memory of his nephew and raised a brilliant €1,000 for the IMNDA.

Shannon Molloy and the team at Allure Salon in Athlone held a raffle and a charity day at the salon which raised a beautiful €553!

AFTERNOON TEA

The ever popular tea and coffee morning proved once again a timeless treat! Mary Duffy from Kingscourt held a coffee morning and brewed up a lovely €735.02. Big thanks also to Stacks Pharmacy in Lusk who treated their customers to some coffee & cake and raised a lovely €335. Ailsa Tyrrell & her fellow students organised a cake sale at her school in Luxembourg! They raised €280 - Well done to all who took part.

Tony Dooley held a coffee morning on July 2nd and Pat McGeogh treated everyone at Michael Deery's Pub, Carrickmacross to some songs & stories. Collectively they raised a fantastic €600. Well done!

MUSICAL MADNESS!

An incredible charity gig in aid of the IMNDA took place in Dolan's Warehouse, Limerick with performances from Acoustra, Moondance, Parliament Square and Hermitage Green! It was all thanks to Michael, Erika and all the Clancy family. We can't thank them enough. It was a fantastic evening which raised a super €5,241. Well done to all!!

It was all happening in Tipperary this year! Cahir Looped Walks organised a 'Musical Evening' at Cahir Golf Course which raised a fantastic €2,495. Cahir House Hotel also hosted a night of entertainment featuring the best of local talent and raised a brilliant €5,300. Cahir were even treated to the King of Rock n' Roll himself when John Kendrick organised an Elvis tribute night at the Abbey Tavern which shook up a brilliant €530! We would like to say a huge thanks to all involved with organising these wonderful events, especially Tim Shanahan for representing the IMNDA at various fundraisers in Tipperary!

Darragh Keating and friends organised a charity gig for the IMNDA, they rocked out at Cyprus Avenue in Cork and collected an amazing €2,317.25. Conor Hayes also organised a charity gig in Fibber Magees in Dublin and drummed up a superb €1,320. Well done to all involved!

Derek Ryan organised the fabulous Clonacody'17, a musical picnic in the beautiful gardens of Clonacody House, Fethard. The event was a roaring success featuring the Clonmel Concert Band and over €2,500 was raised. Big thanks to Derek, Helen Carrigan, Michael Brennan and all involved.

BENEFIT NIGHTS

From pims to prosecco, strawberries to straw bales, music, dance, polo and much more, The June Party in the Park was a summer event not to be missed! Organised by the fantastic June Ball Committee, the event took place in the Phoenix Park. It was a great day out and a magnificent €19,314.53 was raised for the IMNDA. Well done to all involved!

The Summer Gala Ball hosted by Micky and Linda Dillon was yet again a superbly glamorous affair! This year the event was held in the Headfort Arms Hotel in Kells and featured Miriam O'Callaghan as the M.C. for the evening with music by Ronan Collins & Band. The evening proved to be another huge success and raised €9,549. Well done to everyone who donned their glad rags and helped make the night such a success! A special thanks to Micky and Linda Dillon, John Archbold and Collette Nugent for once again organising such a splendid event.

The IMNDA would like to say a huge thank you to the Byrne family in Ballinasloe. They held a fundraising night with a raffle and raised the phenomenal amount of €13,700! Padraig Byrne has sadly since passed away, everyone at the IMNDA would like to pass on our sincere condolences to Ann & Family.

Willie Wolfe and St. Kierans Dance Club in Cloughjordan held their fantastic annual social dance and rounded up a toe-tapping €1,550.15. Well done to all involved.

CARD TRICKS

Big thanks to all the wonderful Bridge Clubs that supported us this year; Michael Byrne and Tramore Bridge Club, Anne Brehon and everyone from Strokestown Bridge Club, Angela Burke and Ennell Bridge Club and Ellen Simmons all held very successful bridge nights for the IMNDA!

Margaret O'Grady & Community raised a fantastic €700 from their annual Winter Progressive 45 Card Game. Thanks to everyone who took part!

DRINK TEA FOR MND

Our national awareness campaign was yet again a huge success this year! You can read more about this further on but we just wanted to say a BIG thank you to some of our amazing supporters; Miriam Meaney & Team Martin who held their 2nd event in memory of Martin Wallace and raised an outstanding €7,000. Aoife O'Donoghue brewed up a storm with her tea day and raised a brilliant €1,640. A special thanks also to Ina Ferris who has been a long-time supporter of the IMNDA. Ina has gone above and beyond organising her tea days and has raised over €8,000 throughout the years.

FARM – RAISING

Michael O'Mahony organised the annual Baltimore Tractor Run which proved to be very successful yet again. They managed to raise a fantastic €5,400. Well done Michael & Team!

CHURCH GATE COLLECTIONS

A huge thank you to all our collectors who shake a bucket outside their local church gates across Ireland as well as other street and match collections throughout the year. There are also far too many people to mention who donate to us throughout the year but we are so appreciative of all your donations, however big or small it all adds up.

As ever, the last few months have been packed full of great events so we applaud you all for your efforts and whacky ideas that truly keep us on our feet.

Thank you for getting active for your Association!

PEDAL POWER!

Big thanks to John Hynes and Panda Power for once again organising the East Meath Cycle which took place on August 13th. There was a super turnout at Stamullen GAA where participants took on a cycle of 45k, 70k or 100k and altogether raised a fantastic €4545!

Paul Brennan took on the challenge of cycling the length of the country, from Mizen to Malin! He arrived home with a superb €1,237.50! Well done Paul

A huge thanks to Carrigans Cycle Group. They really put their foot to the pedal when they cycled 320 miles from Galway to Donegal and held a Tractor Run in memory of David Thomas Duncan. They raised a fantastic €5,785! Well done to all involved.

ON YOUR MARKS!

A massive thanks to everyone who put their trainers on and ran, jogged or walked for the IMNDA. We appreciate each and every one of you!

To all the amazing ladies who braved the rain for this year's VHI Women's Mini Marathon – you are our heroes! The medals were well earned with over €30,000 raised for the IMNDA. Thank you so much!

Thanks to Carol Ryan and the Committee of the Glen 5K for choosing the IMNDA to benefit from their annual 5k walk. A brilliant €1,615 was raised! Well done to all involved.

A big thanks to everyone who joined us for our annual Walk to D-Feet in the stunning grounds of Castletown House in Celbridge on July 15th. A great day was had and over €3,000 was raised.

On Good Friday, there was a super turnout of walkers, joggers and runners at St. Anne's Park in Raheny for the third annual Good Run. We can't thank Olivia & the Tracey family enough for organising this. It was a brilliant family fun day with €21,630 raised. Monies were divided between the IMNDA and Project MinE. Amazing result!

Thanks to everyone who took part in half and full marathons this year - Helen Murphy took on the Rotterdam Marathon and flew home with an amazing €1,355!
Well done Helen.

Big thanks to Jennifer Wallace who completed the Great Limerick Run, Caitriona Kiely who completed the Viking Marathon and Stephen Tempany & Aaron Nicolson who completed the Warrior Run. Well done also to Noelle Higgins & Darren Geaney who smashed the Cork City Marathon!

Big thanks also to Pauline O'Donoghue who organised a walk in Achill and raised a fantastic €2,000! Well done!

A special thanks to Breda Kennedy & Damien O'Sullivan who organised a jog/walk from the village of Kilmacow to the top of Tory Hill in memory of Seamus Kennedy. Damien made the challenge even harder by carrying a bucket of ice and bravely doing an ice bucket challenge! The participants then had a well-deserved rest at the top of the hill and were treated to some lovely songs from the High Hopes Choir. Well done to everyone who took part! A brilliant €2245.25 was raised for the IMNDA.

1, 2, 3… JUMP!

Not content with her feet on solid ground, Melissa Corr bravely took part in a sky dive in memory of her Grandfather and landed home with an amazing €3,174.70.
Well done Melissa!

CLIMBS

A huge thanks to John Kelly who along with Teresa Kelly, Sr Jacinta & Team organised a climb of Croagh Patrick on July 1st which raised an amazing €2579.22. Capita Asset Services also took on a climb of Croagh Patrick and raised a fantastic €2,335.37 in memory of their former work colleague Nigel Boardman. Well done to everyone who took part!

Donegal Civil Defence challenged themselves to climb Mount Errigal in support of their long serving member and friend, John Cunningham. They beat the mountain and raised an amazing €4,854.25. Super stuff!

Mary McPhillips took on a trek of Mount Elbrus – Europe's tallest mountain!! Fair play Mary and well done on raising a superb €788.

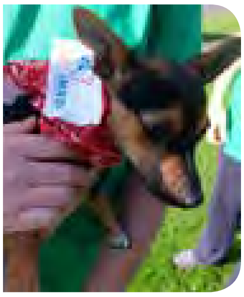
FUN-RAISING

Michelle O'Hanlon is a fitness instructor in Balbriggan who teaches a class called WAR. She held a charity class along with a raffle. A strong €410 was raised! Big thanks to Michelle and all her Warriors and a special thank you to Warrior Cathy for nominating the IMNDA.
Philippa Reid went through Hell & Back to help support the IMNDA and raised an amazing €2575. Thank you Philippa!

Asia and back; 1 bike, 1 man, 2 months, 10,000km! Huge thanks to Adam Gaine who took on the challenge and journey of a lifetime when he rode his motorbike on a solo trip to Asia & Back and raised an amazing €2,947.80 for the IMNDA.

Big thanks to Barry McCabe who organised the annual Paddy McCabe 7aside Tournament. It was a huge success with €2,008.08 raised for the IMNDA.

Chicken Run! Lisa Coen had a hen party with a twist when she gathered her brood of hens and took them on a run in St. Annes Park. They raised a fantastic €1,800. Well done Ladies!



GOLF

To all our golfers out there, thank you! You braved the elements on many occasions ensuring you are not fair weather golfers when it comes to raising much needed funds!

The Finnegan family organised a Golf Classic event at Moor Park in Navan which raised a phenomenal €13,460. Amazing stuff and we can't thank you enough!

Big thanks to The Liam Maher Golf Society who raised €800 from their annual golf trip and all the members of Rathbane Golf Club who raised €500 on the day of the Captains Drive In. Well done to all involved.

Lady Captain of Ballinascorney Golf Club, Rita Flynn organised a golf competition and a tea day. The event was a swinging success with €4537.50 raised for the IMNDA. Special thanks also to Betty Bradshaw and all from Deer Park Ladies Golf Club who raised a fantastic €630 from their Lady Captain's charity event.

D2K Cycle

Many of you may be familiar with Paul Lannon. He often features in our Connect Magazine. Paul was diagnosed with MND in 2011. Since his diagnosis Paul has been very active in creating awareness about Motor Neurone Disease. He is also an avid fundraiser!!

In 2015 a friend approached Paul with the idea of doing a charity cycle. The cycle went from Dunleer where Paul lives with his wife Sandra, to Kilkenny where he originated from and so the D2K idea was born. The first D2K in 2013 saw 26 cyclists taking part and they raised over €12k. In 2014 the numbers grew to 70 cyclists and the amount they raised almost trebled to €34k.

By 2015 the numbers had grown to 112 cyclists and the fundraising to €39,020 and last year the growth continued and the 120 cyclists raised a mind blowing €56,656. This year the route slightly differed as the cyclists headed for Ballinasloe. This year also stood out for another reason – the 139 cyclists who took on the 200Km, raised an outstanding €81,476.28 and it was all raised by 139 cyclists

who cycled 200 kilometres from Dunleer to Ballinasloe in the D2K cycle which has been taking place every year since 2013.

This is a phenomenal amount!! It is no easy fete to raise such a terrific amount and it is no easy fete to continue to organise an event of this magnitude. On behalf of everyone in the IMNDA we would like to say thank you to all the cyclists, all the sponsors and most importantly a massive thank you, congratulations and well done to Paul Lannon and Sandra Fox. You guys are superstars – we don't know how you do it, it is truly astonishing!

Sponsored Silence 2018

Sometimes Silence Speaks Volumes

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

This February we're 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.

Support the Irish Motor Neurone Disease Association this Easter

Easter Sunday - 1st April 2018

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. You could raise up to €400 per hamper and help us to reach our annual target of €40,000!

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

Thank you for your support. Closing date for orders is 23rd March.

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

Global Awareness 2017 & Drink Tea for MND

"I know I sound a bit drunk, but tea is the only thing I've been drinking. My voice is slurred because I have Motor Neurone Disease"

Michael Clancy, or MK as he is known as, bravely fronted our National Awareness campaign this year in June. The father and grandfather was diagnosed with MND in 2016, and is one of hundreds living with the illness across Ireland. Michael had initially tried to hide that his grip was failing before his deteriorating speech prompted him to seek help.

"My sisters were worried I was drinking as I had started to slur my words! It took months of tests but eventually I was told I have MND. I spent the next four days just driving around with tears down my face. I had no idea how me and my family were going to cope", said Michael.

Michael 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.

"This disease has affected my hands so much soon I won't be able to hold my precious little grandson. Soon he won't be able to hear me speak," said Michael.

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

Thanks to Michael's encouragement, over 212 people did just that, they baked and brewed and helped spread the word about MND. We can't thank Michael and everyone enough for their support and want you to know it truly has made an impact.

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 a teatastic €132,000!!! This phenomenal amount is all thanks to MK and you!! We cannot thank everyone enough for the incredible support.

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.

Winnie Callaghan
Padraig Byrne
Joseph Farrell
Edmund McKenna
Michael Kearns
Michael Chandler
Breege Brett
Rory O'Malley
Jim Fitzgerald
Maura Duffy
James Harrington
Michael Connolly
Barry McCarthy
Seamus Kennedy
Martin Giffney
Elizabeth O'Mahony
Noel Langrell
Bridget Fallon
Peter McCourt

Thomas Maher
Annette Kelly
Sean Doyle
Catherine Clarke
Mary Travers
Paul Reid
Richard O'Byrne
Tom Gibbons
Vera Rafferty
Arnold Hickey
Margaret Gabbett
Nuala Armstrong
Jane Kelly
Rita Cosgrave
John Conneely
Walter Herdman
John Harkin
Patricia Thornton

Jane Kelly
Margaret Casey
Deborah Hickey
David Jones
Betty O'Connell
Eileen Kelleher
Maureen O'Brien
Mary Rice
Roy Campbell
Thomas Steele
Shirley Higgins
Anthony Fleming
Evelyn Cullen
Maura Crotty
Tony Dean
Linda Southgate
Monica Meaney
Veronica McCarthy

Ross Coakley
Jerry O'Neill
Dora Hickey
Mary O'Loughlin
Kathleen O'Hara
Margaret Forde
Thomas Donohue
Tony Henry
Stephen Coonan
Sean Radford
Denis Byrne
Sonia Perks
Declan Ryan
Ann Whitty
Kathleen Jones
Joyce Ward
Joseph Harney
Manus McColgan

Remembering Jimmy Magee

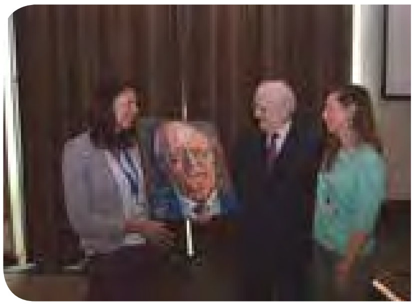
Wednesday 20th September 2017 came as a complete shock to all of us. Despite the fact Jimmy was 82 and we knew his health was deteriorating we did not expect the terribly sad news that was announced on RTE that morning. Jimmy personified life and it just felt that he would always be around, always be at the end of the phone with his wise cracks and jokes and always be in attendance at our events; making time for anyone who wanted to talk to him.

I joined the IMNDA not long after Jimmy's beloved son Paul Magee had sadly passed away from MND aged just 51 and Jimmy had kindly agreed to be our Patron. How lucky we were. Not only was Jimmy so well known and loved across Ireland, he also spoke so eloquently and honestly about losing Paul and helped us raise vital awareness whenever he could. He took his patronage seriously and to heart and emphasised so deeply with our supporters.

We could write a book on the number of things he did for us. He climbed into a boxing ring, swung a golf club, released a charity single, auctioned a greyhound in the pouring rain, managed a soccer team… on crutches; he's even climbed into bed with actress Mary McEvoy to drink tea for MND! The list is endless.

Jimmy never really said no to anything we asked him to do. He was generous to a fault. He never wanted to let us down whether it was attending our AGM or one of our major annual fundraisers. We even sent him along to many events organised by our supporters such as golf classics or table quizzes. He would tell us beforehand he would only be able to attend an event for an hour or so as he needed to work later that evening or the next morning yet hours later he would still be there happily chatting away to people from all walks of life.

Despite the fact Jimmy didn't seem to actually own a physical diary (he alluded to it many times but we never saw it!) – rather random pieces of paper in his top pocket – he always turned up at the right place and on time. He was forever somebody you could count on and nothing was ever too much trouble.



Jimmy was a gentleman who did everything with a smile on his face. He never failed to make us laugh and he truly felt like a friend to us all. I personally was absolutely fascinated and completely bowled over by his sporting knowledge and the superstars he met throughout his life; Pele, Muhammad Ali to name but a few. Well Jimmy you were our superstar.

Having not grown up in Ireland I didn't have those memories of Jimmy's commentary growing up but it soon became apparent to me what a national treasure he was.

I feel truly privileged to have got to know Jimmy so well over the last 9 years and genuinely looked forward to calling him and having the chats ("Is that Birmingham City ringing?" was usually the first thing Jimmy said when I rang!). I'm pretty sure he really thought I was stalking him when I bumped into him in the Excel arena; London at the 2012 Olympics!!

We hit it off from the get go and it was always a pleasure to meet up at the various events we attended together. Even over the last couple of years when he wasn't physically at his best he'd still be there; I'd often give him a telling off for coming along to something when he was feeling so under the weather but that was him to a tea and we will always be so grateful for how committed he was. In March of this year he came to a boxing fundraiser organised by our corporate partner Goodbody that I was participating in. He shouldn't have been there and clearly wasn't well but sure enough like a true professional Jimmy climbed into the ring and welcomed the punters with his usual warmth and humour. After his introduction I told him I'd ring him a taxi so we could get him home to rest; Jimmy turned to me and said there was no way he was going to miss me fight. I was honoured.

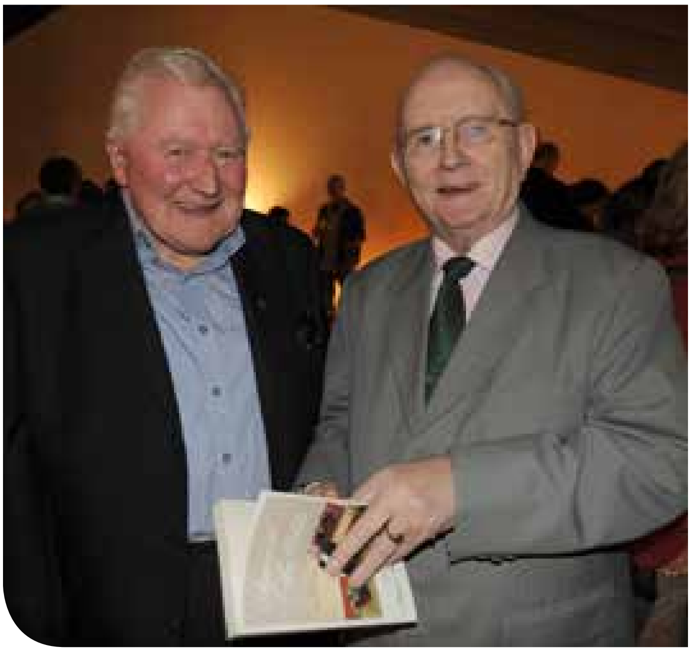
Jimmy; I am sorry we will have no further opportunities to thank you for all you did but hopefully you did know how important you were to us. There will be something missing at our events from now on and you are irreplaceable as our Patron.

Thank you for been a legend. You were a man for everyone and I know every one of us will miss you dearly.

RIP x

Gemma Watts

On behalf of the IMNDA



New Board Member

We are delighted to welcome Orla Clayton to the IMNDA Board. Orla is a member of the Litigation and Dispute Resolution group of Arthur Cox in Dublin, where she provides a wide range of product liability, product safety, regulatory, contractual and commercial litigation advice to companies and organisations within the life sciences, food, beverage, agribusiness, healthcare, cosmetics, consumer goods and retail sectors.

Orla regularly advises on both general and sector-specific EU and national requirements in relation to a wide range of products. Orla has particular expertise in healthcare and personal injuries litigation. She obtained her degree in Law & German from Trinity College Dublin and trained and qualified in the City of London, before joining Arthur Cox. She is a native of Magherafelt, Co. Derry.

Corporate Update

Arthur Cox

Corporate Partnerships play a vital role in the IMNDA. Over the past number of years we have been privileged to partner with many fantastic corporates who have raised awareness and funds for the IMNDA. Sadly our two year partnership with Arthur Cox is coming to an end. It has been an amazing journey for which we are eternally grateful for.

ARTHUR COX

The partnership between Arthur Cox and the IMNDA was inspired by a personal battle with MND by one of their colleagues, Loretto Dempsey. Loretto sadly lost this fight in March but in her memory, Arthur Cox wanted to provide a legacy of support for others suffering with MND by assisting with the services that IMNDA provides day to day. The placement was named the Loretto Dempsey Placement in recognition of their colleague. What a beautiful gesture to a beautiful lady.

Their first sponsored staff placement occurred in 2016. We were very lucky to have Jackie Martin to come on board and assist with all of the IMNDA's fundraising efforts. After the sponsored position ended Jackie stayed on to continue working with the IMNDA team.

The placement worked out so well that we were over the moon when Arthur Cox announced they would be sponsoring a second position and in early 2017 Shauna McGeever joined the IMNDA Team. Shauna assists Tracy and Sarah in our services department liaising with our MND community.

Words can't express how appreciative we are for Arthur Cox's assistance over the past two years. A huge thanks to them for all they have done for the IMNDA.

Goodbody

In January 2017 we were delighted to partner with Goodbody Stockbrokers for two years. Over the past number months the Goodbody staff have run many fundraising events, including a White Collar Boxing night, a Charity Cycle and a raffle raising much needed funds from the IMNDA. We can't wait to see what they are going to do next!!

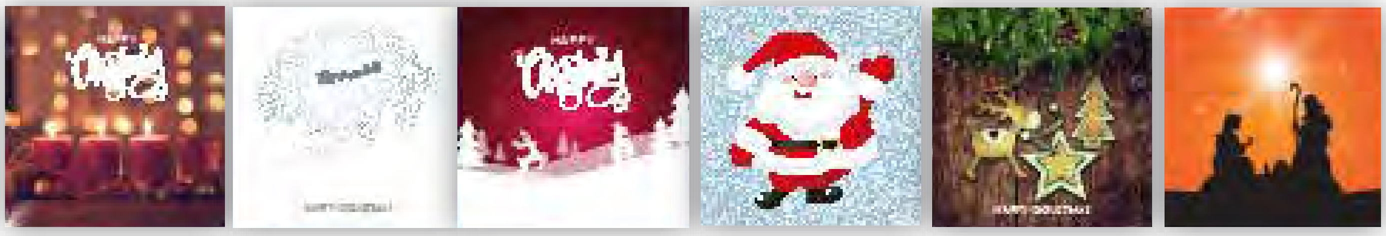
Equifax

A huge thanks to Equifax who chose the IMNDA as their Charity of the Year 2016 – 2017.We were so thrilled to be chosen. They ran many successful events throughout the year including a masquerade ball, a bag pack and a bake sale to name but a few. A massive well done to all the staff who organised the events and to everyone who gave so generously.

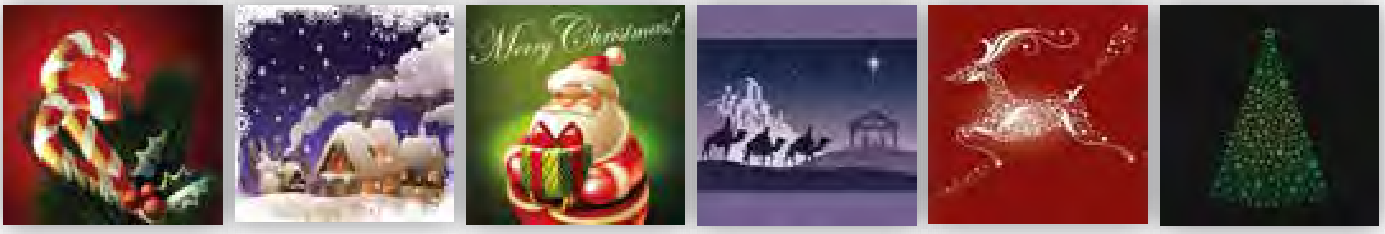
Once again, from everyone here in the IMNDA, we would like to extend a sincere and heartfelt thank you to all of our Corporate Partners. Your support really makes a massive difference and enables us to continue to providing our vital services. If you work for a company or know of a partnership that may be worthwhile us applying for, please get in touch with us. All you have to do is call Marie in the office on (01)8730422 or email mreavey@imnda.ie

Christmas Shop

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 we have 2 sets of cards to choose from. Our latest designs (Pack A), were actually created by Ciaran Moran. He is a graphic designer who sadly lost his father to MND when he was 9 years old. 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

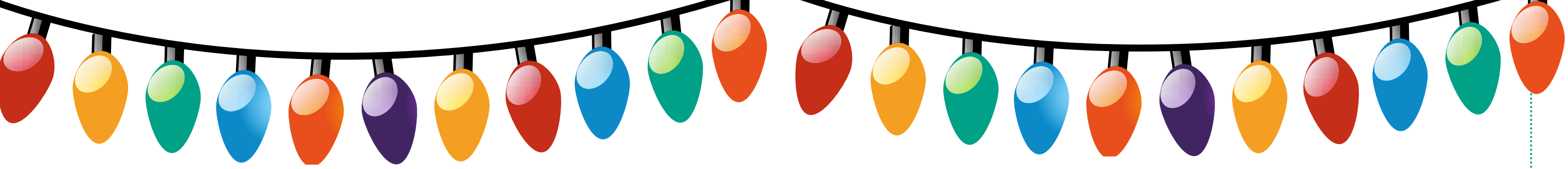
Our special Irish wooden stars are a small token to hang up during the festive period in memory of someone special or to hang in support of a relative or friend. We chose the star as the light of a star continues to shine long after the star itself is gone. Our stars can be purchased from the IMNDA online 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 Wednesday 13th 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.**

Memorial Service

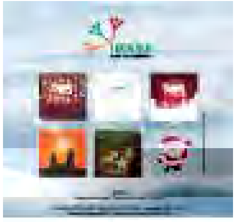
On Saturday 25th November we would like to invite everybody whose lives have been touched by Motor Neurone Disease to come together with family and friends and join us in remembering those we have sadly lost to MND. Our Memorial Service will be taking place at 12pm in the Capuchin Friary, Church Street, 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.



IMNDA CHRISTMAS CARDS 2017 ORDER FORM

Our IMNDA Christmas Cards – 2 fantastic designs to choose from
*Brand new design exclusive to the IMNDA

***A**



B

Why not order our Irish Made Christmas Tree Star Decoration? Only €10 with postage

No. of packs (at €10 each)	Total
A	€
B	€

	Qty	Total
Christmas Star (€10)		€
Food for Hope Recipe Book (€10)		€

Date: ______________________

Delivery Details: (Please complete in **BLOCK** capitals)

Name: ____ Tel No: ________________________________

Address: ____

____

Email: ____

We would like to add your email address to our distribution list – please tick if you would rather not be added ☐

Payment method

I enclose a cheque/draft/postal order (payable to 'IMNDA') for **€**______

or I authorise you to debit my master card/visa/laser account with the total amount **€**______

Expiry Date _ _ / _ _ Security Code _ _ _ (Last 3 digits on back of card)

Cardholders Name: ____

Cardholders Signature: ____

Please return completed form with payment to:
IMNDA, Coleraine House, Coleraine Street, Dublin 7
Freefone: 1800 403 403 / info@imnda.ie
CHY: 8510

(Please do not send cash in the post)

CUT HERE

ANNUAL GRAND RAFFLE 2017

It's that time of year again…..!

We will be holding our Annual Grand Raffle Draw and Christmas Coffee Morning on Wednesday 13th December at 11:30am in the Richmond Room, Carmichael House, North Brunswick St, Dublin 7. All welcome to join us!

We have enclosed 5 books of tickets with this Newsletter and would be very grateful if you could sell some on our behalf. Please clearly fill out the counterfoils and return them with a cheque/draft/postal order (please do not send cash in the post) to the IMNDA office before Friday 8th December.

We are very thankful to everyone who has donated prizes to the raffle.

All funds raised will go directly towards supporting people with Motor Neurone Disease, their carers and families.

We completely understand if you are unable to sell the tickets, please send them back to the office. If you would like extra tickets freefone **1800 403 403 or email fundraising@imnda.ie** and we'd be delighted to send you out more.

The IMNDA is a small organisation that relies heavily on fundraising to enable us to continue providing vital services to the MND community throughout Ireland. Please note the opt-out notice on the back of these tickets should you no longer wish to receive them.

Once again thank you for your continued support.

IMNDA Fundraising Team

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

01-873 0422

www.imnda.ie

info@imnda.ie

https://www.facebook.com/IrishMND2011

https://twitter.com/IMNDA

iMNDA
CARE AND RESEARCH