30 YEARS
iMNDA
CARE AND RESEARCH
1985-2015

CONNECT

ISSUE 13 - Spring 2015

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- 25TH INTERNATIONAL ALS/MND SYMPOSIUM
- HOW THE ICE BUCKET CHALLENGE WILL HELP FUND RESEARCH
- PROJECT MINE
- THE THEORY OF EVERYTHING

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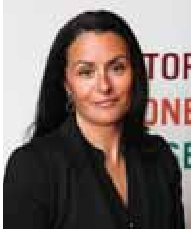


A WELCOME NOTE FROM OUR CEO

On behalf of the IMNDA, I would like to welcome you to the first Edition of the Connect Magazine for 2015.

This year is a huge year for IMNDA as we are marking 30 years of caring for people with MND and we have been providing these services since the 1st May 1985. We have many things planned to celebrate our 30th year anniversary and you can keep up to date on events planned by logging on to our website http://imnda.ie/category/events/.

2014 was a very busy year in the services department and we noticed a huge increase in the need for our top up HSE home help payment, this is down to the increased numbers of people being diagnosed with MND, people living longer with MND and also the reduction in resources within the HSE. The services team provided services to 443 people with MND in 2014. Apart from the Ice Bucket Challenge success, which is ring fenced for various projects; and you will hear more about how that is going to be spent in the upcoming pages, we were actually down € 117k in fundraising income compared to 2013. Therefore as always we thank you for your support in 2014, but we also urge you to continue to support us in any small way that you can to ensure we can still provide vital services to people with MND into the future.

This February we launched a very powerful campaign and asked people to take on a sponsored silence to experience what it would be like to not be able to communicate. Many people with MND lose their voice so we challenged people to stay silent for 30 minutes at work, school or even at home alone. During this time of reflection we asked people 'if today were the last day you could use your voice, what would you say?' The campaign was very successful and one of our clients, Sharon Friel, shared her story in a very powerful interview with Pat Kenny on Newstalk.

And Emma Fitzpatrick shared her story in the press, sadly Emma passed away since then and we were all very saddened to hear this. Our thoughts are with her family.

March brought back the ever popular Dandelion Dust Up and 31 brave fighters took to the ring on the 13th of March. April was a very busy month as we had the Good Friday Run organized in St. Ann's Park Raheny and the very successful Black Tie Primrose Gala Ball in the Ballygarry House Hotel in Tralee. Also don't forget that it's not too late to register for the ladies VHI Marathon, we are celebrating 30 years of amazing ladies supporting us by doing this run.

In May we will be marking our Anniversary in a variety of ways so keep an eye on our Facebook page and website to see how you can be involved and finally don't forget to start ordering your drink tea for MND packs to mark MND Awareness month in June.

As always thank you for all your support, Motor Neurone Disease has finally come to the fore front in the public's eye and we thank each and every one of you for helping us to make that happen. Let's hope that we can continue doing that and fulfill our vision, a world free from MND.

Chief Executive

CALENDAR OF EVENTS

2015

‘Do Something Special in 2015’

APRIL

GREAT IRELAND RUN
Phoenix Park, Dublin
Saturday 11th April 2015
www.greatirelandrun.org

MAY

WEST OF IRELAND WOMEN’S MINI MARATHON
Castlebar, Co Mayo
Sunday 3rd May 2015 @12pm
www.westofirelandwomensminimarathon.com

GREAT LIMERICK RUN
Limerick City
Sunday 3rd May 2015
www.greatlimerickrun.com

JUNE

VHI WOMEN’S MINI MARATHON
Monday 1st June 2015 @2pm
www.vhiwomensminimarathon.ie

CORK CITY MARATHON
Monday 1st June 2015 @ 9am
www.corkcitymarathon.ie

GLOBAL AWARENESS WEEK
‘DRINK TEA FOR MND’
Various events nationwide
15th – 21st June 2015
www.imnda.ie

JULY

WALK TO D-FEET MND
Castletown House, Celbridge, Co. Kildare
Saturday 18th July 2015 @ 11am
http://imnda.ie/get-involved/

SEPTEMBER

AGM / PATIENT & CARER WEEKEND
19th September 2015
http://imnda.ie/get-involved/

CORK WOMEN’S MINI MARATHON
September 2015 (Date TBC)
www.corkminimarathon.com

OCTOBER

CROKE PARK ABSEILS
Hogan Stand, Croke Park Stadium,
Dublin 10th October 2015
(back up date 17th October)
http://imnda.ie/get-involved/

DUBLIN CITY MARATHON
Dublin
26th October 2015
www.dublinmarathon.ie

NOVEMBER

ANNUAL MEMORIAL SERVICE
28th November 2015

iMNDA
CARE AND RESEARCH

Irish Motor Neurone Disease Association
Coleraine House, Coleraine St, Dublin 7
Freefone: 1800 403 403 Fax: 01 8731409
Email: info@imnda.ie

Find us on Facebook

REGISTERING YOUR FUNDRAISING EVENT

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

To register and receive promo items / lodgement slip etc:
Email: fundraising@imnda.ie
Freefone: 1800 403 403
Thank you for your support and co-operation.

IMNDA Bank Account details: AIB, Capel Street, Dublin 1
Sort Code: 93-13-14
Acc No. 077 25002

CONTRIBUTIONS TO THE NEXT EDITION OF CONNECT:

If you would like to submit a story, photo, or something you would like to share then please contact the office.

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.

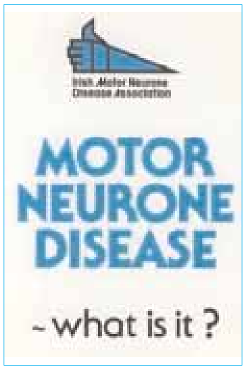
30 YEARS OF HISTORY, STORIES & GREAT MEMORIES!

A LOOK AT THE IRISH MOTOR NEURONE DISEASE ASSOCIATION OVER THE LAST 30 YEARS…

1985: The very first meeting of the Association was held on the 1st May 1985. Over 60 people were affected by MND each person had a strong belief that there was need for a support organisation. The primary goal of the association in 1985 was to break the isolation experienced by MND people, their carers and families. With this goal in mind and a strong determined group the Irish Motor Neurone Disease Association was formed and the rest is history.

1986: The association was slowly becoming established; the first major fundraiser was the premier of 'Eat the Peach' in the Savoy Cinema, this fundraiser raised £14,000 that year.

1987: The first information leaflet was launched – MND – What is it?


Irish Motor Neurone Disease Association

MOTOR NEURONE DISEASE

- what is it ?

1988: The Association moved to a new office run by the Community Services Project at Christchurch Place and is managed by Chairperson Eithne Frost, one of the founding members of the association.
Also in this year the British Director of the MND Association makes a visit to Dublin and offers advice and assistance. Both associations developed a good rapport with each other. The larger and somewhat older UK Group assisted Irish beginnings with practical support.

1989: Eithne Frost resigned as chairperson to take up the first post as administrator in the Association. Eithne's work involved making contact with existing and new patients. The association's service expands and active networking is in place with healthcare professionals.

1990: The Association is on the move again. We move to more permanent and bigger offices in Carmichael Centre.
During this year the John Harty Race Ride takes place, this gives the association a great boost and helped to improve the equipment bank.

1991: Motor Neurone Disease linked to gene…Researchers in the US find certain probes link to the gene causing familial MND.

1992: IMNDA plays an important role in the new international worldwide alliance of Associations working to help people with MND.

1993: The Freefone no is launched 1800 403 403, this is funded by Eircom and today this continues to provide a very important link between the Association and people with MND and their families.

1994: The first patient & carer weekend takes place in the heart of the country – The Hodson Bay Hotel in Athlone.

The Duchess of York, Sarah Ferguson pays a surprise visit to a Cork man who has MND; she spends the afternoon with him before flying back to England.

That year the committee and staff of the IMNDA also meet the Duchess of York, Sarah Ferguson at the International Alliance that year.

MND features on the television; Check Up programme is screened on RTE.

Professor Stephen Hawking visits Dublin to give lecture on ‘The Beginning of Time’. Patients and members of the organisation get to meet him

1995: The tenth anniversary of the Association, one of the highlights for the association is the Gala Concert that is held in the national concert hall.

Mary Robinson opens the 6th annual ALS/MND Symposium which takes place in the Burlington Hotel in Dublin, with 370 delegates representing 21 countries.

1996: MND Liaison Nurse Bernie Corr is assigned to care for MND patients on a full-time basis.
Also during this year The Film Premiere of ‘The Last of the High Kings’ in association with Dublin Film Distribution Co Ltd and First Independent Films Ltd. The event raises a staggering £11,500 IR for the association.

1998: The launch of Andy McGovern’s first book, They Laughed At This Man’s Funeral, this launch is held in Easons Book Shop in Dublin City and is attended and supported by the great actor Mick Lally. Andy is one of the Irelands longest survivors of MND.

1999: By the end of the 1990’s the Association is in touch with over 200 people with MND. A broad network of supporters is established throughout the country and credibility with the Department of Health and other statutory bodies is built.

2000: 15 years of caring and the Association is on the move again, but only across the road this time, Coleraine House, Coleraine Street our current location

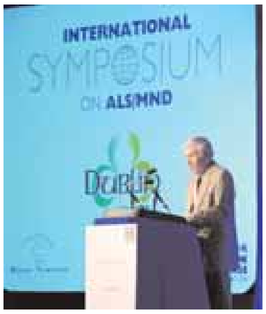
2001: Launches the new email address for the association info@imnda.ie

2002: The Launch of the book Fear of the Collar, by Patrick Touher takes place this year in Balbriggan, Co Dublin.

2004: The launch of the National Radio Advertising Campaign, “My legs won’t walk, My Mouth won’t talk, I’m loosing control of my body but my Mind Works perfectly” this 30-second radio advert runs for three weeks on RTE’s radio and receives a massive response from the general public.

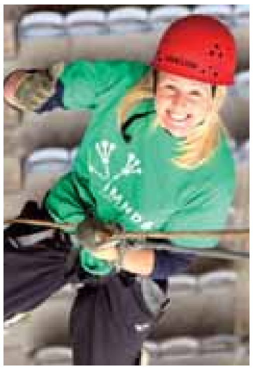
2005: Motor Neurone Disease goes live, the Association’s Web-site is launched during this year and the domain name is www.imnda.ie – the home of where we are today! One of the association’s clients Mark Worth is responsible for the design of this new website and our initial launch on the World Wide Web!

This year also see’s The 16th International Symposium return to Dublin and is held in the Burlington Hotel. This is the biggest event in the world to stage Research into Motor Neurone Disease also known as ALS or Lou Gehrig’s disease.



2006: The Film Premier – The Tigers Tail takes place in the Savoy Cinema with an after party in Croke Park. The film is about Ireland’s Celtic Tiger years and features English-Canadian Actor Kim Cattrall, Irish Actors father & son: Brendan & Briain Gleeson.
This year also sees Olympic Gold Medallist, Michael Carruth take to the stage to perform some Irish dancing in the Celebrity Jigs n ’Reels TV dance show.

2007: The Association employs two specialist MND nurses to provide people with practical advice and emotional supports on how to manage the disease. Fidelma Rutledge is one of these nurses that joins the IMNDA team.



2008: The Association appoints a new patron – RTE’s sport broadcaster Jimmy Magee. Jimmy’s son Paul was diagnosed with MND a few years earlier but he sadly passes away in 2008.

2009: The Association abseils off the roof of the Hogan Stand in Croke Park for this first time – this has since become a major event for the association and has raised a lot of awareness and funds over the year for the association.

2010: The Association visits Aras an Úachtaráin where we meet President Mary McAleese in April of this year, we are joined by many of our people with MND, their families and many of the associations supporters who have been with us down through the years.

That year also see’s the Celebrity Soccer Classic organised by World Title Boxer Bernard Dunne. With big names like Liverpool’s Ian Rush, Ireland’s Packie Bonner and Ronnie Whelan to name but a few! This celebrity team was managed by the IMNDA’s very own and much loved Patron Jimmy Magee.

2011: Sports commentator Jacqui Hurley gives up her time for IMNDA to help with the promotion of the Women's Mini Marathon. The first ever Tag Rugby Cup is brought to Blackrock RFC and is organised by the association.

2012: In January of this year we see the most thought provoking and inspirational documentary entitled 'MND- The Inside Track' the famous sports broadcaster Colm Murray's documentary on his journey with MND. Colm passed away the following year in 2013.

2013: The longest person living with MND in Ireland Mr Andy McGovern takes to the books again!! Andy dictated his book "Against the Odds" through the use of voice recognition technology and this inspirational book is about his life and his diagnosis of MND and was launched on Andy's 80th Birthday on the 10th February.

This year the Association also welcomes a new CEO Aisling Farrell who joins in May of this year. Aisling comes with an abundance of experience from the Charity Sector.

2014: Jimmy Magee releases a single called "These old eyes" in March of this year and launches it at the Aviva Stadium with the help of Ryan Tubridy!

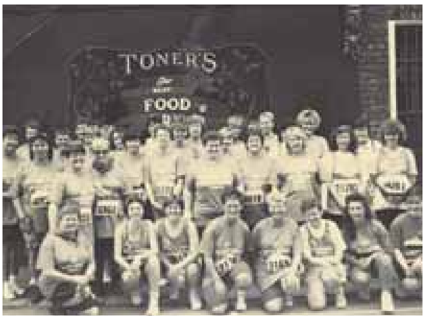
New National Awareness Campaign, the new awareness campaign featuring two people living with MND. Jan Battles and Paul Lannon bravely record their experiences of living with MND. These adverts are aired nationally as well as a poster campaign on Dublin Bus and new text no is set up to take donations!

Also in 2014, the IMNDA holds two exclusive concerts with KODALINE in Whelan's on Wexford Street in Dublin. These special performances take place because of the dedication and determination of Jan Battles. It's an unbelievable night with all proceeds raised from the event going to the IMNDA.

August of this year will not be forgotten for a long time! The Ice Bucket Challenge which originated in America– this absolute phenomenon that raised incredible awareness and funds for the IMNDA by someone simply recording a video of another person pouring a bucket of ice over themselves and uploading it to social media, nominating another 3 individuals to do it and donating €2 to the association! And it spread…like wild fire!

2015 - 30th Anniversary…Let's hope there will be only one story in the next era and that is…'A World Free of MND.

Here's how you can help this year to mark the 30th Anniversary, visit our website http://imnda.ie/category/events/



Eithne Frost pictured with members of the committee from the early years A significant and very special May Day 1985

The Irish Motor Neurone Disease Association celebrates the 30th anniversary of its foundation this year. The first gathering in Ireland of people interested in Motor Neurone Disease took place on a calm sunny early summer evening, Wednesday, 1st May 1985, in the Friends' Meeting House, Lower Churchtown Road, Dublin. The founding members of our association were Carmel Ross, Mary Callinan and Cathy Feeney who were the initiators and organisers of this meeting.

These three caring and altruistic women had a close friend, Mary Murray, who was battling MND at that time. Although they had made many attempts to get information about MND and to access more assistance for their friend they felt very frustrated by this nasty progressive illness with the strange name. Nobody seemed to know anything about it and they didn't know any other family that had been affected by it. So, in order to try to make contact with some other people who had been touched by MND they wrote a letter to the editors of the national newspapers outlining their concerns, including a contact phone number and announcing a first meeting of any interested parties on 1st May. Luckily, the editors reacted positively and the letter was published in all the daily and evening papers.

The response to that letter was quite unexpected. Men and women, young and old, people with MND, carers, family members, healthcare professionals and bereaved people from many counties wrote and phoned expressing interest in the proposed gathering. Within a week it was clear that there would probably be about 25-30 people in attendance. An excited buzz and a palpable sense of anticipation were generated around the preparations for an occasion that, for most attendees, would be their first encounter with another person or family affected by this devastating disease.

As people arrived at the Quaker Meeting House on that quiet balmy evening a certain sense of tension and anxiety permeated the atmosphere. However, as the crowd grew and it became 'standing room only' and men were asked to help bring in extra chairs from an adjoining room the tension dissipated and people began to chat. An attendance notebook was circulated and 66 attendees signed it. People came from all areas of Dublin, city and county; from further afield, as I recollect, people with a personal interest in MND arrived from Kildare, Louth, Meath, Cavan, Wexford, Cork and Tipperary. I attended the meeting and brought my mother with me for moral support. My husband, Noel, had had MND and had died in October 1979. I hoped, because of my previous experience of MND, that perhaps I could support and help other individuals and families going through their own difficulties and especially address the feeling and sense of isolation, which had impinged greatly on me during Noel's illness.

I cannot recall all the details of that evening but I do remember a short presentation from Carmel Ross, who took the Chair, and spoke about her hopes and ideas for a future organisation; a lot of contributions from the floor, mainly seeking information and recounting personal experiences; a very pleasant interlude of tea and biscuits and an opportunity to mingle; the unanimous decision to hold another meeting; the suggestion to take up a collection to start a fund to cover expenses and that my mother took off her hat, put a £10 note in it and passed the hat around; and most especially, the emotionally charged episode at the end of the meeting when a group of the women came together in the little kitchenette to wash up the cups and saucers. My memory is that we talked, laughed and cried in equal measure for almost an hour. I believe that a firm bond of common cause was forged between us that formed the nucleus of the budding organisation and became the bedrock on which the association was launched and expanded and flourished over the following months and years.

The organising trio had been in touch with MNDA, based in Northampton, and had acquired some leaflets for distribution. People were delighted to get medical and social care information from a reliable source and, although the health and medical systems were quite different in the two jurisdictions, it was very reassuring and empowering to know what was available elsewhere when negotiating with service providers here. Our sister association in the UK, which had been founded in the autumn of 1979 and covers England, Wales and Northern Ireland, sent a goodwill message of support also. It was the beginning of a sustained and far-reaching relationship and friendship between the two organisations.

Sadly, Mary Murray passed away within a few weeks but her death reinforced our determination and kept us focussed on securing the future of the newborn association. Over the following weeks many of the people who had attended the May Day meeting spoke to each other in person and by phone and plans were formulated to formalise the structure, select officers and find a location to hold future meetings. By September 1985 the Irish Motor Neurone Disease Association was up and running. Carmel Ross from Birr, Co Offaly was the founding Chairperson and Mary Callinan became Secretary, agreeing to undertake her duties from her kitchen table in Dublin 8. Through a wonderful act of generosity and support for a fledgling neurological group our subsequent fortnightly meetings were held in the office of the MS Society in Sandymount, Dublin 4.

This is my happy recollection of the early tentative small steps which helped bring to fruition the successful, dynamic and vibrant organisation that IMNDA is today.

Eithne Frost

A SYNOPSIS OF THE INTERNATIONAL SYMPOSIUM

Around 900 researchers attended the 25th International Symposium on ALS/MND held in Brussels, Belgium from 5th -7th December. The Ice Bucket Challenge and the awareness it raised of MND, both with the public and worldwide research community, was evident in the buzz around the event.

From around the world; MND Association (England, Wales and Northern Ireland) -funded researchers reveal they are a step closer to creating a diagnostic test for MND, thanks to the participation of people with the disease. There is currently no diagnostic test for MND. This means that other diseases have to be excluded first before a clinical diagnosis can be made by a neurologist – which can sometimes take several months.

An effective 'biomarker' for MND would change this. A biomarker is like a biological 'fingerprint'. It could be something specific in the blood that could potentially be used to develop a diagnostic test for MND, or to monitor disease progression. More information on this can be found at http://www.mndassociation.org/news-and-events/2014-news-page/day-two-of-our-25th-international-symposium-on-alsmnd.

From an Irish perspective a number of Prof. Orla Hardiman's research team from MNDR attended the 25th International Symposium on ALS/MND. The diverse program highlighted some of the exciting research being carried out in the field and was an excellent platform for the exchange of knowledge and ideas.

From Ireland; Dr. Marwa Elamin gave a talk on her work 'Predicting prognosis in ALS: A simple algorithm'. The talk was about the team's research to find a simple but reliable way to help predict how a person with MND will progress over time. The system is being developed and tested using data from Ireland and Italy. Such a system would be very helpful in improving the design of future trials looking for potential treatments for MND. The talk was met with a lot of interest at the meeting and was selected as one of the highlights of the meeting.

The 'Ask the Experts Session'

Prof Orla Hardiman gave a presentation at the "Ask the Experts Session" at the International Symposium which was attended by people with ALS/MND.

In the opening of her presentation, she spoke about how she is often asked by her patients and family members that attend her clinic in Beaumont hospital why scientists can cure ALS/MND in the mouse but not in people with the disease.

To explain this, she spoke about the history of drug development and how in the past; drugs were developed by pre-existing knowledge from our ancestors. A lot of it was trial and error and drugs were developed by observations, sometimes drugs were found by pure coincidence or by accident and lastly of course some were made by scientific approach.

These days the approach is very definitely more scientific. There has been an explosion in science and research over the past 50 years. Nowadays drugs are made in a laboratory setting with the use of test tubes, worms, fish and mice which are models that are used to build new molecules or drugs that can work in people. She discussed the outcomes of two different trials in particular: The Riluzole Trial which has been the only effective one to date and The Dexpramipexole Trial which worked well on mice but unfortunately failed in a late stage clinical trial

Part of the problem for drug development is that ALS is not a single disease - it is probably more than one condition. One of the big challenge for clinicians and scientists is to find the best way to identify different subgroups of disease to make sure that we get the right drug to the right subgroup at the right time...So what is the evidence that ALS is heterogeneous? We know that there are at least 24 genes that cause ALS. These genes include SOD1 and C9orf72. There is no SOD1 related ALS in Ireland, whereas C9orf72 causes ALS in 11% of patients The rates of C9orf72 related disease are much lower in Asia..

For the non-genetic form of ALS, it is likely that interactions between combinations of genes and environmental exposures contribute to the disease. It is also likely that different populations carry different genetic susceptibilities of ALS. Understand how these gene/environment interactions occur in different subgroups will help us to develop new drugs - some of which might work on multiple different pathways.

Another approach is to use drugs that work together much is the same way as new and more effective cancer treatments have been developed. Understanding the causes and finding new treatment for ALS require cooperation among scientists and clinicians across the world. In Europe, this takes place through ENCALS, which is the European Network for the Cure of ALS . ENCALS researchers work together to understand how best to subgroup people with ALS by undertaking extensive clinical studies (called "deep phenotyping") including neuropsychology testing, muscle testing, brain imaging, brainwave mapping and other research studies; how best to understand the interactions between our genes and environmental exposures, and how to best develop new drugs by engaging in clinical trials.

More information on Professor Hardiman's talk can be found at http://alsliga.be/en/Ask-the-Experts-symposium-2014

The Poster Sessions was another highlight at this year's Symposium

It was the second year that poster prizes were a feature of the conference. The purpose of the prize was three-fold: to increase the profile of the poster sessions of the meeting; to recognise the quality of the work presented there and to reward presenters of outstanding work.

A shortlist of 18 posters was drawn up ahead of the meeting. During the poster sessions on Friday evening of the Symposium, each of the shortlisted presenters was asked to give a short, 10 minute presentation about their poster. The judges considered the content of the poster – the data presented and how it advanced (or will advance) MND research or clinical practice, and the clear presentation of the work. It's important that researchers can explain the detail and importance of their work – as well as doing the work itself

From Ireland, Dr Katy Tobin's poster 'Discrete choice experiment for preferences of care in motor neurone patients and their carer', made the shortlist of highly commended clinical posters.

This Discrete Choice Experiment is a collaboration between Dr. Katy Tobin, Dr. Sinead Maguire, Professor Orla Hardiman and Professor Charles Normand and funded by the HRB Interdisciplinary Capacity Building Award (ICE) and funding from the IMNDA.

The study is being carried out with patients and their caregivers attending the national MND clinic in Beaumont hospital. Participants are asked to take part in a questionnaire asking them to choose between different packages of care. The choices are repeated with different scenarios of care services.

Results are analysed using a Discrete Choice Model, which describes the most important features of the care packages for our study participants. The model also measures the relative importance of the different aspects of care and looks at how the preferences of patients and caregivers differ.

This project is ongoing and we presented some preliminary results at the international MND symposium in Brussels in December 2014. Our poster was highly commended by the judging panel, which has given us great encouragement as we progress with the study. We hope to publish our final results later this year.
(A copy of the poster is included in this article)

Also from Ireland, Dr James Rooney, HRB Research Fellow presented a Poster entitled: 'Cluster analysis of ALS risk in Ireland'.

As ALS is a disease that manifests later in life, genetic factors present at birth are likely to interact with later-life environmental factors. Identifying environmental factors is difficult – therefore there is interest in mapping the risk of developing ALS for local geographic areas. We combined data from the Irish ALS register, the Census and Ordnance survey Ireland to produce a smooth map of ALS risk for each Electoral Division in Ireland. The map showed a pattern of weak variation in ALS risk across Ireland, with mildly elevated risk in North Dublin, Louth & Meath, Cork, the Dingle peninsula in Kerry, the southwest coast of Donegal, and larger areas of lower than average risk in Kilkenny and Clare. Statistical analysis revealed that only the low risk areas in Kilkenny and Clare are of importance (i.e. the higher risk areas may be explained simply by random chance).

Further work is needed to explain the cause(s) of these low risk areas. We know from studies in other countries that having a more mixed genetic heritage reduces risk of ALS. Therefore our working theory is that the ALS risk of people in these low risk areas may have been influenced by historical population migration patterns. We are now actively engaged in an international genetics project using DNA from people with MND and controls from across Ireland to test this theory. (Project MinE http://www.projectmine.com/country/ireland/)

All in all, the symposium in Belgium was a great success, this year we will see the 26th International Symposium on ALS/MND will take place in Orlando, USA from 11 - 13 December 2015.

For more information on this in the coming year, visit the association website at www.imnda.ie.

And we are very proud to announce that the 27th International Symposium on ALS/ MND in 2016 will be held in Dublin. This will be the third time this huge international event has come to the green isle….. And what a year to come!

P124

Discrete Choice Experiment For Preferences Of Care In Motor Neurone Patients And Their Carers

INTRODUCTION

RESULTS

AIM

METHODS

CONCLUSIONS

FURTHER WORK

WHAT THE MND RESEARCH TEAM PROPOSE TO DO WITH THE ICE BUCKET FUNDS RECEIVED FROM IMNDA!

After the whirlwind of the Ice Bucket challenge, the IMNDA sent out a survey to each of our members to find out how they would like the proceeds from the major fundraising event to be spent. Not surprisingly, most if not all of our members came back with Research being the top choice. The IMNDA is committing € 600,000, over 37.5%, of the funds raised to go directly to research.

The team is headed up by Professor Orla Hardiman. The Ice Bucket Funds will enable the IMNDA to increase its funding on new areas of research into causes and treatment of the disease. The Research team have told us how this money will help with their projects;

The Irish MND Research Group is based in Trinity College Dublin, with clinical work based at the National Centre for Neuroscience at Beaumont Hospital. The group is led by Professor Orla Hardiman, Professor of Neurology at Trinity College Dublin and Head of the Academic Unit of Neurology at Trinity Biomedical Sciences Institute.

Prof. Hardiman is a senior Consultant Neurologist at Beaumont Hospital, where she leads the weekly National Multidisciplinary Clinic for ALS/MND.

We plan to use the funds allocated from the recent Ice Bucket Challenge to advance research to beyond the current state of the art in 4 main areas. These projects have been carefully chosen as cutting edge research initiatives developed by our group that capitalise on the unique properties of the Irish population.

Advancement of these projects is likely to significantly enhance our understanding of the disease, and improve our ability to develop new and more effective drugs, and that will promote management that enhances quality of life.

BACKGROUND TO SELECTION OF THE 4 THEMES

The Irish Register of ALS/MND is the longest continuously running Register in the world, and is recognized internationally as an extremely valuable resource. Over 2,000 Irish patients over 20 years have been captured by the Register, and DNA from over 1,000 patients is stored in our DNA bank.

As the Register is part of our research infrastructure rather than a research project, it has been difficult to generated sustainable funding through competitive grant awards. Over the years, the Register has been funded from a combination of restricted research grants from Industry (Sanofi Aventis), as part of a funded Clinician Scientist programme by the HRB (2007-2012) indirectly as part of our clinical trials programme. Continued funding of the Register to permit high level data capture is essential to the quality of all of our research. Limitations in funding can lead to catastrophic gaps in the Register, as has happened in Scotland, rending high quality modelling of changes in disease incidence, prevalence and survival impossible.

It is increasingly recognised that MND is a spectrum of disorders of diverse presentation and aetiology. Our research has shown that up to 60% of people with MND develop mild cognitive and behavioural impairment, and 13% develop a full-blown fronto-temporal dementia. Conversely, we have shown 40% of people with MND remain completely cognitively intact throughout their illness.

Up to 15% of Irish people with MND have a family history of MND or a related condition. At least 20 major causative genes have been identified – the most important being the gene C9orf72 which accounts for approximately 11% of all MND in Ireland. Mutations in 3 further genes- TDP-43, FUS and SOD1 are also common causes of familial MND in some countries but are rare in the Irish population – no familial cases of SOD1-related disease have been identified to date.

Some genes are associated with a characteristic phenotype. For example, we have shown those carrying the C9orf72 gene variant are more likely to develop cognitive and behaviour impairment. However, not all people who develop cognitive or behavioural impairment and who have a family history of MND and related conditions including fronto-temporal dementia carry the C9orf72 gene variant, indicating that other important but un-characterised genes are also present in the Irish population. We have also shown that in some MND families, other conditions are present with a higher than expected frequency – these include family members with a history of schizophrenia, obsessive compulsive disorder, autism and other related neuropsychiatric conditions. This exciting and novel observation by our group implies that the genetic basis to some forms of MND is shared with some forms of psychiatric disease, opening a new avenue of research into the genetic causes of MND. This in turn could help to identify new pathways from which drugs could be developed to slow down the progression of disease. The majority of people with MND do not have any family history of MND, fronto-temporal dementia or of neuropsychiatric disease. Recent work by our collaborators in Kings College London using the Irish MND Register has suggested that MND in these people may develop as a result of 7 different steps – suggesting that a combination of genetic and environmental factors contribute to the disease in these people.

Identification of genetic susceptibility genes is challenging, as it is likely that many genes with small effect contribute to the risk of developing disease. Identification of these genes, and how they act in combination with one another, and with environmental factors, is a major international challenge. A recent initiative entitled Project Mine (www.projectmine.com) , which aims to sequence the genetic code of 6000 people with MND and 12000 controls, will help to identify these susceptibility genes and begin to explore how the interact to increase disease risk. Ireland is a partner in Project Mine- we have pledged to sequence the genome of 400 people with MND and 200 controls.

To date, we do not have any clear evidence of causative environmental exposures- this is partly because MND is a rare disease and large numbers of patients and controls are required to identify truly pathogenic exposures. We are part of a large European-wide study of environmental exposures in MND. This study will gather detailed information about the life and employment experiences of over 1,500 people with MND and 3,200 controls, in an attempt to identify possible lifestyle /exposure factors that might have occurred more frequently in people with MND. Funding for this study (EUROMOTOR) has been through the European FP7 programme. To date we have recruited over 200 Irish patients and 350 Irish controls to this study. Although European funding to recruit patients and controls for this study expired in June 2014, it is imperative that we that we continue to recruit to this study to increase the statistical power of the study, and to provide a rich dataset of Irish patients to permit detailed gene-environment and clustering studies.

Currently, treatment of MND is based on the use of the drug Riluzole, coupled with high quality multidisciplinary care provided through the National MND clinic in Beaumont Hospital. We have recently shown that people who attend the Beaumont MND clinic experience a significant survival benefit. We need to further understand this, and to determine whether attending the clinic also improves quality of life, and whether it provides enhanced patient and carer satisfaction with health services, and whether existing integration between the multidisciplinary clinic and palliative care services adequately meet patients and carers needs.

PROJECT FUNDING

We will use the Ice Bucket funding to support 4 interlocking projects as outlined below

1. A study of genetic and environmental risk factors in MND

We will maintain the Irish Register to the highest international standards by ensuring continuous funding of a dedicated research manager to ascertain, capture and verify all new patients who have consented to their inclusion on the Register.

2. Family Aggregation of Neuropsychiatric Disease in MND

We have already published our observations that neuropsychiatric conditions occur with a higher frequency among MND kindreds. However, a great deal more work is required to understand the wider implications of this important finding.

3. Genomics of MND

The Irish MND Research Group has a strong track record in genetics research, including the identification of a new causative gene in MND in 2006. Genetics research has developed considerably over the past 3 -5 years, and requires highly trained statisticians and bioinformaticians to analyses the trillions of data points generated from genomic sequencing.

4. Multidisciplinary Care and Health Services Research

We have already published our observations that those who attend our Multidisciplinary clinic enjoy a survival advantage. It is imperative that we seek to understand the factors that lead to enhanced survival of those attending the multidisciplinary clinic, and that we engage with patients and carers to determine quality of life, carer burden and palliative care needs.

To keep up to date with all the current research, please visit www.mnd.ie
and www.medicine.tcd.ie/neurology

PROJECT MINE

Project MinE is a ground-breaking large scale investigation into the genetic causes of motor neurone disease (MND). It will involve the study of the entire DNA sequence (genome) of at least 15,000 people with MND and 7,500 control subjects (healthy individuals without the disease). Research will be carried out by Prof. Orla Hardiman's team in Trinity College Dublin, as well as collaborators across the world. Through the Project MinE website, members of the public can make a donation to help fund this important scientific research, or set up their own fundraising campaign page for the project. We know the genetic mutations that cause 10-15% of MND cases in Ireland. For the reminder the cause is still unknown, although genetic factors are thought to play an important role. MND is a complex disease and information on the full DNA sequence of a large number of individuals would be extremely useful in discovering the genes that cause MND and contribute to its differing progression and symptoms in different patients. Project MinE will give us the chance to better understand the genetic causes of MND, which in turn will inform treatment and drug development.

For more information and to support Project MinE please visit www.projectmine.com/country/ireland
Follow our progress on Facebook (www.facebook.com/ProjectMineIreland) and Twitter (@ProjectMineIRE)

POTENTIAL NEW TREATMENTS FOR MND

Research led by Dr Julie A. Kelly of the Academic Unit of Neurology, School of Medicine, Trinity College Dublin has identified an exciting neurotherapeutic drug candidate and a related novel neurotherapeutic target in human brain. A paper describing these significant findings was recently published in the international journal Neuropharmacology. Dr Kelly, the lead and corresponding author on the paper, noted that both findings have important implications for the possible treatment of neurodegenerative conditions, such as MND, for which new, effective therapeutics are urgently needed.

THE THEORY OF EVERYTHING

MND is once again in the global spotlight thanks to an Oscar and Bafta-nominated box office hit film which explores the relationship between Professor Stephen Hawking, and his first wife Jane.

The Theory of Everything, released on New Year's Day, is a biographical romantic drama based on 'Travelling to Infinity: My Life with Stephen', written by Jane Wilde. It focuses on the challenges of being a carer and partner to someone with a progressive condition. The film's star Eddie Redmayne is nominated for a multitude of awards and has already scooped a Golden Globe for his role as the renowned astrophysicist while Felicity Jones' portrayal of Jane, has also been widely acclaimed.

Prof Hawking was diagnosed with MND aged just 21 while studying at Cambridge. Now aged 73, he is recognised as one of the world's greatest minds.

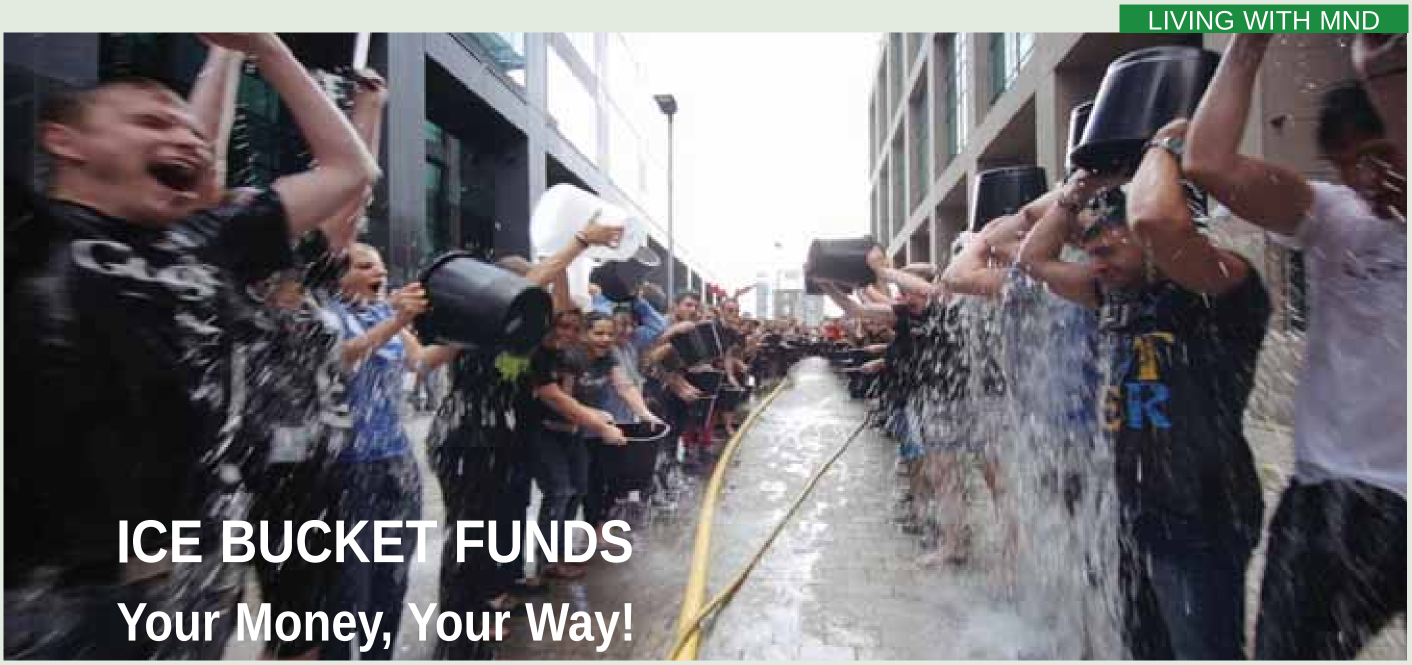
The films portrayal of MND is very accurate in that the film's set designers and production team consulted with the MND Association in England and got advice since July 2013.

The English MND Association worked closely with the film designers who were looking for contemporary care equipment or aids and specifically wheelchairs from the 1960s to1980s. Using original family photos and thanks to specialist wheelchair services and engineers across the country of England, the MND association was able to help. "It was clear very early on that the depiction of MND would be as accurate as possible on all levels.

This is why it is such a fantastic tool for spreading awareness and such a powerful film too." This attention to detail was something echoed by the actors' approach too. Eddie and Felicity spent time with people living with MND and their carers to get an insight into MND. The actors really did their homework, its amazing how Eddie Redmayne managed to portray the disease.

The Film went on to win awards: The Stephen Hawking biopic The Theory Of Everything was named Outstanding British film at the Bafta awards.

And the actor Eddie Redmayne received universal critical acclaim for his performance as Stephen Hawking in The Theory of Everything, for which he won the Academy Award for Best Actor, the Golden Globe Award, the Screen Actors Guild Award and the BAFTA Award.



ICE BUCKET FUNDS

Your Money, Your Way!

The Irish Motor Neurone Disease Association (IMNDA) is delighted to announce that the income received so far from the sensational phenomenon Ice Bucket Challenge is €1.7m!
So to all of you who have participated and donated, we send a heartfelt thank you! The outpouring of support that we have received over the past few months has been incredible. To everyone who has donated, doused themselves in icy cold water – we salute you! Thank you for joining the fight against Motor Neurone Disease (MND).

Now it's time to spend the money raised. It is important that we make every cent count to ensure we maximise the difference it makes to people living with, and affected by, MND.

After a consultation process with stakeholders including the MND community to discuss the most meaningful way to use this enormous sum of money, we have been able to make some short term and long term decisions. Below is a list of the confirmed projects where the money will go to:

1. RESEARCH

€600,000, over 37.5%, of the funds raised will go directly to research. The team is headed up by Professor Orla Hardiman. The Ice Bucket Funds will enable the IMNDA to increase its funding on new areas of research into causes and treatment of the disease.

2. EXPAND AND IMPROVE THE NURSING SERVICE

The Ice Bucket money will enable the IMNDA to employ a third nurse for a minimum of 2 years. Expansion of the nursing service will cost approx. €180,000 across the two years. We have two qualified full time MND Nurses that provide services to people with MND nationwide, these services include telephone support and home visits. We receive no funding towards our nursing service. With patient numbers increasing an additional nurse would enable us to continue and expand the amount of home visits nationwide that we can provide

3. INVEST IN NEW TECHNOLOGY TO ASSIST CLIENTS IN THEIR DAY-TO-DAY LIVES

One of the key services of the IMNDA is the provision of specialised aids and appliances. This equipment plays a vital role in providing some quality of life for people living with MND; assisting their independence and dignity and especially facilitating their care at home in a safe environment. At least €300,000 of the Ice Bucket funds will be invested in specialised equipment

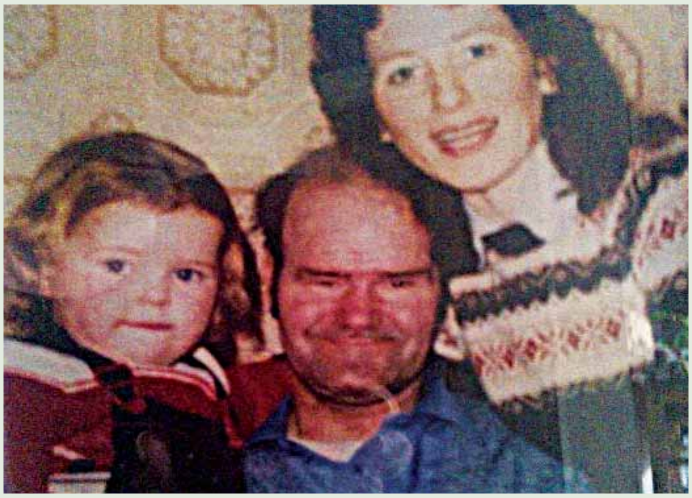
4. SAFE GUARDING THE FUTURE OF THE IMNDA

The numbers of registrations have been increasing over the years; this has meant an increased demand for our services. Our HSE funding is continually being cut. We rely on fundraising and the generosity of the general public to fund over 86% of our service. We experienced a reduction in cash flow in 2013 due to a number of reasons. Our vision at the IMNDA is a world free from Motor Neurone Disease, and in order for us to fulfil this mission we feel that we need to provide for the future of IMNDA to ensure that we stay in existence to see this vision through. €500,000, a little over 30% of the ICB money will be held in reserve to ensure the future of the IMNDA.
Our Board of Trustees are ultimately responsible for deciding how the money is invested but they and the whole Association want to ensure that the support and service we provide is improved and continued.
We will continue to keep you updated with any arising projects and decisions that will be made on the Ice Bucket funds.

The impact that the Ice Bucket funding will have on the lives of people living with MND will be priceless. Hopefully it will help us realise the vision – A World Free of MND.

THANK YOU ALL FOR YOUR SUPPORT DURING THIS CAMPAIGN

THE STORY OF OUR DA MICHAEL GRANT & HIS JOURNEY THROUGH MOTOR NEURONE DISEASE



The Grant family lost their Dad who passed away 33 years ago after living with MND for 12 year with just their mother caring for him, along with 12 children. Here is their story;

Our Da was born in the nineteen thirties, he was a quiet man and my Mam was his first girlfriend. He was the eldest of 10 children. He was a pioneer and had a passion for football. He played football at local and county level. Below is an account of memories from some of his children. It reflects their experience of living with a parent with a disability.

Annmarie and Lorna memories: Our da was a great da to all of us, Lena, Bernie, Michael, Breda, Susan, Philip, Annmarie, Declan, Brendan, Martin, Mandy & Lorna, and a great husband to our ma Lily.
My sister Annmarie left school in 1979 at the age of 14 to assist our ma with the running of the home and with our da, but the whole family mucked in where needed and all had a job to do, either helping our ma with da or helping around the home. Bernie would run our baths and got us younger ones our first toothbrush. Our ma took on the role of nurse, where she washed and dressed him. Whoever was available to feed him, would, to let ma get on with other things around the house and take care of my needs as I was only 1 year old. 1980 our family moved to a purpose built home which had a downstairs shower room, toilet and bedroom as our dad was unable to use the stairs. The same year, our ma started to take jobs outside the home, cleaning houses to earn extra money and have a break from home life. Annmarie took on the role of a parent and carer at home; she took care of myself and young siblings and also made dinner for the older siblings who were working.

This continued until my da's passing in June 1981. The district nurse did a house call which I'm not too sure was to see me as I was only 3 or specifically to see our da. On this visit the nurse advised our ma the dad was dying and it would be best if he went into hospital. I remember that day as it were yesterday, watching from the neighbours window as my da was lifted into the back of the ambulance, it was the last time I seen him alive. When speaking to my family I was told that da was crying in the ambulance and said if he goes into hospital, he would come out in a box. He was in hospital (The Richmond) for 10 days when the nurse, knowing he wasn't feeling well, asked him would he just like dessert today and he replied, no, I'd like my dinner, they were his last words as he then just dropped his head and was gone, so very quick.

Breda's memory: My Da was my Hero, He worked very hard, was clever and handsome. He was interested in all of his children; I reckon we were his greatest achievement. He was always interested in how we got on in school. He would come in from work and ask, "How was school today" or "did you get any slaps today" have you homework, is it done yet........

He worked very hard because there were lots of little mouths to feed. By day he would catch the train to Donabate along with his bike, to work in Lambs. He would then cycle home to Balbriggan, have his dinner and go to work in the coal yard until 10pm. He loved to sing and I remember him sitting on the bed singing for us and teaching us the words of all the rebel songs and songs from the charts.

Every Friday or pay-day he would arrive home and we would all run across the green to meet him when we'd see him off in the distance. A gang of kids racing to him to catch his hand, hang out of him and see what nice stuff he brought us home.

He would lift two of us high on his shoulders and his pockets would be bulging with sweets or chocolate bars, the pay-day treat for us. At birthday time we would get a card with a large bar of chocolate inside, we would wait all day for him to come home from work or it would be on our pillow the next morning. God I loved my Da. Then my Da got sick, I think I was 8 or 9 years old.

I remember him telling my ma one evening that he was carrying a bucket of cement up a ladder and it just fell out of his hand, he lost his grip. There were many tests then and initially he was diagnosed with MS. He arrived home from the hospital with two sponge pieces to put on his knife and fork so it was easier to handle. He was unable to work anymore at physical work. He got a job delivering Carmelite pools. All of his children in turn helped him with this job. I don't ever remember him being depressed about his condition. He was mostly good humoured and happy.
We all helped out when asked to do things like, helping him with his coat; eventually he needed more help and support.

My Mother did all the personal care however we could do things like shaving him or feed him, wash his face and hands. I could give him a perfect wet shave by the time I was a young teenager. I suppose it never really dawned on me that this was not normal for a child. But it was in our house and we all helped.

Even my little sisters Mandy and Lorna would press the button to the station he needed. They also got to know that they could sneak his polo mints out of his pocket and know he couldn't chase them. He loved them doing this and always pretended to be annoyed. I remember as time went on he got more unsteady on his feet and shuffled along. As a young teenager I sometimes felt embarrassed when I would meet him out. I know that is awful and I am ashamed of it now, but that was the way I felt. I wanted my healthy Da back. I missed him. I remember one day walking down from Mass and I was on the opposite side of the road with my friend when Da fell. I nearly got killed with a car running over to him and trying to lift him up from the ground with blood everywhere as he couldn't put his hands out to break the fall.

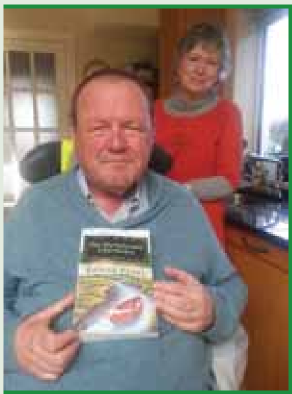
My Mother was nothing short of amazing. I never heard her complaining other than maybe if he didn't get home for dinner as she tried to keep it warm on a pot of boiling water. She has 12 children to care for lots of little ones. She never had a minute, always busy. She was brilliant and I feel my parents loved each other very much. Da called her Lily the Pink.

Eventually Da needed everything done for him, right down to scratching his nose. He used a wheelchair which I suppose was easier on us and we could keep him safe. Looking back that must have been terrible for him. He never was in hospital for the whole of his illness. We all just got on with it.

He went into hospital 10 days before he passed away. Looking back I reckon they knew he didn't have long and they felt it would be difficult if it happened in the house with all the children. I was 19 when he died and it broke my heart. He was only 50 years old and had coped with Motor Neurone Disease for 12 years or more. The Doctors were amazed at how he survived that long with just my Ma and us caring for him.

I am so proud to have had my Da in my life for the length of time I did, I know my younger brothers and sisters have very little memories of him. My fondest Memories of him are of a young strong man always happy go lucky with a love for life and his family and friends. This love for life stayed with him throughout his illness.

He was a great man and I am so proud to be his daughter. God bless you Da…sleep easy, love you loads Breda, Annmarie and Lorna x



Roland's Story and his exciting new book- The Marshlander Chronicles

I was born in Oxford in 1951 and my parents had a farm. They sold up in 1952 and moved to Ireland where land was cheaper and I spent a few years in North County Dublin. Farming proved difficult and we moved between Dublin, Kildare and Meath before Meath became our family home as we built on the banks of the Boyne near Navan.

I was educated at Headfort preparatory School in Kells and Portora in Enniskillen. My parents ran a hotel in Navan and kept a herd of bullocks and the occasional racehorse.

My adult life was in Teaching, I taught at 2nd level in the UK and primary level back in Ireland after marriage to my wife Annette in 1978. My final school was a country school in Co, Wicklow. I have two children a stepson and a daughter.

I was diagnosed nearly 5 years ago with MND. At the time I was working, walking slowly but otherwise I was living a full life. Since then I have lost my mobility, my hands and arms have weakened and I cannot lie flat or sleep without a bi-pap breathing machine. I am dependent on my carers who get me in and out of bed, get me to the toilet and wash and dress me. I am fortunate to have my voice and the ability to swallow.

I live a full life thanks to the IMNDA. Not only have they provided equipment promptly and ahead of time but they give expert timely advice and huge emotional and financial support. So that others may have the same support and so that vital research can continue, I am giving the full proceeds of the sale of my book 'The Marshlander Chronicles' to the IMNDA.

I grew up on the banks of the Boyne and in winter it over spilled its banks. It was rich in wildlife and after the waters retreated in spring the rushes and reeds were rich for childhood exploration. In 1969 the river was dredged and deepened and all this disappeared. The memory lingered and I began to imagine the marshes many thousands of times bigger and the book set on another planet was born.

The Marshlander Chronicles

'WATER IS OUR LIFE. WITHOUT WATER WE ARE SLAVES.' The words of Solomon Drake rang in the ears of 14 year old Prins, citizen of Marshland, a wetland rich in animal and plant life. prins is despised by his peers because of his physical weakness. The story opens with the arrival of CORE (the council for renewal and enlightenment) who want to persuade Marshlanders to sell their wooden houses on sstilts so the marsh can be drained in return for gold.

One of his tormentors, a representative of CORE, drops paper from his pocket. Prins has a secret. He can read, one of the few in his world who can.

The Marshlander Chronicles will be available shortly from the IMNDA Shop for € 15

CELEBRATING 30 YEARS WITH A WONDERFUL ASSOCIATION!

30 Years is a long time in a person's life. For me, a person living with Motor Neurone Disease, the past thirty years have become a humbling milestone. Those years have filled me with so many emotions. As I recall the past, the faces of those I loved and lost to MND appear to the fore of my mind. Brave, wonderful people whose friendship was bonded with me because of this disease. I pray that God now holds them in his care until we meet again. I think of those who gave so much of themselves to our association, the volunteers who were there to support and help those diagnosed and their families. Without these wonderful people, each patient would travel a dark lonely path.

I am very thankful for the fruits of those thirty years. From humble beginnings, the IMNDA was a small voice in the wilderness, a lone cry for the plight of those living with MND. Today, I celebrate that I have survived to witness the day when over 1 million people in our country understood what MND was, and were prepared to do their bit to support MND patients as the water from the icy bucket fell.

In the year 1993, the then Minister for Health, Brendan Howlin allocated funds to the IMNDA for the purpose of giving patients and their carer's a week-end break in a hotel. This was a welcome recognition of our plight and I am thankful that this great tradition continues, as annually we come together to support each other, laugh with each other and share our stories, both good and bad.

It is now forty years since my first symptoms appeared. They were coal face days when feelings of fear, anger and embarrassment consumed my life. Thankfully I have managed to free myself from the shackles which ignorance of this disease had bound me, and today I find myself in a New Ireland, where we wait with understanding and support for a cure. I know that there were never as many people working in Laboratories all over the world, striving on our behalf to find a way to beat this cruel disease.

We are very fortunate here in Ireland to have a person of the calibre of Prof Dr Orla Hardiman working tirelessly in conjunction with global research, trying to find a cure or at least something to arrest this cruel disease. She is hopeful that something to arrest this disease will be discovered within her professional life!.

I would like to pay tribute to the present staff of the IMNDA, who man the office at Coleraine House, you are there, five days a week, to listen to our tales of woe, and to help us in any way possible.

YOU ARE OUR CRUTCH!! GOD BLESS YOU!
ANDY MCGOVERN, MND SURVIVOR...

IS THE ‘PRACTICE OF MINDFULNESS’ A PASSING FAD OR HERE TO STAY?

Mindfulness as a practice is neither new or a trend. Rather it is something that has been around for a very long time and has been repackaged to broaden its appeal. It’s just become mainstream. On a personal level and within the Corporate World. It’s another way of being respectful, to ourselves and others. What it means to me, to you, to those around us can mean very different things. In the broadest sense it simply means being aware of what is happening around you now. Being aware of what surrounds you, the impact of your behaviour on yourself and others. Living deliberately and consciously like this helps us get more out of our lives and often build a better future. Yet, as everybody knows, it’s easier said than done.

Now that said, as I recall when I was young…. we were brought up to be considerate, respectful and kind. Always to be on time. Not to interrupt. To say please and thank you. In fact, my dear dad used to say that you could get help with most things in life depending on how you asked. I soon learnt that help was indeed often available if only I could get over my fierce pride for our mother taught us to be independent, never dependent on anyone, so you can imagine the continuing journey of learning I have. A life which honours my values, the values which are my guiding principles for how I think and act. These values embody too the traits I most admire in others. Respect and Kindness feature high on my list and Mindfulness for me is based on respect, firstly for myself and for anything and everything that surrounds me. It keeps me grounded. Helps me focus on what’s most important and rationalise irrational thoughts most of the time. Mindfulness is one of the hardest practices of all even though I know if my mind is busy thinking about a past incident that I can do nothing about and my time is best spent on the task in hand, something that I want or need to do now, something that will benefit me now and in the future, there’s often a little devil in my head, taunting and teasing me, distracting me. But what exactly is mindfulness? In the last year, I’ve learnt a great deal on this from Roland Evans who has MND and his wife Annette.Over the summer when my cottage was being re-built, I lived with them and saw mindfulness in full flow, every day. I asked them what the secret of their relationship was and in particular coping with MND.Acceptance they both replied, almost in unison. As we spoke more about what acceptance meant, a clearer picture emerged. It was acceptance of everything. Of all relationships, within the family, with friends and acquaintances. Not dwelling on what life was like before learning to live with MND, rather than waiting to die. Of being grateful for the day in hand. For the friendships, the daily kindnesses of others, the joy of sharing time with people, in conversation, in silent companionship of a pastime like painting or writing, of simply knowing that other people were around. Knowing that what was going on right here, right now, was the most important thing of all. Instead of wasting time in asking why, realising why not and getting on with making the most of every moment available. Is this not the ultimate embodiment of Mindfulness?

Being mindful, well it stops my mind zig-zagging around’ said Annette. Roland feels it calms his mind and described his practice of mindfulness as a form of ‘secular prayer’. In asking others, ‘being mindful gives me sense of order, flow, a calmness which seemed to have a knock-on effect to other areas of my life.’ Call me old fashioned, but the way I see it when you’re with someone, is it not just good manners to give them your full attention, rather than only half listening because unconsciously or otherwise, you’re busy thinking of what you want to add to the conversation? Is it not better for everyone to concentrate on what they’re doing instead of multi-tasking all the time? The answer of course is yes. The key, it seems, to getting more out of everything in our lives is being aware of what we’re doing and the impact of our thoughts and actions both on ourselves and others. Being clear about what it is we want, whilst being kind and polite in our communication. Treating others as we would like to be treated ourselves. The secret I feel lies in the word ‘practice’. The regular practice of being aware, of being mindful, of consciously choosing to focus on what’s going on in our lives now is what matters most. Some things do not change. Mindfulness is and always was, an essential part of life.

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MND GLOBAL AWARENESS DAY 21ST JUNE

This coming summer we are launching our National Awareness Campaign in the run up to 'MND Global Awareness Day' 21st June. We will be airing an infomercial on national radio stations with one of our clients Loretto Dempsey. This is following on from the success that our National Awareness advert had last year that featured Jan Battles from Waterford and Paul Lannon from Kilkenny. Loretto has bravely agreed to get involved with our new radio campaign for 2015 to help raise awareness of motor neurone disease.

We want to share with people the real life impact of MND. The radio advert will convey the emotional and physical reality of receiving a diagnosis of MND. It tells the real life story of Loretto and her own personal experience of MND.

As well as being an awareness campaign this will also be a fundraising opportunity for the association and we will be asking people to organise the 'Drink Tea for MND' Campaigns in their local areas on or around the 21st June. More information on the awareness campaign and on Loretto will be up on our website soon, so check out **www.imnda.ie**

THIS IS LORETTO'S STORY:

It all started when I couldn't move the fingers on my left hand. I let it go for a couple of months thinking it was a trapped nerve. I found I couldn't lift heavy objects; things that I could usually lift became a problem, even a shopping bag. I kept dropping things. Going up stairs became very difficult for me. I thought that it was just because I was reaching middle-age. My fingers would freeze for only for a couple of seconds. My muscles would twitch. I went to the doctor she sent me for tests which were all clear so she then sent me to a neurologist in the Mater hospital. I was diagnosed with MND last March.

Overtime my limbs got weaker. I now spend 99% of the time in a wheelchair and I don't have much use of my hands. I can still type with a couple of fingers which is great because that means that I can still work. I work on the IT help desk in Arthur Cox. I told them when I was first diagnosed and they have been incredibly good to me. They pay for taxis to bring me to and from work; they paid to put a stair lift to my house. I have voice recognition on my PC which I'm sure the others in the office find distracting but they are too polite to say so. They've taken down walls and put in sliding doors into my office. If they were not so good to me I wouldn't still be working. Every week they ask me if there is anything they can do for me. I never imagined that they could be so considerate and kind to me. And I will always be grateful to them for making my last few months working so pleasant. I think it's important to work because it allows me get of the house for a few hours every day. Let's me interact with people and it gives my parents a break.

I feel I have deteriorated quite quickly but I know that this disease affects everybody differently so I don't have anybody to compare myself to but I just know that in March last year, the week before I was diagnosed I was in London for a weekend. I walked around London, up and down the stairs of the tube but within a couple months walking long distances and climbing stairs were completely out of the question. Physically the thing I worry most about is my breathing I know 90% of MND patients die from breathing difficulties and my breathing has deteriorated quite quickly since last October. I am using a BiPap Machine at night. I find it a little bit difficult but I have to use it. Every time you face a new challenge you find a way to deal with it. Weather it is getting your Dad to hold the hairdryer and point it in your direction or asking your mother to put on your makeup. Sometimes I think it is unfair that as well as dying young you have to waste away slowly.

I never had any pain which I always thought was a good thing because I always thought there can't be anything seriously wrong with you if you have no pain. I used to say that to doctors until one doctor told me that they worry when you have weakness and sensation but no pain.

Mentally I'm quite relaxed about my diagnosis, I always was. When I was waiting on my appointment I wondered if it could be something serious so I googled the symptoms and it kept coming back to MND. So you think maybe I have it but you don't think that you do have it until it is confirmed. After the diagnosis was confirmed my family were devastated. We've always been a very close family that has talked a lot about everything so it helped to know I was not alone and I had the best support I could wish for.

Just because I can't physically do things doesn't mean I can't do the things I enjoy doing. I don't think I am reacting any differently from other people. No one knows how they will react. You can't say "Actually I don't want MND. I want to give back thanks, I kept the receipt". So you have to get on with it and deal with the challenges it gives you. It's like the old saying what doesn't kill you makes you stronger and you are not going to be sent anything you can't handle. People don't know what to say to you when they hear about your diagnosis. I always say "it's okay, I understand there is nothing you can say". If there were words that anybody could say to help me they would've already been said.

I don't really think about dying. I think about my parents and how they will cope after I am gone. They are very fit and healthy which is great for me to because they have to do everything for me and I hope looking after me doesn't wear them out too much. I think about my niece and nephew and how I hope they will remember me. I want them to miss me. If one day they have children I want them to tell those children about me. I know it's really really easy to forget about people.

Probably one of the worst things mentally is I think about things that are never going to happen. Things like I'm never going to retire to Florida, which is something, I had planned to do with my sisters. I'm never going to see my niece and nephew get married and have children. Even little things like I am never going to cook again, I'm never going to drive again which I'm told is probably not a bad thing for other road users, I'm never going to win Masterchef. It was never really going to happen but I could still dream. I'm never going to win the lottery but one doctor did say the odds of me getting MND were the same as winning the lottery.

I think one day there is going be a cure for this disease. There are some really intelligent people working on a cure. There should be no limits to the amount of funding they are given to do their jobs properly. Nobody knows what causes the disease.

I read somewhere that statistically athletes were more prone to get it. I was certainly never athletic but finding out why people get it would be a step in the right direction towards a cure.

The IMNDA is really good about giving you tools, advice and equipment to help you cope with the disease. Electric wheelchairs, hoists, eye gaze for the computer and even an arm attached to the table so you can feed yourself rather than having somebody feed you, these all help to improve your quality of life and to keep you as independent as possible for as long as possible. We joke a lot about MND. I have a sister who we call Betty Davis, because I am convinced that one day she will served me up a rat for dinner like Bette Davis did in the movie "Whatever happened to baby Jane". The same sister says she is convinced I don't have MND; she says I'm just being lazy and I am pretending to make her push me around in a wheelchair.

My niece once asked me if I had any regrets. I told her the only regret I had was spending so much money on anti-ageing cream. I don't have a bucket list. All my life I've done everything I wanted to do. I have travelled all over the world. When you are terminally ill you don't worry about things that you used to worry about. You don't think about money, you don't think about having a nice car. All I want to do is to spend quality time with family and friends. I am very grateful for the friends I have. They have made great efforts to spend time with me.

Thanks to Loretto for agreeing to take part in our national awareness campaign in June to mark MND Global Day 21st June. Listen out for the radio advert that will be running in early June.

For more information or to hold a tea day, visit our website www.imnda.ie
Thanks for your support!!

FIGHTING FATIGUE

Fatigue is a common symptom for people with MND. In a recent study, people with MND who experienced fatigue described it as a “whole body tiredness” or a “muscle weakness related to exertion of the limb and bulbar muscles”(1). The terms fatigue and tiredness are often used interchangeably when discussing this topic. However, it is a tiredness that is only partially relieved by rest or sleep.

Fatigue is caused by a number of factors. One of the main reasons is that because of muscle weakness, a smaller number of muscle and nerve cells are doing the work and therefore, muscles tire quickly. Weight loss and reduced food intake due to swallowing difficulties will most likely affect a person’s energy levels as well as difficulty with breathing. If the breathing muscles are weaker, less air is drawn into the lungs and therefore, less oxygen is available for more strenuous activities(2).

Factors that may aggravate fatigue include immobility, overexertion, sleep disturbance, difficulty with breathing, stress and anxiety and some medications.

If you suffer with fatigue, you may have difficulty with day to day activities such as showering, dressing, cooking, housework, work, walking distances, shopping.

HERE ARE SOME TECHNIQUES THAT MAY HELP TO REDUCE FATIGUE:

- Plan activities in advance: Try not to arrange too many activities for the same day. For example, if you are going to the supermarket in the morning, plan an afternoon at home. If you have gardening to do in the afternoon, take it easy for the morning.
- Find short cuts where possible: prioritise jobs - can you delegate a task to someone else (especially if it is one that you don’t particularly care for). Examples are elements of housework, ironing, shop on line instead of trudging around the supermarket.
- Pace yourself: take regular breaks and stop an activity if it causes breathlessness. Alternate hard and easy tasks. Don’t try to complete all difficult tasks at once to get them out of the way.
- Sit rather than stand: this uses less energy especially if you have balance problems or pain. Consider using a perching stool to access counter surfaces, sink etc. Use labour saving devices (gadgets or aids) to make tasks easier: speak to your Occupational Therapist (at your local health centre) for advice and provision under the medical card scheme.
- Make your environment easier to move around in: don’t keep walking around that chair between your kitchen and living area, move it so that you have a free path. Keep clutter to a minimum so as to find items easier. Keep clothes that you wear most often at hip level in drawers and wardrobes to save bending and reaching.
- Establish a regular sleeping pattern: while rest only partially relieves fatigue, lack of sleep can aggravate the condition.

When you experience fatigue, there is a fine line between not doing enough and doing too much. You may feel discouraged from keeping active but this may lead to a greater loss of energy, which in turn will lead to more tiredness. Listen to your own body.

When you feel good enjoy it, but don’t take on too much. Overdoing it will bring you back to square one.

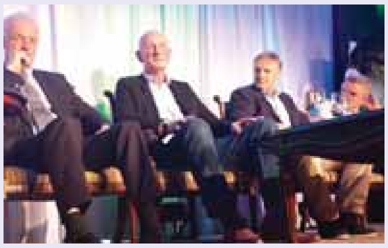
Try some of the energy conservation techniques outlined above and see what works for you.

References: (1) Gibbons, Thornton, Young. “The patient experience of fatigue in motor neurone disease”. Frontiers in Psychology Journal, Oct 25 2013, 4:788(2) MND Australia 2014.

Fighting Fatigue by Niamh Doyle .

THE DIFFERENCE WE MAKE TOGETHER...

The IMNDA would like to express huge thanks to each individual who does something special for the association; every penny is hugely appreciated. Your continuous support allows us to continue our vital work. We are lucky to have so many people who support us throughout the year and unfortunately it is not possible to thank everybody personally, to those who aren't mentioned here, please accept our sincere thanks.



THANK YOU TO...

LEGENDS

On the 15th Oct the Woodford Dolmen Hotel in Carlow, an incredible event, orchestrated by Mark Attride and Carlow Friends of IMNDA, took place. It was an evening of 'Legends with Miriam O'Callaghan'. The RTE presenter was joined by some very well-known Irish faces including Míchaél Ó Muircheartaigh, Mario Rosenstock, Sean O'Brien, Joe Schmidt, Michael O'Leary, Brian Cody & Willie Mullins. The event was an incredible success and raised over €56,000. All at the IMNDA would just like to thank everyone who made this event possible.

TEA TIME!

The ever popular tea and coffee mornings proved once again a timeless treat. Else O'Neill's Coffee Morning in Lucan raised a tea totalling €1,500. Thanks to Edel Dockrell and everyone in Stacks Pharmacy and to Ann & Clare Mohan who also had a cuppa for the IMNDA. Siobhan Lynch held her coffee morning in Macroom in Cork, and together with friends and family raised €3,787.

Eileen Carroll put on a splendid Afternoon Tea for her friends and raised €1,700 for the IMNDA. Well done Ladies!

Margaret Farrar organised a spectacular coffee morning with Annette & Roland Evans and raised a brilliant €2,050. The house was full of tasty baked treats so well done to all who made it such a success!

BAKE SALE

Fionnuala Minto and everyone from B&Q in Limerick, were taking lessons from Mary Berry when they organised a Bake Sale and raised €460 for the association. Elaine McCormack and everyone from AIB on Adelaide Street also baked up a storm of goodies and whipped up over €540 for the IMNDA. Well done everyone!

FISHING FOR ANSWERS

The quiz masters were out in force! Raymond Scullion and the ALMC Motor Club organised a Table Quiz and raffle and raised €470 for the IMNDA. Joe O'Rourke's Pub Quiz proved to be a triumph raising over €1,600 and Maura Carmody- Coffey's Monster Quiz was a mighty success in Ballykisteen Hotel & Golf Resort, Co. Tipperary.

Margaret McGuinness also put on a great evening in St. Mary's GAA in Leixlip, her quiz raised over €800. Thanks Margaret and Frank! Thanks to every person who supported these quizzical events. Thanks also to Amanda Robinson and her Fine Gael colleagues as their quiz raised €500.

THE DIFFERENCE WE MAKE TOGETHER Cont:

FUN-RAISING!

Ann Sinnott had her party hat on when she threw a big Family Day Party in her house. Everyone had a super time and Ann and the gang collected an impressive € 3,285.00. Niamh Ní Dhrisceoil and all from Cape Clear Island held their family fun day and this raised over € 2,400. Thanks to everyone who pitched in and made the event so special.

Brendan Duffy had it right when he organised a Summer BBQ. It raised a sizzling € 2,300! Thanks Brendan!

A huge thanks to Anto Kerins, Mike O'Connor and Dominic Dillane along with everyone else from DIT Cathal Brugha Street. They held their Christmas Dinner in aid of the association. We were thrilled to have been presented with the fantastic sum of € 1,650. Thanks to all the committee who made it happen.

Lights, curtain, action! Thank you to Mike Treacy and everyone involved in the play in Killaughton Hall. The play brought in over € 1,600; we give you all a standing ovation! The Donore and Rossnaree Drama Group also put on a play and raised € 860 for the IMNDA.

Dropping pounds and raising euros! Síle Hammond took on a weight loss challenge and raised over € 1,600! Well done Síle!

Thanks to Chris Hussey and Glen Cullen who grew facial hair for the association and raised over € 600 collectively.

Special thanks to Sandra Tolan for organising a Vintage Clothes and Accessories Sale and raised nearly € 1,000. Thanks to Leanne Parle and all from SuperValu Waterford, they held a bucket collection and raised € 1,350.

Thanks to all the lovely couples who got hitched this year and donated their wedding favours.

A huge thank you must also go to everyone who helped us in 2014 with our annual Church Gate Collections.

We collected over € 26,000. We could not have done this without, so thank you for giving your time, we deeply appreciate it.

Special thanks to Linda Saunders and the Neptune Bridge Club, their fundraiser in the Grand Hotel in Wicklow Town really hit the jackpot as they raised € 1,420 for the IMNDA.

MUSIC MOMENTS

Nuala Maher may not have been 'Born in the USA' but this did not stop her from organising a Bruce Springsteen Tribute Act. Everyone was 'Dancing in the Dark' and Nuala raised an on 'Fire' € 2,000!

Geraldine Collins and her choir went carol singing in Dundrum this Christmas and through their heavenly voices they collected over € 760 for the IMNDA. Mark Attride and friends in Carlow also held a carol singing service and raised over € 1,500. Thanks to all the singers!!

Maria Butterly had everybody singing and dancing at her beautiful Evening of Song in St Patricks Church in Trim. Margaret Murphy and Sharon Friel gave Maria a hand and over € 2,500 was received in donations. Thanks to all for making this concert such a success.

Thanks also to Neil Rawles and all those involved in the Monster Barn dance in Rawles Pub Ballinalee Co Longford bringing in the Monster amount of € 20,000!!! Thank you and congrats!!

SPOOKTACULAR!

Eddie Barrett and the Knocknagoshel Halloween Group set up a Ghost Trail and scared people out of € 500!
Charlene McGough threw a Wild West Halloween party in Galway. Playing cowboys and Indians can raise a pretty penny and the themed affair roped in a wicked € 860.

THE DIFFERENCE WE MAKE TOGETHER Cont:

MOTORING FOR MOTOR NEURONE DISEASE

This year was the 75th Oldcastle Agricultural Show in Oldcastle and they decided to mark it with a Pit Stop Challenge event. The winners of this challenge won the Rory Galligan perpetual cup in memory of Rory Galligan who sadly passed away with Motor Neurone Disease. Rory was a very successful and talented rally driver and Motorsport enthusiast! In memory of Rory and to help someone else who is living with MND, Margaret Caffrey and all from Oldcastle Agricultural Show made a donation of just over €150. Special thanks also to the North East Vintage Car Club Committee; their annual Vintage Car event was a classical success coasting in a fantastic €2,600.

CORPORATE DONATIONS

We must give a huge thank you to everyone at Towers Watson. They organised countless events throughout the year including an Ice Bucket Challenge, a Bake Off, a comedy night – they even went as far as Kilimanjaro for us!! The incredible team raised a whopping €23,478.95!! Unbelievable achievement!

Thank you for getting involved so whole heartedly.

Thanks to all at Sigmar. They held a coffee morning, run, Table quiz and a Christmas Jumper Day for the IMNDA and have so far raised nearly €2,000.

Huge thanks to the Association of Irish Floral Aritist (AOIFA), who have chosen us as their charity for the year. They have been organising floral shows the length and breadth of the country and their efforts have not been in vane with money flowering in from their exhibitions!

Intel have also chosen us as their charity partner along with St. Luke's Hospice for 2015. We are thrilled to be working with Intel. They have been brilliant so far already raising €5,000 from their Site Charity Day in 2014; they raised over €3,800 from participating in our Croke Park abseil and hugely helped us at our Walk to D-Feet last year!

They have great events in the planner so 2015 is going to be very exciting. Special thanks to Stephen Doyle for the nomination.

THE JUNE BALL IN AID OF THE IMNDA RETURNS TO THE DOUBLE TREE BY HILTON HOTEL (BURLINGTON ROAD, DONNYBROOK, DUBLIN) ON SATURDAY 27 JUNE 2015 FOR THE SECOND YEAR RUNNING.

The June Ball 2015 promises to be an amazing night packed full of fun and entertainment, so dust off your best ball gowns and tuxedos, get a group of your friends and family on board and secure your tickets for what will be the night of the Summer 2015! Last year's event proved to be a massive success with over 600 guests attending an incredible evening, which, with your help, we will be aiming to surpass! If you would like to donate a prize (or prizes!) for the raffle or auction on the night, or know of any friends or businesses who would like to make a donation or sponsor a prize, we would love to hear from you.

Tickets are priced at €90 (excl. booking fee).
Follow us on Facebook at 'The June Ball' or Twitter @thejuneball for further updates and event details (and be sure to spread the word by sharing and retweeting our updates!)

FOR ANY QUERIES IN RELATION TO THE EVENT, PLEASE EMAIL US AT: THEJUNEBALL@GMAIL.COM

THANK YOU FOR GETTING ACTIVE FOR YOUR ASSOCIATION!

PEDAL POWER!

On your bike! Cycling continued to be popular with many of you taking the tyres to the tarmac to raise funds for the IMNDA. One of these people was Josephine Roche who organised a cycle from Avoca to Enniscorthy and raised €1,100. Well done to all involved!

Another biggie was the New Ireland Assurance Charity Cycle which raised nearly €12,000. A massive thank you to Michael Gordon and all from New Ireland Assurance, who participated and organised this fantastic event.

Ben Garry and friends cycled all the way from Nenagh to Galway and they raised a pretty penny too. The group raised over €2,700 – well done guys! Thanks also to Clodagh Kavanagh took part in The Leinster Loop Cycle and raised an impressive €865.

Special thanks to Gerry McGovern and the Marble City Cyclists for organising the Tour de Kilkenny and raising over €1,500 for the IMNDA. On the day they had torrential rain but still 550 cyclists turned out to take part in the 40km, 70km, 110km and 160km route options.

ON YOUR MARKS!

Green IMNDA t-shirts were pounding the pavements the length and breadth of the country. Special thanks to Eileen Crowley, Maria Fehily, Lorraine Walshe for taking part in the Cork Women's Mini Marathon.

Thanks to all those who took part in half and full marathons this year. Thanks to Paul O'Rourke for taking on the roads in Dingle and Gillian O'Hare for completing the Dublin City Half Marathon. Huge thanks to Madeleine Carroll for taking on TriAthy and raising over €1,000.

Thanks to everyone who took part in the Dublin City Marathon, collectively over €15,000 was raised. A massive thank you to you all. Special thank you to Kathlenn Cullinane, Paddy Healy and Fergus Murphy for going above and beyond!

Miriam Maher decided that running just a normal marathon wasn't enough of a challenge for her so she took on the Trail Marathon in Wales. She ran 42km over trails and tracks in the world-renowned Coed y Brenin forest in the Snowdonia National Park. Her tale at the end of the trail was that she had raised over €950. Congrats Miriam! Ciara Smyth went all the way to the Big Apple to take on the New York Marathon and raised a tasty €520!

Brendan Monaghan and some troops from Tuam Athletic Club, ran over 22 miles from Eyre Square to Tuam and raised €1,603 from their efforts. Trojan feat guys! Also thanks to Ciara & Aisling Conway for raising over €250 from going to Hell & Back for the IMNDA. Special thanks to Anne McGee and everyone from Lucan AC as their Turkey Trot raised €800.

WALK TO D-FEET

Our annual walk to D-Feet MND will be taking place on Saturday 18th of July. Other people were too eager to get walking and decided to hold their own. Special thanks to Melinda Hayes for organising her 21K Coastal Walk which raised over €3,670. Mighty work Melinda!

Mabel Norton had similar coastal aspirations as her walk took her from Howth to Dunlaoghaire. The sea views saw her raise a worthy €350. Thanks Mabel!

Stephen Smith along with friends and family embarked on a journey from Home to Home. Stephen and friends walked from Armagh to Mayo, over 147 miles and raised over €4,000. What amazing trek and phenomenal achievement.

Áine and Gabby McFadden organised a walk with Athlone IT in memory of their sister, former TD Nicky McFadden. The walk was well attended and over €9,500 was raised. Many thanks to all who turned out and supported the event.

THANK YOU FOR GETTING ACTIVE FOR YOUR ASSOCIATION! Cont:

HOLE IN ONE!

Well done to Josephine Fahy. Her Golf Event in Loughrea Golf Club raised over €4,000. Huge thanks to everyone who teed off on the day. Thanks to Kathleen Bray and everyone from Collinstown Pitch & Putt Club as their draw raised over €200.

SMASHING EVENT

Betty Hogan sure played an ace. Her Tennis Tournament in Offaly raised a smashing €605. Thanks to everyone for participating and playing in the event. Pat Mooney from Greystones was also onto a winner as his tennis event raised over €400.

ABSEIL

Here's to the 48 thrill seekers who climbed onto the roof of the Hogan Stand in the famous Croke Park in October and abseiled the 100ft to pitch side! Each abseiler committed to raising sponsorship money to take part in this unique and exciting event of which we are extremely grateful. Thank you to everybody who took part especially those who overcame their fear of heights in order to do something special for the IMNDA and together raised over €28,000!!!

OTHER CHALLENGES

Jessica Mahon and Sarah Ennis took to the skies; they took on a leap of faith and skydived to raise over €619 collectively. Peter Walsh had a more zenful approach to fundraising and organised a yoga class. After a lot of downward facing dog and warrior poses, Peter raised €345. Respect!

THE VERY BEST OF LUCK TO ALL OUR ACTIVE FUNDRAISERS WHO ARE TAKING PART IN THIS YEAR'S MANY MARATHONS – FULL, MINI AND HALF – WALKS, SWIMS, CYCLES. ENJOY!

THE DANDELION DUST UP – ROUND 2!

The IMNDA organised another very special White Collar Boxing Charity Fundraiser which took place in Dandelion Night Club on Stephens Green in Dublin on Friday 13th March.

A massive well done to all our 31 participants who signed up to take part in the Dandelion Dust Up Round 2. Back in January 24 men and 7 ladies started an 8 week training programme with White Collar Boxing in White Collar HQ in Harold's Cross. We had the incredible Ritchie Connell coaching our boxing fledglings and pushing them to be the contenders we knew they could be!

Over the 8 weeks fitness levels improved and boxing techniques were learnt, some laughs were had too we hope!! The Dandelion Dust Up Round 2 was a truly fantastic night, 15 fights with everybody giving it their all and around 550 spectators piled in and brought the house down. The night raised approximately €20,000! Thanks boxers, thanks Ritchie, thanks spectators, volunteers, White Collar Boxing, sponsors and everybody else who helped to make this night such a success!

WALK TO D-FEET MND

On Saturday 18th July at 11am, the IMNDA is hosting its 3rd 'Walk to D-Feet MND'. Last year over 100 people came together with friends and family on a blazing hot summer's day for a beautiful 5k walk (or run!) in the stunning grounds of Castletown House, Celbridge, Co Kildare in aid of Motor Neurone Disease.

Register online - just €20 per person at www.imnda.ie or alternatively complete the below form and return it to us with payment. Walkers will also be able to pay on the day. The IMNDA will be based in front of the house and registration opens at 10am on the 18th. All children under the age of 12 go free. All walkers receive an IMNDA t-shirt and light refreshments. The route is fully wheelchair & buggy accessible.

Every step makes a difference. We walk for hope, we walk in support, we walk in memory and we walk so that one day we will see a world free of Motor Neurone Disease.

Can't make Castletown on the 18th July? Why not organise your own Walk to D-Feet MND in your local area this summer! We'd love to have as many walks taking place across Ireland as possible in conjunction with our own so we can spread the message further afield. Get in touch to discuss your walk and we will provide you with some tips and practical information.

Freefone 1800 403 403 or email fundraising@imnda.ie

Together, lets take steps to D-Feet MND

Your Details (Please Use BLOCK CAPITALS)

First name:______________________________ Surname:___________________________

Address: ____

____

Phone _________________________________ Email _______________________________________

How many walkers over the age of 12, including you, are registering (€20 per person)? ________

How many walkers under the age of 12 are registering (no charge)? ______

Total payment amount due: €________

I enclose a Cheque/Postal Order/Draft for €______ made payable to IMNDA.

OR I authorise you to debit my master card/visa/laser account with the total amount

☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐

Expiry Date _ _ / _ _ Security Code (last three digits on reverse of card) _ _ _

Cardholders Name: _________________________ Cardholders Signature:_____________________

Please send me a sponsorship card (TICK) _______ (NB Fundraising for this event is **OPTIONAL**)

Please tell us why you are walking to D-Feet MND: ____

____

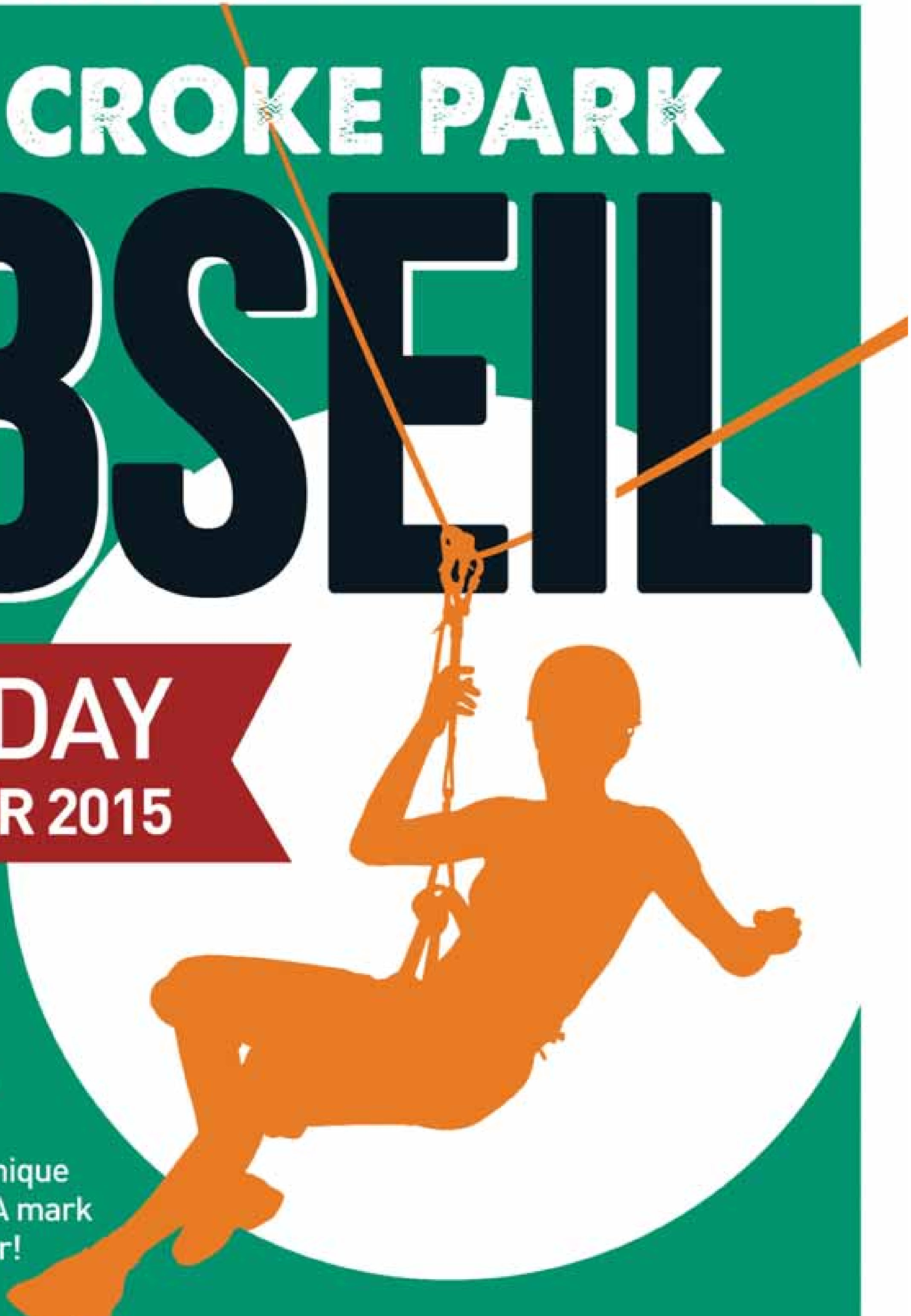
30 YEARS
iMNDA
CARE AND RESEARCH
1985-2015

The Irish Motor Neurone Disease Association

DARES YOU TO TAKE PART IN THE

CROKE PARK

ABSEIL



SATURDAY

10TH OCTOBER 2015

Experience
the *ULTIMATE*
ADRENALIN RUSH!

Abseil 100ft from the roof of Croker's famous Hogan Stand!

Don't miss out on this unique fundraiser as the IMNDA mark its 30th Anniversary Year!

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

ARE YOU GAME? Then contact the IMNDA today!
Freefone: 1800 403 403
Email: fundraising@imnda.ie / www.imnda.ie

Over 18's only / no experience necessary / full training provided on the day
Event run in association with www.adventure.ie
Places are limited; a non-refundable deposit of €100 and fundraising is required of all participants. *All proceeds raised will go directly to supporting people affected by Motor Neurone Disease; a progressive, incurable and terminal condition.*

adventure.ie
The Adventure Agency

Charity No. 8510

DRINK TEA FOR MND

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

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

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

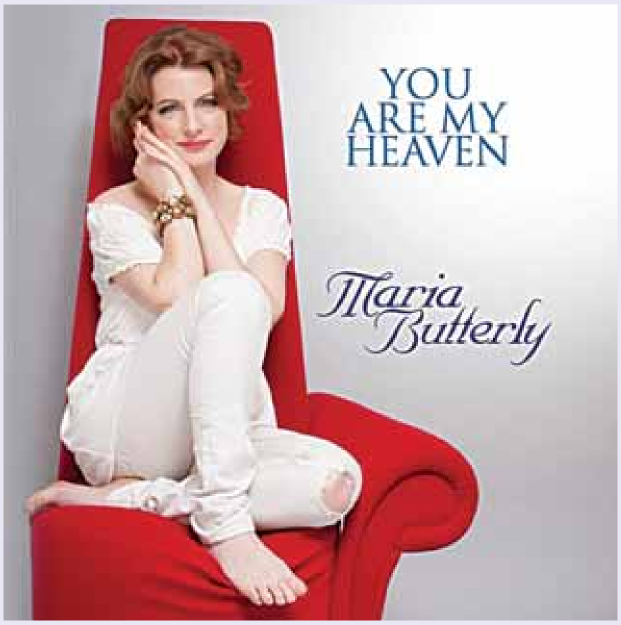
We are looking for people affected by MND to talk about their experience on local radio or in their local paper to raise as much awareness of the disease and the work of the IMNDA as possible. If you would be interested in helping us with this we'd love to hear from you, please email us on fundraising@Imnda.ie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

The IMNDA would also like to invite you to "Drink Tea for MND"!! Everyone loves a cuppa especially in Ireland so why not organise an afternoon tea / coffee morning in your home, local pub, restaurant, GAA club, workplace, community centre, garden...anywhere in fact! We want as many people as possible drinking tea for MND throughout Global Awarenessweek this June. Tea packs will be available from the IMNDA office closer to the time.

To kick off the tea drinking this June the IMNDA and TCD MND Research are once again hosting a very special joint "Drink Tea for MND" event on Tuesday 16th June in the Knowledge Exchange, Trinity Biomedical Sciences Institute in the world famous Trinity College and the base of MND Research in Ireland. The event will take place at 12pm where Professor Orla Hardiman and her Research Team will be presenting the latest research news. Invites going out soon!

MARIA BUTTERLY SINGLE

After recently receiving an award for ‘Best New Original Single 2015’ from the Irish Farmers Journal, Maria Butterly, is thrilled to release her eagerly anticipated 3rd single ‘You Are My Heaven’ in aid of the Irish Motor Neurone Disease Association. Maria is one of Ireland’s most talented singer/songwriters and this beautiful song is very close to Maria’s heart. We are very honoured that Maria is releasing this single for the IMNDA, please support by purchasing the single from our online shop for € 2 at www.imnda.ie



CHURCH GATE COLLECTIONS

Church Gate Collections still bring in a fantastic amount of income and the IMNDA are always looking for trustworthy people to co-ordinate and carry out Collections in their local area throughout the year. Just pick a weekend that suits you and your church and contact the IMNDA with your preferred date. We will then apply for a permit on your behalf from the Chief Superintendent's Office (Please note, you can't collect without a permit).

Once the permit has been granted we will send on a copy along with the required number of buckets and posters for your collection.

A FEW TIPS FOR COLLECTIONS:

- All collectors carry a permit each during the collection
- Make the public aware that the collection is for the IMNDA by displaying promo material
- Please ensure that all collection buckets are sealed and do not collect alone
- When counting the funds raised from the collection, do so in the presence of another person to avoid discrepancies and also for safety purposes.
- Try to avoid leaving cash in your house and lodge the proceeds as soon as you can.

THANK YOU FOR YOUR SUPPORT AND WE LOOK FORWARD TO HEARING FROM YOU.

REGIONAL FUNDRAISING

Would you like to get involved in Regional Fundraising?

We are looking for people who are interested in setting up Regional Fundraising groups. Please contact our Regional Development Officer, Marie Reavey either via e mail mreavey@imnda.ie or phone 1800 403 403.

Once we have enough interest in setting up a Regional Fundraising Group in your area, Marie will organise and host an information meeting with representatives from the IMNDA giving a presentation on what the IMNDA does, how Regional Fundraising groups work, how funds are raised and where the funds raised are spent.

Look forward to hearing from you.

SILENT FEBRUARY

February is famously celebrated as the month of love where couples from across the world openly celebrate their affection for each other. But imagine not being able to say ‘I Love You’ to your nearest and dearest on Valentine’s Day.

Sadly most people with Motor Neurone Disease (MND) can’t. Between 80-95% of people living with MND will experience some loss of speech before they die.

To create awareness around this fact Sharon Friel and Emma Fitzpatrick bravely helped us in our 30minute sponsored silence campaign. We asked people to take on a sponsored silence during the month of February to experience what it would be like to not be able to communicate.

We wanted people to take on the challenge at home, in work, in their communities or even on their own. We had a great response with families coming together to take on our silent task.

They took sponsor cards and donated by texting MND to 50300 to donate €2. They then shared on social media what their last words would be if they knew they would lose their voice by using #Voice4MND.

SHARON FRIEL is 40 years old from Donabate in Co. Dublin. She was diagnosed with MND in 2012. Since her diagnosis, sadly Sharon can no longer walk and is confined to a wheelchair.

She can no longer speak and communicates mainly with the use of a communication aid.

She can no longer speak to her husband Conall or little 6 year old boy Senan, and say the words I love you.

“Communication is made up of words, tone and body language, I've lost all three. It takes all my energy to say each and every word and I end up repeating myself several times to be understood, it's exhausting and very frustrating.

I'm missing out on parenting my son, it’s hard to correct a child when it takes a few minutes to type your message, he just bounces away oblivious, lucky he's such a good boy. I'm so proud of my 6 year old son, how much he accepts my disability and how he treats me normally. My husband is my rock, he does everything for us. As well as working full time he is effectively a single dad, a carer and an Irish mammy fussing over Senan and myself,” said Sharon Friel.

EMMA FITZPATRICK was 47 years old living in Kinsale with her husband Jonnie and her two children Kitty and Rowan. She was diagnosed with MND in 2010. She communicated with friends and family mainly with the use of Eyegaze technology. Emma met her husband Jonnie 16 years ago on the eve of Valentine's Day. She had a blog called Shape Shifting Emma that shone a light on what it was like to live with MND and she was always trying to make people aware of the impact of this 'cruel disease' as she called it.

"I hope Irish people become more aware of MND. Before I was diagnosed, I hadn't a clue about it. I refused to google it out of fear of what I might discover. I laugh now at the thought of what I said to Jonnie the day I was diagnosed, do people die from it?" said Emma.

And because of Sharon and Emma championing the Sponsored Silence the Irish people did become more aware of MND. The awareness created was unbelievable with interviews in the Herald, Evening Echo, the Irish Examiner, the Sun and the Star to name but a few. Sharon also went into the radio studio with Pat Kenny and gave a very emotional interview on Newstalk.

The campaign has so far raised over €13,000 with more coming in. Emma and Sharon's story reached over a thousand people through facebook, online media and news publications. So many of you took on our challenge #Voice4MND and we are extremely grateful for this. However, none of this would be possible if it wasn't for Sharon and Emma and their willingness to share their fight and let the world in.

Sadly Emma lost her fight with MND.

The last words posted on Shapeshiftingemma were by her husband Jonnie "I am so sorry to have to let you all know that lovely, amazing, beautiful Emma lost her battle with MND last Friday morning, the 27th of February. We are all grieving her loss here and can't believe that she has left us".

Emma fought tirelessly to create awareness of MND. Even when she was unwell she battled on to complete pieces for journalists to make sure her story was heard. We cannot thank Emma or Sharon enough for their courageousness throughout this campaign, so instead we will quote the words of Declan O'Rourke, a favourite singer of Emma's

"All the moments we share just between me and you, are among those I'd care to treasure my whole life through. I don't know where we're going; who knows what we can be? I just know we are glowing, we have so many possibilities".

Thank you both Sharon and Emma. Your honesty gave people all over the country a glimpse into your lives and daily struggles, showing that sometimes silence really does speak volumes.

30 YEARS OF RUNNING THE WOMEN’S MINI MARATHON FOR THE IMNDA

This year the Irish Motor Neurone Disease Association marks 30 years of providing care for people affected by Motor Neurone Disease.

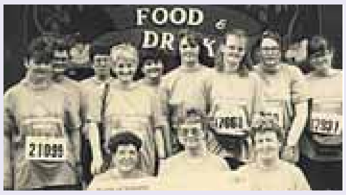
Since 1985 ladies from all over Ireland have been taking part in the women’s mini marathon to raise funds so the IMNDA can provide support services to families living with this debilitating disease.

The IMNDA cannot slow the progression of MND or change the outcome but together we can continue to alleviate the feelings of isolation and improve quality of life. Over 86% of our income is raised because of people like you.

Run the VHI mini marathon this June and help us to continue caring for as long as we’re needed.

FOR YOUR SPONSORSHIP PACK:

Email: fundraising@imnda.ie
Phone: 01 873 0422 or
Visit: www.imnda.ie



MUSCULAR DYSTROPHY IRELAND FULLY ADAPTED APARTMENT

The ‘Home from Home’ Self Catering Apartment is located at MDI House and National Resource Centre in Chapelizod, Dublin 20. It is a self-contained fully wheelchair accessible apartment which is available for short term stays for people with a physical disability. This four star approved self-catering apartment consists of 4 bedrooms, a kitchen and a lounge area. Free Wi-Fi is available throughout the apartment.

The apartment has been recommended by MND clients and is useful if you are staying in Dublin to visit family/friends or are attending a hospital appointment. The apartment is fitted with equipment such as: ceiling track hoists, shower chairs, grab rails, Hi-Lo electric/profile beds, an intercom system, emergency call buttons, an emergency evacuate chair, air mattress, bed linen etc. Towels are not provided.

On arrival at the apartment you will find a handbook giving you details about how to access the Wi-Fi, how to use equipment within the apartment and other necessary information to help you to make the most of your stay. This will also provide you with information about services available in the local community, places to visit while you are in Dublin and details about local public transport and other ways to get around Dublin.

The kitchen is equipped with an adjustable motorised worktop which enables the work surface height to be adapted to a suitable level for all users. It contains all modern appliances including a kettle, toaster, sandwich maker, microwave, blender, electric oven and hob, fridge-freezer, washing machine, dryer, iron and ironing board. The kitchen is fully stocked with cooking utensils, crockery and cutlery. Milk, sugar, tea, coffee, salt & pepper are also provided.

The lounge area has 2 sofas and a multi channel television and DVD player.

Visitors to the apartment also have the option to avail of our transport hire facility. You can get more details when you make your booking.

MDI requests a donation of €25 per room per night for the use of the apartment. Please note that if you only book one room, the other rooms may be occupied by other guests during your stay. To make a booking or for more information on the apartment please contact:

Muscular Dystrophy Ireland on 01 6236414 or email reception@mdi.ie.

FUNDRAISING DO’S AND DON’T’S

Why your fundraising matters so much.
Without the generosity of people like you, the IMNDA would simply not be here. On average we receive 14% of our funds from statutory funding. 86% of our overall income comes from our supporters.
It costs approximately € 1.5 million for the IMNDA to operate each year.

For more information on where the money you raise is spent please visit the About IMNDA section on our website www.imnda.ie

We want to help you make your fundraising event as successful as possible, please read our do’s and don’ts guide to help you.

DO

- Register your event with the IMNDA – we need to know about all fundraisers that are taking place on our behalf, then we can help you however possible.
- Ask friends, family, colleagues, local businesses for support – people are usually delighted to be asked to help especially if it is a cause close to you and them.
- Choose an event that suits you – part of a dance group, why not organise a danceathon?! Don’t pick a huge event like a ball unless you have the time and the resources to give to it.
- HAVE FUN!! – if you’re enjoying yourself organising the event the people who take part in the event will too.
- Contact your local media Don’t forget that your local paper, radio station, noticeboards & parish newsletters are great for plugging events along with online resources & social networking sites.
- Ask the IMNDA to promote your event on our website, Facebook page and contact local media in your area.
- Apply for collection permits from your local Garda Station if you are planning to collect money in a public place e.g. street. The IMNDA can apply for the permit on your behalf if you prefer we’ll just need dates and locations
- Be Transparent You may just be fundraising for the IMNDA or splitting the proceeds between a few different charities. Either way you need to make it very clear on all advertising relating to the event so people know exactly where their money is going e.g. Table Quiz in aid of the IMNDA and Our Ladies Hospice.
- Set up a fundraising page at www.mycharity.ie - think of all those people that you don’t see very often or that live abroad, no excuses they can still sponsor you online!! Any funds automatically come through to our bank account each month.
- Forward proceeds to the IMNDA via our AIB bank account The IMNDA will always provide a bank lodgment slip for our AIB account (Branch: Capel Street / Sort Code: 93-13-14 / Acc. No: 07725002) and we ask that you aim to lodge the funds within 2 weeks of the event. The lodgment slip has the name of your event in the reference and your name and address on the back. When you lodge your funds that slip is returned to the IMNDA by AIB and we then issue a thank you letter to the contact on the slip unless otherwise advised by you.

OR

- Send a cheque / postal order / draft made payable to ‘IMNDA’ to our address (IMNDA, Coleraine House, Coleraine Street, Dublin 7) with a note telling us what the money is for and who you are.
- Give us a ring (01 873 0422) with your credit / debit card details or submit them online through our website (www.imnda.ie).
- Electronically transfer proceeds into our account by using the following info (pls email us after the transfer has been made to let us know): IBAN: IE32AIBK93131407725002 / BIC: AIBKIE2D

- Provide necessary info so we can say thank you; It is very important to say thank you and we’ll always send a letter to you, the main contact/organiser of the fundraising event once the funds have been received. If there are extra people you feel should be thanked please just let us know. Remember, if money is lodged in a way we can’t trace, a thank you letter won’t be sent unless you get in touch so PLEASE do let us know if you are using another method to get the funds to us other than the lodgment slip we provide you with.

DON'T

- Undertake any fundraising without speaking to us first – as well as the IMNDA wanting to know about all the wonderful people who support us the Charity Regulator is making fundraising stricter in Ireland. This is a positive move to ensure nobody is fundraising under our name dishonestly so please let us know!

- Just ask people for money there are many other ways people can help you. You may need prizes donated, volunteers to help or posters displayed.

- Take the IMNDA logo from our website as the quality will not be of a high enough standard. Contact us and we will email it to you.

- Forget to lodge your funds after the event! The people who have supported your event will want to know that their money has been received by the IMNDA and how much was raised etc.

- Lodge money anonymously. If you use the ATM Express lodgment machine the IMNDA do not receive your information so PLEASE contact us to let us know what and when you lodged. Again is you lodge through your local post office the IMNDA do not receive any information around An Post lodgments, you need to contact us to let us know you have lodged this way (fundraising@imnda.ie or accounts@Imnda.ie)

- Forget to let us know when you are registering your event if you'd like IMNDA presence - The IMNDA staff would love to be able to thank all fundraisers in person after an event by attending cheque presentations or even go to the event itself, however we are a tiny team and we're very lucky to have several fundraisers taking place every week across Ireland. To keep travel & accommodation costs to a minimum and ensure funds raised go directly to the services we provide we always try to call on our trustworthy and committed volunteers in the local area to represent the IMNDA in our place where possible.

IMNDA STATEMENT OF COMPLIANCE OF THE STATEMENT OF GUIDING PRINCIPLES FOR FUNDRAISING

WE IN THE IRISH MOTOR NEURONE DISEASE ASSOCIATION (IMNDA) ARE FULLY COMMITTED TO ACHIEVING THE STANDARDS CONTAINED WITHIN THE STATEMENT OF GUIDING PRINCIPLES FOR FUNDRAISING. WE COMMIT TO DOING THIS BY:

- **MAINTAINING GOOD FUNDRAISING PRACTICE**
- **PROVIDING HIGH LEVELS OF ACCOUNTABILITY AND TRANSPARENCY TO OUR DONORS AND PROSPECTIVE DONORS FROM THE PUBLIC**
- **PROVIDING CLARITY AND ASSURANCES TO YOU ABOUT HOW WE SPEND YOUR MONEY**
- **IMNDA'S REPORT ON OUR CURRENT FUNDRAISING ACTIVITIES IS AVAILABLE IN OUR MOST RECENT SET OF AUDITED ACCOUNTS**

THE IMNDA HAVE CONSIDERED THE STATEMENT AND WE BELIEVE WE MEET THE STANDARDS IT SETS OUT.

FOR MORE INFORMATION VISIT
HTTP://IMNDA.IE/GET-INVOLVED/FUNDRAISE/FUNDRAISING-PRINCIPLES

IN REMEMBRANCE

Eleanor Garrett
Eamonn Kiely
Theresa Carbery
Patricia Flaherty
Mary Byrne
Theresa Cunningham
Carthage Berry
Sean Connell
Maureen Mitchell
Sean Barry
Edmond Mortell
Mary Shannon
Columba Dargan
Michael O'Toole

Bridget Ellis
Ellen O'Mahony
Margaret Doyle
Robert Brady
Claire Kenneally
Michael Roe
Maura Burns
Joe Barnwell
Teresa Burke
Carmel Burns
John Flynn
Margaret 'Mona' Ross
Raymond McCann

Ann Regan
Eileen McGurry
Anna O'Mahoney Clarke
Patrick J (Stocky)O'Mahony
James Reynolds
Clare O'Beirne
David JohnO'Brien
Ann Langheld
Josephine Nash
Nancy Dillon
Eithne Herbert
Josephine Nash
Oliver Spellman

Eileen Conneely
Marie Hogan
Vera Kelly
Michael Walsh
Sharon Malone
Kathleen O'Neill
George Smith
Marie Molloy
Mary Donnelly
Jack Heaslip
Sheila O'Boyle
Emma Fitzpatrick
Brendan Mills
Catriona O'Brien

Look for me in Rainbows

Time for me to go now, I won't say goodbye;
Look for me in rainbows, way up in the sky.
In the morning sunrise when all the world is new,
Just look for me and love me, as you know I loved you.
Time for me to leave you, I won't say goodbye;
Look for me in rainbows, high up in the sky.
In the evening sunset, when all the world is through,
Just look for me and love me, and I'll be close to you.
It won't be forever, the day will come and then
My loving arms will hold you, when we meet again.
Time for us to part now, we won't say goodbye;
Look for me in rainbows, shining in the sky.
Every waking moment, and all your whole life through
Just look for me and love me, as you know I loved you.
Just wish me to be near you,
And I'll be there with you.

Music and lyrics: Conn Bernard (1990). Vicki Brown

Darragh Murphy who is 14 years of age wrote this poem in memory of his gran, Pam Gilligan who passed away 5 years this Easter. Darragh is very proud of his poem and asked if we could include this in our edition of Connect and we are delighted to share this with you….

GRAN

Peaceful as she lay,
like the still water in the bay.
Her face was as pale as the clouds,
and her clothes were as beautiful as herself.

No pain, no agony, no sadness,
Just the still peace of a Christmas night.
The short blond hair she adored,
finely brushed down unto her cheeks
when I saw her it made me weep.

7 years she had her disease,
never down, she would stay happy.
She was as strong as a rock that wouldn't move,
ever hopeful for whatever came next.

She celebrated an amazing life,
but most of all she was a fantastic wife.

In memory of Pam Gilligan (RIP, 3 April 2010)
By her grandson, Darragh Murphy (14)

STAFF NEWS

Congratulations to our National Development Manager, Gemma Watts on the birth of her daughter Florence Jennifer Byrne. Florence decided to surprise everyone and make her entrance into the world a whole month early!

Both Gemma and Florence are doing well.

A big IMNDA welcome goes to Gayle Cummins who is covering Gemma’s maternity leave. Gayle is settling into the IMNDA office very well and is working on a number of events which will take place over the summer months.

We also welcome Kate Kinsella who has joined our nursing team for the next 12 months. Kate has lots of experience in the neurology area and has previously worked with people with MS and MND.

30 YEARS
iMNDA
CARE AND RESEARCH
1985-2015

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

Walk to D-FEET MND

HELP US MARK OUR 30TH ANNIVERSARY YEAR!

SATURDAY 18TH JULY 11AM

CASTLETOWN HOUSE , CELBRIDGE, CO KILDARE

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

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

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

Under 12's walk for free & all walkers receive an IMNDA t-shirt and light refreshments. The route is fully wheelchair & buggy accessible. Can't make Castletown on the 18th July? Why not organise your own Walk to D-Feet MND in your local area! Freefone 1800 403 403 or email fundraising@imnda.ie for more information.

www.imnda.ie

Charity No. 8510