IMNDA
CARE AND RESEARCH

CONNECT

ISSUE 12 - Autumn 2014

#ICE BUCKET CHALLENGE!

Also IN THIS ISSUE...

- AGM & PATIENT & CARER WEEKEND
- LIVING WITH MND
- KODALINE GIGS
- CHRISTMAS CARDS

CONNECT

AUTUMN 2014

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Contributions to the next edition of Connect:
If you would like to submit a story, photo or anything else you would like to share please email pr@imnda.ie / info@imnda.ie
or Freefone 1800 403 403.

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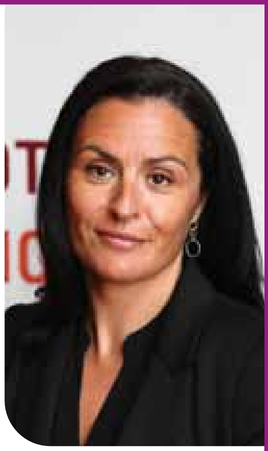
NEWS & RESEARCH

LIVING WITH MND

FUNDRAISING & PR

EDITORS DESK

A WELCOME NOTE FROM OUR CEO



On behalf of the IMNDA, I would like to welcome you to this Autumns Newsletter and talk about some of the major events that have happened in 2014 so far! This year has been the biggest year for the Association since its foundation on the 1st May 1985.

I would like to take this opportunity to thank all our members and supporters who have continued to support the association over the last year.

Some of the significant events of this year included National Awareness in June where two people with MND, Jan Battles and Paul Lannon bravely recorded an advert for radio which described their experience of Motor Neurone Disease.

This was broadcasted nationally for two weeks along with a poster campaign on Dublin Bus.

More major events included the June Ball at the The Double Tree by Hilton in Dublin, The Kodaline Gigs at Whelan's in Dublin, the numerous cycles including the 'Life your Life Cycle' in the Beara Peninsula in Cork, The D2k Cycle from Co Louth to Co Kilkenny and we were also very lucky to be one of the chosen charities for the Ring of Kerry Cycle event this summer.

And finally…The Ice Bucket Challenge, this was one of the biggest events of our entire existence as an organisation. It's amazing what social media can do 'most importantly' for awareness and for raising funds. All those €2 texts you donated, all those donations you made through our website and my charity, all the cheques that were posted in and all the transfers through the bank that were made, these were all endless and we are forever grateful to all of you out there who took on the challenge and helped raised awareness of a condition that affects a small percentage of our population. A mass of celebrities in Ireland took up the challenge, from TV presenters to performers, from sporting people to politicians and to the Irish Public who really stepped up to the mark and raised the profile of MND once again, but this time to an epic level. This money is to be used in a variety of ways to be outlined following a detailed consultation with the IMNDA's clients, their families, their carers and supporters of IMNDA. A questionnaire is in the process of being prepared which will be sent to every person with MND who has access to the IMNDA service across Ireland to identify where the need is greatest. We will be also be keeping our website up to date in the coming months ahead.

To express our gratitude we put together a video to say thank you to everyone. Please visit our you tube channel to view this https://www.youtube.com/user/MNDireland

So once again and most importantly, and I know this has already been said but it can't be said enough. Thank you to all of you, our MND community, you inspire and motivate us all every single day to continue to do what we do. So sincere thanks to you all we couldn't have had such a successful year without you.

Aisling Farrell

Aisling Farrell

Chief Executive

CALENDAR OF EVENTS

‘Do Something Special in 2014’

2014

2014 Oct

1. CROKE PARK ABSEILS
Hogan Stand, Croke Park Stadium, Dublin
11th October 2014 (back up date 18th October)

2. “LEGENDS with Miriam O’Callaghan”
Woodford Dolmen Hotel, Carlow
15th October 2014

3. DUBLIN CITY MARATHON
Dublin City
27th October 2014
www.dublinmarathon.ie

2014 NOV

4. ANNUAL MEMORIAL SERVICE
Capuchin’s Friary, Church Street, Dublin 7
22nd November 2014

2014 DEC

5. ANNUAL GRAND RAFFLE DRAW & CHRISTMAS COFFEE MORNING
Richmond Room, Carmichael House, North Brunswick St, Dublin 7
Wednesday 10th December @ 11:30am

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6. “THE DANDELION DUST UP – ROUND 2!” WHITE COLLAR BOXING EVENT
Dandelion Nightclub, Stephen’s Green, Dublin 2
March 2015 Date to be confirmed

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.

AGM / PATIENT & CARER WEEKEND DUNDALK 2014

In September of this year, the IMNDA's AGM, Annual Conference and Patient & Carer weekend took place at the Crowne Plaza Hotel, in Dundalk Co. Louth. The event was well attended with around 85 delegates coming along. The business part of the weekend took place on Saturday morning where the IMNDA's Board of Directors reviewed the operations and financial performance of the organisation in 2013.

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

Aisling Farrell, IMNDA CEO welcomed everyone to the conference and thanked everyone for their participation in the Ice Bucket Challenge and spoke about the amount of awareness and funds that has been raised from this phenomenal event that has dominated social media as well as a recap of all the fundraising that took place during the year.

Dr Sinead Maguire from the Neurology Research Registrar in Beaumont Hospital and the Academic Unit of Neurology in Trinity College Dublin, delivered a presentation on developing a framework for early intervention palliative care in MND.

Dr. Aisling Ryan is a Consultant Neurologist in Cork University Hospital and also Clinical Senior Lecturer in UCC. As well establishing and leading the specialist MND clinic in CUH, Aisling has been medical patron of IMNDA since 2013. She delivered a presentation on 'Why we should look at Palliative Care and the benefits of it, she integrated this into the 'care plan' for someone with MND.

Jennifer Bonus & Tara O'Donovan: Jennifer's husband and Tara's dad Noel O'Donovan was diagnosed with MND in March 2011. Jennifer & Tara cared for Noel until he passed away in July 2012. Jennifer appeared on the RTE show Operation Transformation earlier this year. Both Jennifer & Tara spoke very openly about their experiences of caring for Noel as he progressed with the disease.

Presentation to Jimmy Magee Patron: IMNDA Staff members, Gemma Watts and Maeve Leahy gave a very moving speech about Jimmy Magee's contribution as Patron to the Association since 2008. They both thanked Jimmy on behalf of the IMNDA and presented him with a painting by a local Co Louth artist Michael Gavin Duffy who like Jimmy is from the Cooley Peninsula and who also knew Jimmy's son Paul who sadly passed away with the condition.

Prof Orla Hardiman is a Consultant Neurologist in Beaumont Hospital and Professor of Neurology at Trinity College Dublin as well as Head of Academic Unit of Neurology in Trinity. She gave us a detailed overview of MND Research that is currently taking place by her and her colleagues in Ireland and answered many questions asked by our guests.

Derbhla Wynne is PR & Communications Executive with the IMNDA. She has been working with the association since 1999 and has seen many changes in that time. She delivered a presentation on the IMNDA website which went live earlier this year. After the conference talks were over Aisling Farrell CEO presented the Silver Pin Recognition Awards to people who contributed to the IMNDA over the last year.

The association couldn't function without the fantastic support received from so many people across the country. Each year at our AGM we like to select a small percentage of the people we feel dedicate their time and effort to our organisation. We like to acknowledge this by presenting them with an IMNDA Silver "Thumbs Up" pin and were delighted that so many of the recipients could attend and accept their award in person.

(If you feel that there is someone you know who has contributed greatly to the association and you feel that they deserve a 'Silver Pin', send in an email to info@imnda.ie outlining why you think they should get an award, thank you.)

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

The evening entertainment resumed later that day when everyone spruced themselves up and met over some Punch at a drinks reception followed by a delicious 3-course meal. The evening's entertainment was provided by 'The New Originals', who gave us covers from 'The Beetles' and had some of us on the dance floor all evening!! Thanks to everyone for making it such a memorable weekend. We hope you enjoyed it, see you next year!

TRINITY RESEARCH EVENT

The MND Global Awareness campaign kicked off again this year on 17th June with the second Drink Tea for MND event in the home of the Academic Unit of Neurology – The Knowledge Exchange, Trinity Biomedical Sciences Institute on Pearse Street, Dublin.

The IMNDA and TCD MND Research joined forces for the second year running and were delighted to welcome approximately 100 guests who came along to the event. Whilst there were tea, cakes and sandwiches galore to enjoy the major focus was the research into the causes of MND that is currently been undertaken by Professor Orla Hardiman and her team.

Professor Hardiman gave an overview of the research that she is currently doing and she introduced her team of clinicians who talked briefly about their own work.

Prof Hardiman also introduced the Research Register Dr Sinead Maguire and the IMNDA is funding this Research position. Dr Maguire has experience in MND and the main thrust of her work includes identifying the limitations of current management of motor neurone disease. This is done by comparing existing practice with best practice guidelines and the development of better ways to decide when and how people with motor neurone disease should access these services.

The main topics that were up for discussion by Prof Hardiman and her team of clinicians on the day were:

1. **Epidemiology:** The number of people with MND in the country, the differences between Ireland and Northern Ireland, and differences internationally

2. **Genetics:** Looking for genetic causes using new technologies and capitalising on the Irish genetic substructure; Looking at families with MND and related conditions. Do other conditions occur with higher frequency in family members of people with MND?

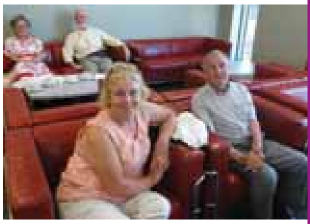
3. **Neuropsychology:** Thinking changes that can happen with MND

4. **Biomarkers:** What MRI can tell us? And using new EEG technologies to uncover what his happening in the brain

5. Health services and mapping the patient journey; why we need to listen with people with MND and their families

6. Clinical trials, international collaborations and new research consortia

Guests were also treated to a tour of the research facilities. The IMNDA would like to extend a big thank you to Professor Orla Hardiman, Zhanna O'Clery, Dominique Plant, Grace Lavelle, Dr Mark Heverin, Dr Russell McLaughlin, Taha Omer, Parames Lyer, Tom Burke, Alice Vajda, Kevin Kenna, Chloe Heslin and the rest of the Research Team who helped make the day such a success. Here's to next year!!!



Please visit:
http://www.medicine.tcd.ie/neurology/
for more info.

DR SINEAD MAGUIRE EXAMINES PALLIATIVE CARE & MOTOR NEURONE DISEASE

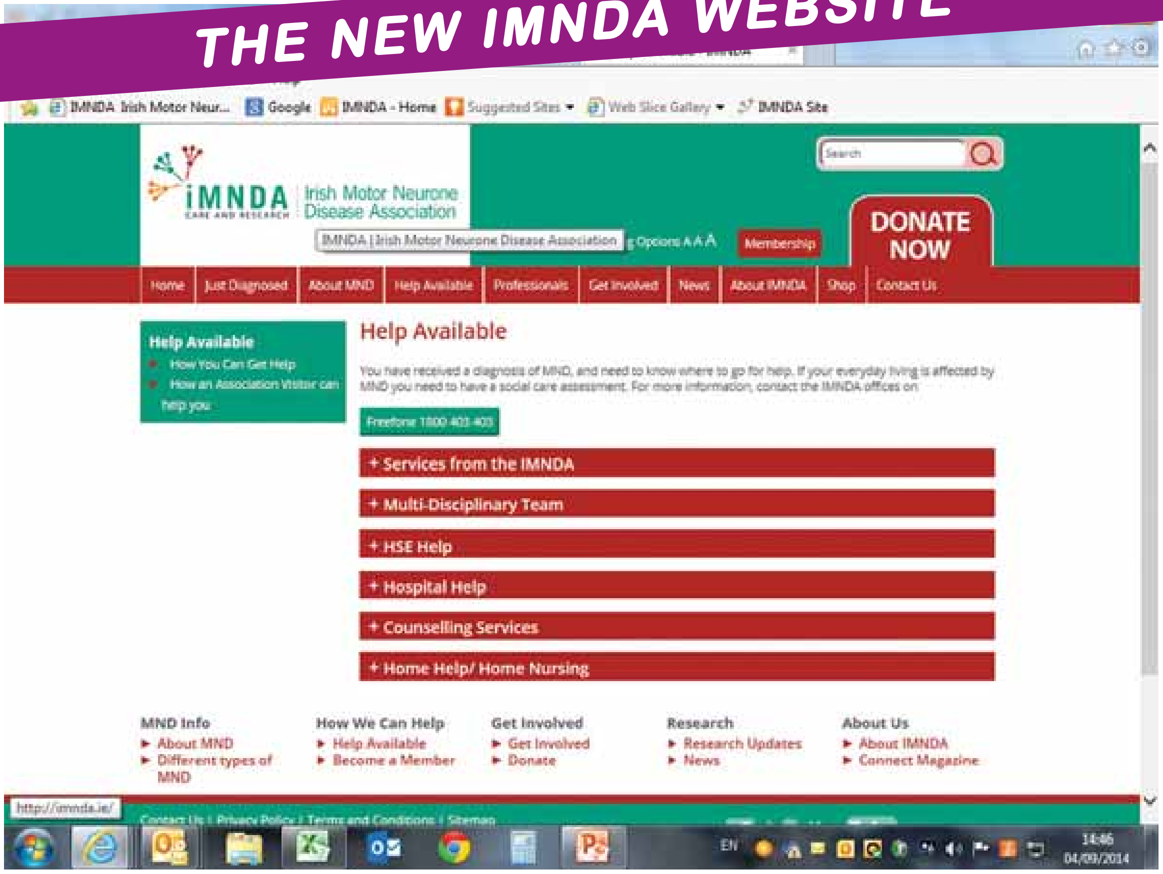
I am currently a Neurology Research Registrar in Beaumont Hospital and the Academic Unit of Neurology in Trinity College Dublin. My clinical commitment which is linked to my research is based around the Motor Neurone Disease service at Beaumont Hospital where I address medical needs and help to coordinate care. In the past twelve months I was the examining physician in the worldwide Cytokinetics Phase II clinical trial of a new agent in motor neurone disease. The trial ended in March 2014. My clinical commitment extends also to providing clinical support at the National Motor Neurone Disease clinic at Beaumont Hospital. I am also Co-ordinator of the International ALS European Joint Programme in ALS-CarE - A programme for ALS care in Europe.

My research is Palliative Care for Motor Neurone Disease where I intend to develop a framework for early intervention palliative care in Motor Neurone Disease. International best practice recommends early palliative care intervention from time of diagnosis of motor neurone disease. As palliative care in Ireland is moving from a “cancer only” discipline to become an integral part into the management of non-malignant conditions such as MND and other chronic diseases such as COPD and heart failure, there is now an urgent need to identify points at which specialist palliative care intervention is maximally beneficial to patients and carers. However in Ireland access to palliative care is limited and the clinical indications for specialist palliative intervention are not clearly defined. The aim of this project is to identify the deficits in current palliative management of motor neurone disease by comparing existing practice with best practice guidelines, and to develop a structured framework based on a multidisciplinary approach towards the palliative management of motor neurone disease. Prospective longitudinal clinical, health service, quality of life and burden of illness data relating to the patient journey of 100 patients in Ireland with motor neurone disease and their caregivers will be available for analysis. Currently we have reviewed 150 medical charts, analysing the patient journeys. We have developed vignettes for discussions with clinicians in neurology, palliative care and other health care professionals and from these discussions we have identified specific factors that trigger palliative care consultation.

At the MND clinic each week we are also using the Palliative Outcome Scale (POS) to identify triggers for Palliative care intervention. POS is a questionnaire which measures outcomes and assesses quality of care in palliative care patients. We have designed “Discreet Choice Experiments” for patients and carers to identify what patients and carers want, what they need and we are conducting this research each week at the MND clinic. Access to and utilisation of palliative care services will be assessed and comparison between current management and best practice will be evaluated. A multifaceted care framework will be developed and piloted with health care professional and users. The perspective of service providers will be captured and the perceived utility of the services evaluated from a patient and carer perspective. On completion the project will provide a road map for specialist palliative services intervention for MND, and will assist in the future development of palliative services in Ireland.

Finally I would like to thank the IMNDA for funding my research, they are an instrumental and vital part of my research project and I would like to acknowledge the importance of their continued support. I am enthusiastic and very dedicated to this most crucial research work. Of course their support is not only limited to my own project, but there is a great tradition of collaboration between the IMNDA and Professor Hardiman and the research work done by her group to date. I would also like to thank the patients and their carers that give their time and are so willing to help us and their contribution is invaluable to our research.

THE NEW IMNDA WEBSITE



You have received a diagnosis of MND, and need to know where to go for help. If your everyday living is affected by MND you need to have a social care assessment. For more information, contact the IMNDA offices on

It was decided a long time ago that the association needed a new website. The Association wanted something brighter and more user friendly. So in 2013 we consulted with a company called Design Minds where Diarmuid and Rob came on board to help us along the way! It took about 6 months to get the design and information altogether. The site was up and running by the middle of May 2014 just in time for the National Awareness Campaign.

Firstly, the site is designed around the colours of the Associations logo. The home page of the website gives you access to all the different pages on the site itself from client care to fundraising to contact us. After the home page we have: Just diagnosed, About MND and Help Available sections, these are all client and carer focused and give the user a clear pathway to getting help in the beginning of their journey with MND.

We have created a new section and this is called ‘Professionals’. This section gives a guide to the IMNDA Services that are provided from ordering equipment to other useful links.

The’ Get Involved’ Section is about how you can help the organisation by making a donation, raising funds, organising events and volunteering your time as well as giving you a list of up-coming events.

The News section contains recent news items, press release, advocacy and real life stories contributed by MND clients as well as a Journalists guide to MND.

The About IMNDA section tells you who the staff are and what their roles are within the organisation. We also have who the Board Members are and what their backgrounds are also. We have the Vision, Mission & Values of the Association, Making a Complaint, Use of the Associations Logo for fundraising & PR and very importantly Where the Money Goes?

One of the last sections of the website is the Shop – where people can support us by purchasing some of our merchandise and watch out for any specials offers that we may have!!

Finally the last section is the ‘Contact Us’ section of the website. So, if you take a tour @ www.imnda.ie have a look around and see what you think. If you want to send in feedback or make suggestions for the future you can do this by simply filling out the contact us form on the site! Thanks for browsing!!

MEDICAL CARD SURVEY

Earlier this year, we wrote out to everyone living with Motor Neurone Disease who has contact with our organisation and asked them to provide us with information about their Medical Card situation.

We asked if people had the medical card before they were diagnosed with MND and if not how long it took to get the Medical Card once they were diagnosed with MND

We also asked people if they had any further issues once they received the Medical Card or if they had to re-apply and also how long they were granted with the Medical card for.

We wrote out to 276 people with MND and the response rate was average as 46% of people that were contacted came back to us with their responses (127 people in total).

- 86.6% of people with Motor Neurone Disease that responded to the survey have the medical card
    - 6.3% of people that responded don't have the medical card at all
    - 3.1% of people that responded have had their cards withdrawn or have been refused
    - 2.4% of individuals that responded didn't apply for the card at all for different reasons
    - 1.6% were in the process of applying

We also asked people to share any additional information with regards to the application process and their experience in obtaining the medical card proved to be very mixed.

47% of the people that responded reported that they had a positive experience with the medical card process. 39% of people that responded reported that they had a negative experience with the medical card process.

Some people with MND had no problem getting a medical card, had it renewed quite easily and were just asked to submit some more personal information and they were granted the card.

However, some people were asked to submit more information but felt the process was stressful, information was asked about income details and in some instances people had to apply up to three times. Some people mentioned that they had to get a person in authority to help them with the process as well as involving their local radio station to get their voice heard.

Others reported that their card is currently on hold and under review. Some people are being told by their pharmacist that their medical card has been cancelled. Others said that numerous calls were made to the department to find out an answer, some people said their medical card was being reduced to GP only card. Others reported that they had not got a response to the appeal at all. And finally, discretionary cards were granted after a lot of stress was caused to the person with MND and their family.

In June of this year the association was asked to attend a meeting with the then Minister James Reilly in Hawkins House to discuss the Medical Card issues. From that meeting it was decided that the HSE and Department of Health would put together a panel to review the application process and the entitlement criteria for medical cards.

So to conclude there is a consultation happening internally in the HSE around medical cards. We have had no feedback as of yet. So we will await more information from this and will communicate the outcome of this to our members in an email format and well as on our website www.imnda.ie under the News section.

Also if you or some one you know hasn't returned a form, please do so as soon as possible (even if you don't have a medical card).

All information will be held in a confidential manner.

Thank you.

ASSOCIATION VISITOR PROGRAMME 2014-2015

The IMNDA is once again looking for new volunteers to participate in its Association Visitor Programme (AVP). We have now secured funding from Pobal for this programme for the year and we are looking to train volunteers in January & February 2015. Below is some information about what is required. Have a read and if you are interested in becoming a volunteer, please contact our services team in the IMNDA offices by email: avp@imnda.ie
or Freefone 1800 403 403

These new volunteers will join our existing team of Association Visitors who successfully completed their training last year. Some of these visitors are working with families and both clients and visitors are benefiting from the programme.

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DETAILS ABOUT THE PROGRAMME:

The Association Visitor (AV) plays a vital role in helping us to ensure people with MND their families and carers receive the support and services they require. They carry out this role by either visiting someone in their home or by making contact with the person over the telephone.

We ask that the Association Visitor (AV) is required to have the following qualities & skills:

- The AV must have commitment of 2-4 hours per week to include supporting people with MND and attending support & supervision meetings every 8-10 weeks
- The AV must have good listening and communication skills
- The AV must have the ability to work within the boundaries of the role
- The AV must have the ability to develop and maintain supportive relationships with people with MND and their carers whilst respecting different lifestyles and ways of managing problems in a non-judgemental way
- The AV must have an understanding the need for confidentiality and carrying out the role in accordance with the Association's policy
- The AV must be prepared to increase their knowledge of MND, its effects and the impact it has on individuals, their families and carers
- The AV must have the ability to recognise situations where they are unable to meet an individual's needs or are unsure what action to take and seek support from the relevant staff member

So just a reminder of the contact details:
Call the services team in the IMNDA offices by email: avp@imnda.ie or Freefone 1800 403 403.

Alternatively, if you or your primary carer would like one of our Association Visitors to come and visit you in your home or provide telephone support, please contact our services team also at the above contact details.

Thank you.

WHEELCHAIR ACCESSIBLE PUBLIC TRANSPORT

When mobility becomes affected by MND, transport options may need to be looked at. Perhaps you previously used public transport regularly and are now unsure how to access a bus or train as you are using a wheelchair or walking aid. Or maybe you now find it too difficult to get in and out of a car and public transport would be a more comfortable way for you to travel. We understand that public transport has its limitations due to travel routes, accessibility & timetables but hope that you will find the following information helpful.

DUBLIN BUS

All low-floor buses have one space for a person using a wheelchair. This space fits a standard manual or power wheelchair. As mobility scooters can be larger than wheelchairs you must get a permit from Dublin Bus to travel on their services using a mobility scooter. All buses will stop if there is a wheelchair user at the bus stop so you don't have to worry about trying to hail the bus. To assist your entry onto the bus the driver will lower the ramp at the front door.

If you feel unsure of using Dublin Bus services with your wheelchair you can avail of their Travel Assistance Scheme. This scheme is run in the Greater Dublin Area to help you use public transport on your own. An assistant can accompany you the first few times you travel and give you advice on planning a journey using Dublin Bus, DART or Luas. This service is also available if you are visiting Dublin. A Travel Assistant can meet you at the train or bus station and help you with your journey for a hospital appointment, visiting friends or a days shopping. The service is available from 8am-6pm Monday to Friday.

For more information email travelassist@dublinbus.ie or phone 01 703 3204.

BUS EIREANN

As Bus Eireann has such a variety of services and a fleet containing single deck buses and coaches the accessibility of their service varies. They have 4 Expressway coach routes which are fully accessible for wheelchair users. These are Waterford to Cork (Route 40), Galway to Ballina (Route 456), Galway to Athlone (Routes 20 & 430) and Navan to Dublin City University via Dublin Airport (Route 109a). This route has accessible stops at Collins Avenue/DCU, Dublin Airport and Navan.

While the coaches on a route can have a space for a wheelchair the footpath at the bus stop may not be suitable for the wheelchair lift to be used. Each Expressway service has one wheelchair space so a reservation system is in place requiring an intended customer to book 24 hours in advance of his/her journey by telephoning the local Bus Eireann travel centre.

Town and City Services in the following areas are fully accessible: Dundalk, Cork, Limerick, Galway, Waterford & Sligo. These single deck bus services all have a low floor access system similar to Dublin Bus and do not need to be booked in advance. For more details see www.buseireann.ie.

There are a limited number of wheelchair accessible spaces on each train, it is important therefore that you book your space in advance.

You should also notify Irish Rail of assistance required to allow you to access the station or the train.

It is best to contact Irish Rail as far in advance of your journey as possible, but try to give at least 24-hours' notice. You can contact Irish Rail by emailing access@irishrail.ie or calling 1850 366 222 (Monday - Friday 08:30-18:00hrs excluding public holidays).

When contacting your local station or the accessibility office, please give the following details:

- Date of travel and departure time of the train
- Destination station and any intermediate stations where a change of train is necessary
- Nature of mobility impairment
- The nature of assistance which will be required at the departure and arrival stations and if so how staff will be able to identify you

If you need to cancel a journey for which special arrangements have been made, Irish Rail ask that you let them know so that staff can be made available to assist others.

Because scooters come in a wide variety of shapes and sizes, many have problems on trains, being unable to manoeuvre safely inside a carriage. These problems mean that trains cannot carry some scooters, if you are a scooter-user who wants to travel by rail, you should contact the station to ensure your scooter can be accommodated. Further details are available on www.irishrail.ie.

KEEPING ACTIVE by PADGE KELLY

Patrick (Padge) Kelly, 27, from Dublin, was 17 when he was diagnosed with MND. He was in sixth year in school when he noticed his handwriting was getting very messy. Soon, even carrying his school bag became difficult and he started to struggle when he was playing football. Immediately after diagnosis, the Kelly family went on holiday. Joan, Padge's Mum was determined to keep everything as normal as possible but as the disease began to ravage Padge's body, living a normal life became increasingly difficult.

A year after his diagnosis, Padge was walking with a crutch, two years later he was in a wheelchair and three years on, his speech started to become affected. In the 10 years since, Padge has kept himself busy: enrolling in an online natural science course and playing Boccia – a Paralympic sport similar to bowls. Boccia gave Padge an outlet and gave him the chance to be involved in sport despite MND.

"I have to set goals that I work towards. If I didn't, I would go crazy with boredom," said Padge Kelly, "I'm determined to live a normal life for the time I have left".

WHAT IS BOCCIA?

Boccia is a target Sport played by individuals, pairs or teams. It is a strategic version of the game bowls. Boccia developed in Europe as a sport for individuals with disabilities in the early 1980s. However the game seems to originate in Greece where individuals used to throw large stones at a target. A game very similar to Boccia was played throughout the Roman Empire, and later developed variants such as lawn bowls, nine pin, and boule. A lot of European countries found that there were a large number of individuals with disabilities who were unable to take advantage of other sports so Boccia was successfully adapted for people with disabilities.

Boccia is a target sport played by individuals, pairs or teams. Boccia is played with 13 balls (6 red, 6 blue, 1 white). The jack ball is used to start off the game and is thrown by one of the competitors on the court. It requires a high degree of muscle control, accuracy, concentration and tactical awareness with the goal being to land six of the coloured balls closer to the white target ball than the opponent's balls.

Boccia is a non-contact sport, where the game focuses around a target. The balls used are solid but pliable; they have a good rolling quality and are easy to grip. The balls also have the effect of reducing the advantage of physical strength, so that skill becomes the overriding factor. The player may propel the ball into court by any manner he or she desires as long as the player is in control of the movement at the moment of release. In certain classifications, where the player is unable to propel the ball onto court using their hands, they are allowed to use an "assistive device". These assistive devices are more commonly known as ramps or chutes. Any athlete that is unable to release the ball down the ramp using their hand, may use a head or hand pointer.

The game must be played from a seated position, which makes it perfect for either manual or motorized wheelchair users.

Why is Boccia such a great game and could it be good for you?

- It can be played on any flat indoor surface.
- All levels and abilities can play
- Provides an outlet for social contact
- All Age Levels can Play
- Develop New Skills
- Game is very easily learnt
- Non-disabled individuals can play
- Stimulates mental capacity
- Can be played recreationally or competitively
- Boosts confidence and self esteem
- Provides an outlet to participate in sport

"I like playing it for the competitive part of the sport. I love winning and hate losing," says Padge. Padge is travelling to play in Poland on the 8th of October with Lucan Bocciaclub. Best of Luck Padge – we hope you win!

HOW DO YOU GET INVOLVED?

Boccia is being played in Irish Wheelchair Associations (IWA) centres across Leinster and the rest of Ireland. Lucan are in the early stages of setting up a programme and are looking for members.

In Ardee the members there are playing all hours of the day and have competitions regularly. The Ardee Sports Project have set up a league that is expanding to a wide area and at the moment there are teams (normally 16) from Ardee, Drogheda, Cavan, Navan, Clontarf, Clane and hopefully Lucan very soon. On a monthly basis the teams meet up in Navan (Simonstown GFC).

The IWA centre in Athy have held their first open Boccia competition last month and had a big response. There is also a Boccia league run in the midlands region.

For more information you can contact Robbie Hurr in Ardee at rhurr@iwa.ie or contact your local Irish Wheelchair Association Centre.

A FAMILY STORY

We are the Kellys. My name is Shane and my parents are Christy and Mary. 6 years ago this month our whole lives changed. My dad Christy retired on a Friday night and the following Monday morning was diagnosed with at first Bulber Palsy by a neurologist in the Hermitage clinic in Lucan. Talk about bad timing. That October was the worst month of our lives in many ways. I had just been informed that I was being let go from my job as a civil engineer, Dad's brother John died suddenly and a very close family friend was killed in a car crash, throw in the largest banking crisis in history and a terminal illness diagnosis and you have our 2008 episode of reeling in the years cracked.

Of course it was not bulber palsy, after being referred to Dr Orla Hardiman later that month Dad was diagnosed with Motor Neurone Disease and our page in IMNDA Connect magazine was set in stone.

My father Christy was a postman in our local area of Killoran, Galway for over 40 years. He married my mother, a Mayo woman 34 years ago and had one son, me. Dad is a typical country man, loving his GAA and farming. He was your old style post man. Letter boxes did not exist on his route only back doors and kitchen dressers. The entire parish relied on him for information and the odd bit of juicy gossip, the women fed him and the farmers got him to block the odd gap. It's funny how things change. Six years after his diagnosis we are all still here and very strangely upbeat. Dad can no longer speak or write hence the reason we are writing a family story. There is just the three of us so when one member gets a blow like he did the shockwaves are hard and heavy. We all dealt with it in different ways, I tended to over exaggerate everything even getting to the stage where I began to get similar symptoms as my father. These symptoms were brought on by large amounts of stress and anxiety almost Psychosomatic and is perfectly normal as many offspring of people with terminal genetic* illnesses eventually discover.

My mother tended to gloss over everything and pretend everything was okey dokey. It worked for her and balanced my reaction out. Most importantly my father, Christy, got on with living. He did as much as he could while he could without an ounce of complaining. In fact, he still does! Having a patient in the house can create an invisible dark cloud but when the patient acts like Dad has there is a lot more blue skies than gloom.

Don't get me wrong, we are not the Waltons and often the three of us curse and shout one another out of it. It's

healthy and clears the tension. The disease has been very hard on us and has taken a lot out of us. I returned from the States 4 years ago when Dad started falling. This was a huge surprise for me as I thought everything was running smoothly. From then on I went from job to job locally and even went back to college. During this time my Mother was stuck to the house while I was not there and this eventually took its toll on her. She eventually got carers burn out as the lack of help from the HSE was astounding. I then left employment to become Dads full time carer and help my mother free up some time for herself. This was a tricky manoeuvre as I wanted to be an independent 30 year old but still had to live under my parent's roof and rules. At that time it was a very confusing stage of Dad's illness. His medication was constantly changing; his communication and mobility equipment needs were changing and all at a rate that we and the HSE were not able to keep up with. This often left us dizzy and annoyed that the small things he needed in life to have a shred of independence were out of reach for that one week or month too long.

This whole process has toughened us all. And there is a lesson in it for all families in our situation. We have learned to go with our gut feeling and that the professional is not always right. Example, Our Occupational Therapist insisted we stop using a sit-stand hoist over 2 years ago, this would have completely taken away my Father's dignity or in his own words "be rolled around like a barrel" in a sling every time he needed the toilet. She is currently eating humble pie.

We have learned not to be afraid to take risks. Example, while searching in vain for a Wheelchair accessible motorhome to holiday around Ireland I asked Dad "Would you get the ferry to France to pick up the camper?" He then replied by typing out on his card "Fly." Believe it or not people that "Fly" comment escalated into a Christmas family holiday in Lanzarote for 7 days! All the facilities are there to be used and life does go on. We would never have dreamed of doing this only for dads fighting spirit and hunger for life. P.S Don't forget to pack EVERYTHING! We have learned a busy mind is a happy mind. Example, from morning to night we have a schedule setup to help keep Dads mind engaged. At 7am, the TV in my parents' bedroom is timed to switch on Ireland AM. Dad is awake and gets all the news before everybody else, his carers arrive and they discuss the goings on of the world that day. By 11am we load him into his van with optional docking system (a necessity) and bring him to our local day-care centre in Ballinasloe.

The staff there are excellent and he often arrives home covered in lipstick. He's home again at 4:30 and from here on Judge Judy takes over until it's news time.

or The Xmas Special of Ireland West Country Music Television, Mrs Brown also makes an appearance if we really need a boost.

We have learned that "no!" does not mean "no!" if you badger and harp on enough. Example, we are now gladly receiving 26.5 hours of HSE home help a week, when the max they allow is 17. We have learned that respite does not suit every illness, especially for sufferers that have no voice. Example, Dad has tried every respite facility in County Galway and none with satisfactory results. For our next break we plan to have a mixture of family, friends and private home help to help keep Dad at home.

We have learned that there is no place like home. A nursing home is 100% out of the question for a Motor Neurone sufferer in our opinion. Their needs both physically and mentally cannot be met by even the best nursing home in the country. Without the use of limbs and a voice being away from home becomes a form of torture. We have learned the hard way and Dad has paid the price as we found him to be only half the man he was after only 1 week of respite in nursing home/ hospital / hospice.

So what I hope you can see from this little excerpt of our lives is that if we can do it anybody can. We are LIVING with Motor Neurone Disease not trying to escape and hide from it. We were dealt a bad blow and at last I have the confidence to say we are making the most out of it.

We are now part of the IMNDA family. We know all the staff on first name basis, we trust and care for them as they do us. This battle is tough but we could not imagine going through it without the IMNDA. For anybody reading this that is feeling a bit lost or helpless, pick up the phone and call the IMNDA for help and they will either provide it for you or guide you in the right direction.

Now back to booking Xmas holiday 2014!

**Approximately 5-10% of people diagnosed with MND will have an inherited, or familial, form. This form of MND is extremely rare; the great majority of people diagnosed with MND (90-95%) have the sporadic form, occurring for no known reason*

LIVING WITH MND by Sinead & Catch Berry

Looking back to 18 months ago, we are fondly reminded at just how fit and full of life our Daddy was at the age of 73. Watching him play football with the grandchildren, taking his daily walks to the town, meeting and greeting friends and neighbours – he was full of chat, a hugely sociable person who was enjoying his independence and everyday life. We never anticipated the dreadful blow that would be dealt to him & us the following year.

In April/May of 2013, Daddy started noticing the initial symptoms of MND such as a weakness in his legs, severe muscle twitching and a general weakness that was not present before. Immediately his concern was that he had MND. Why, you ask?

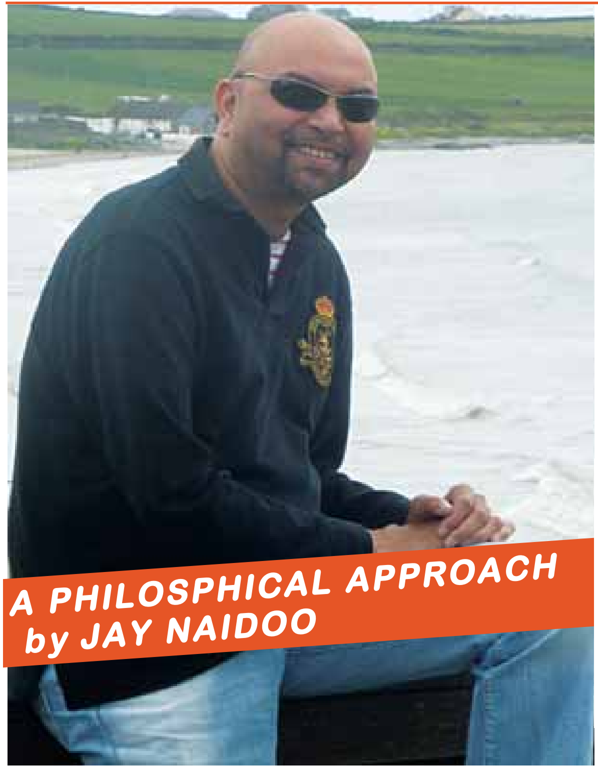
Well there are two reasons: Firstly, he had educated himself over the years by reading various medical books, something he had a keen interest in most of his life and was immediately alarmed at just how many of his symptoms portrayed those of MND mentioned in these books. But secondly and more sadly was because his sister Pauline lost her life at the tender age of 56 to MND 14 years previous and the signs were all too obvious to him.

For the rest of us, we just didn't want to think that he might have MND and had led ourselves to believe that it could be one of a number of things. We tried to offer many reasons as to why he was feeling how he was but there was no convincing him otherwise. In fact, Daddy had diagnosed himself before the long process he endured in advance of receiving the official diagnosis of MND in March of this year. He wasn't shocked with the diagnosis, but felt incredibly sad about it. As a family, we were devastated. And so here we are in September 2014 facing new challenges everyday which is what this disease brings to those suffering from it and their families. Since the diagnosis in March, Daddy has come to rely on everyday family support, as well as the Community Nurses, OT, Speech & Language Therapists, Dieticians etc for his normal day to day activities. He has recently kick-started his relationship with the IMNDA, meeting one of their treasured nurses last week to discuss many things associated with the disease. The disease has progressed at a rate which has taken us all by surprise. Currently his speech is badly affected as is his mobility. We've learned as a family that with MND, we take each day as it comes, one day at a time. We tackle each challenge as it arises.

At the moment the sitting room has been transformed into a bedroom because going up the stairs for him is no longer possible. We are also in the process of having a washroom built as the original bathroom in the house is much too small for wheelchair accessibility and therefore does not suit his needs and requirements. We hope that this will be completed by the end of November and will offer some form of comfort to him. We are proud of Daddy for so many things, but want to mention in particular just how proud we are that throughout this emotional journey, he found the strength and energy to organise a spectacular Fundraiser for the IMNDA.

On 25th August, we had a night of 'Music & Memories' which took place in our hometown. The night was made up of many wonderful musicians and artists who gave up their time to support this great cause. There was a huge attendance on the night and to date the amount raised is €8,000.

We hope to officially present to the IMNDA very shortly.
There have been so many changes over the past number of months, but one thing MND hasn't affected or changed is Daddy's sense of humour and ability to continue to make his family laugh and smile. As a family, we will continue to 'Fondly Remember'.



A PHILOSPHICAL APPROACH

by JAY NAIDOO

Back in early 2009, I was busily enjoying going about my life, M.D. of a Software company, hopping on and off airplanes every week, catching up with family and friends at weekends. I barely noticed the visculations that had started in my upper arms, 3 months later and I decided I had better investigate…initially I did some rooting around on the internet, and MND kept appearing on the screen.

Those early days after diagnosis of MND, are a distant memory to me, I am now in the final stage of MND- unable to move a muscle, and my speech and swallow, are very dubious. I am now resigned to my fate, but back then, I was determined to fight it, and continue to enjoy my life, and what I had left of it to the full.

I decided to enroll in a 20 week Practical Philosophy course, in Northhumberland Road. My wife would drop me off, for the weekly session and I got to know so much about myself, and my situation in life. It taught me to be pragmatic, and not to ask questions like WHY ME? Infact, what right did I have for it NOT TO BE ME?

Philosophy taught me to live, as best I could, in the PRESENT MOMENT, and to be MINDFULL of the here and now. It also taught me not to go back to the past too much, I could not change it, and also not to worry about the future – ones worst fears might never happen….

Philosophy classes taught me to live in the now, and to make the most of every day. In addition it introduced me to MEDITATION, which has an amazing calming effect on the mind.

All I can say is that I can definitely recommend it to anyone, there is no race, religion or creed involved with PHILOSOPHY.

THE IMNDA NURSING SERVICE

We have two qualified full time MND Nurses: Fidelma Rutledge & Eithne Cawley.

They provide services to people with MND nationwide, these services include telephone support and home visits. Upon registration the client should receive a first contact call within 7 working days where they will arrange a first home visit which should happen within 6 weeks.

In 2013, the nurses provided this service to 351 clients nationwide.

During the year the association developed new standards to the nursing services and these are as follows:

Standard 1: This is the 'first initial telephone contact' to the person with MND or a family member. This service achieved a 95% outcome that was achieved within 14 days of the person being diagnosed with the condition.

Standard 2: This is the 'home visit' by the Nurse to the person with MND in their family home. This service achieved a 60% outcome that was achieved within 6 weeks of the person being diagnosed with the condition.

For more information or if you would like a visit or call from one of the nurses, please contact the Services Team on Freefone 1800 403 403 or email info@imnda.ie

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…

HAIR RAISERS!!

Plenty of locks were lost as people across Ireland donated ponytails, grew beards and shaved their heads in order to hair-raise for the IMNDA! A massive thank you to Breda O'Sullivan Head Shave, Catherine Noonan, Belinda Moxley, Colum O'Regan, Gerard Crean, Jane Campbell and Pauline Fitzsimons. Collectively nearly €13,000 was raised. (PHOTO A & B)


A


B

FISHING FOR ANSWERS

Gerard Ramsbottom and Anne Marie O'Flynn with Mayo Club 51 had their thinking hats on! They organised table quizzes in their localities and both were storming successes. Gerard raised over €4,000 whilst Anne Marie and Mayo Club 51 collected a cool €537.

TEA TIME!

The ever popular tea and coffee mornings proved a timeless treat. Áine Wade, Patricia Freeney and Sarah Jane Cullen and the Total Fundraising Team raised a fan-tee-tastic €5,400 from their tea and coffee mornings. Thanks to Breda Crehan and Patricia Freeney who like a bit of drama with their cuppa, their Theatre and Tea event raised a thrilling €1,000. Well done ladies. (PHOTO C)


C

MUSIC MADNESS

Music events were a singing success this year. Heavenly choirs and home-grown musicians took to the stage to raise a few notes for the IMNDA. Special thanks to Eamonn Walsh for organising his Athy Gig, everyone had a strumming good time.
Linda & Micky Dillon held a Status Quo Night while Killian Fitzgerald was in the mood for love as his Night of Love Songs struck a chord and helped raise over €500.
Many thanks to Margaret Murphy and Sharon Friel, their Summer Choral Service with the Portmarnock Singers and the Aber Valley Welsh Male Voice Choir in St. Anne's Church Portmarnock raised over €8,000. (PHOTO D)


D

BIRTHDAY BASHES

Bring on the cake! A very special girl called Aoibheann O'Meara held her 7th Birthday party for the IMNDA. She asked all her friends to donate to us instead of getting presents. Aoibheann collected a super €265!! Thanks Aoibheann, well done on your party. Kitty Lanagan and Patricia King also had the same idea and their celebrations for Kitty's Birthday collected €550 for the association.
Hilary Hogan celebrated his birthday with the IMNDA and donated €735 to us instead of receiving gifts. Paddy McCabe Fundraiser and birthday bash was as big as ever and raised over €2,700. Thanks to all the McCabe family and everyone who gave so generously. Cathy Corrigan also donated her gifts and raised an impressive €3,790. Please thank all your guests Cathy for their kindness. (PHOTO E)


Aoibhinn's 7th Birthday

E

THE DIFFERENCE WE MAKE TOGETHER

EASTER EGG RAFFLE

It was another egg-cellent year for our Easter Raffle with over €25,000 raised.
We would just like to specially thank everyone who took an Easter Egg Hamper in to their work places, homes and businesses – we could not have achieved this without your help!! Eggceptional work everyone! (PHOTO F)


F

CARD TRICKS

Jack Moore and Ellen Simmons had their poker faces on when they organised their card drives. Both events collectively raised over €3,000. Well played Jack and Ellen.

SCHOOL FUNDRAISERS

Aaron Bulger and his school mates at Ashbourne Community College could hold a class on fundraising. The students held a bake sale and sold wristbands. They whipped up a fantastic €241 so well done to all who supported them.

LOVE IS IN THE AIR

We would just like to thank all the lovely couples who got hitched and made donations in lieu of their wedding favours. Special thanks to Bernie Blessing, Martha Mackey and AnneMarie Keohane. Also special mention to Lisa Eccles who turned Cilla Black for one night and organised a blind date event.

FUN-RAISING

Michael O'Mahony had more than horse power on his side when he organised his tractor run. The event pulled in over €5,000. (PHOTO G)


G

Some say the skies are the limits but not for Trisha Hehir, Tony Langsford, Jessica Mahon, Lisa Kenny, Barry Flynn and Thelma Stackpoole! They all took up the challenge of doing a sky dive and together their fundraising soared over €2,000. (PHOTO H)


H

DANCE THE NIGHT AWAY

Put on your dancing shoes! And that is exactly what Chris Owens did when he organised a set dancing evening and raised €500. Clodagh Fitzpatrick and the Carlow Lions Club danced the night away to the tune of €1000. Thank you to everyone who got involved, we deeply appreciate it.

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

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

THE JUNE BALL

The June Ball was held in the DoubleTree by Hilton Hotel on June 28th 2014 to raise needed funds for the Irish Motor Neurone Disease Association (IMNDA). On the evening of the ball guests were welcomed with a Disaronno drinks reception followed by a four-course meal including wine. There was a jam packed evening of entertained planned for guests by the June Ball Committee including games, bands, DJs and a super raffle, which included Rob Kearney's Six Nations-winning jersey signed by the Irish rugby team. The event was a massive success and raised over €66,000. We just want to extend our sincerest thanks to all of the June Ball committee for doing a smashing job! Well done to you all.

THANK YOU FOR GETTING ACTIVE FOR YOUR ASSOCIATION!

PEDAL POWER!

The cycling craze continues with more and more of you taking to your bikes than ever before. We had some extraordinary cycles this year. Thanks to Carol McCarron, John Battles and Gordon Kellett. They all took on the challenge of cycling from Malin Head to Mizen Head, although Gordon did it in reverse! Together they nearly raised €30,000 for the IMNDA. Ivor Walsh took part in the Sean Kelly Tour and from his pedalling power managed to raise €350. Thanks Ivor!

Jason Devers and Lloyd Moore looked passed the shores of this Fair Isle and took on challenges further afield. John cycled approximately 1,600Km from Land's End to John O'Groats. John was cycling for over two weeks and doing 110Km a day. John took on the cycle as his work colleague was diagnosed with MND. John raised over €13,000 from this amazing feat. (PHOTO A)

Jason along with his friends Brian and Colum embarked on a cycle across Europe from Ballina to Berlin! A 2,200Km route that took them through Ireland, Wales, England, France, Belgium, Holland and Germany. They somehow managed to complete this incredible distance and fundraise along the way. Well done lads, unbelievable achievement!

The Annual Sheridan Cycle was once again another hit. Over 40 cyclists took to the roads of Cavan to fundraise for two great charities, The Irish Motor Neurone Disease Association (IMNDA) and the Kevin Bell Repatriation Fund (KBRF). We would just like to say a massive thank you to Helen and Francie Sheridan for all their hard work on this event. (PHOTO B)

A huge thank you to Paul Lannon and all the 70 cyclists who took part in the D2K 2-14 cycle. Participants cycled over 180K from Dublin to Kilkenny and a fantastic €33,600 was raised for the IMNDA. The IMNDA would like to thank all the cyclists, volunteers, medical staff, drivers, bike marshals, sponsors and especially Paul Lannon and Sandra Fox.
Well done once again - terrific event!! (PHOTO C & D)

John Hynes organised the East Meath Cycle again this year. 60 cyclists took on either a 70K or 100k route through County Meath in a bid to raise funds for the IMNDA.
So far over €2,200 has been raised. Special thanks to John and all who took part.

WALK TO D-FEET

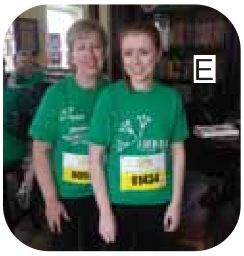
This summer, the IMNDA hosted its second 'Walk to D-Feet MND' in the picturesque grounds of Castletown House in Celbridge, Co Kildare. Kildare GAA players Cathal McNally, Tommy Moolick and Fergal Conway got things underway when they gave the boot to MND and helped launch the event. On the day of the walk, the rain held off and a great time was had by everyone. We just want to say a massive thank you to everyone who joined us in Castletown and walked in D-Feet.
Thanks to all the Intel Volunteers who pitched in - we would have been lost without you! Over 110 walkers took to the course, next year we are hoping for over 200! A special thanks to the Frankland family for joining us on the day, you made the occasion all that more significant and our thoughts are with you during this time.

THANK YOU FOR GETTING ACTIVE FOR YOUR ASSOCIATION!...cont.

However, we weren't the only people to walk to D-Feet MND. Jacqui Tallon did the London Moon Walk Half Marathon and Peter Stewart and the Stewart Family organised their own Fun Walk and Bucket collection. Well done guys!

ON YOUR MARKS!

So many of you pounded the pavements for us in 2014. Dublin was flooded with thousands of ladies walking and running the Flora Mini Marathon. To all those who donned the green t-shirt and took on the 10K on the day, we salute you. Over €43,000 was raised from the Flora Mini Marathon this year. Keep up the good work ladies! (PHOTOS E, F,G,H)



Others wanted something a little more challenging. Special thanks to Thomas Davidson and Jackie Hennessy. Both cajoled groups to sign up for Hell & Back and to sport the IMNDA colours. Thanks guys – we hear the ice bath and 8 foot wall were delightful!

Thank you to everyone who took part in marathons this year. Thank you to Anthony Martin for taking part in the River Moy Half Marathon, thanks to Niamh Keane and Mark Burns for running in the Cork City Marathon, thank you to Mark Ryan for competing in the Connemara Marathon and to Anna McMahon for taking on the Paris Marathon and thanks also to Jennifer Frawley for participating in the Achill Marathon and Dr Peter Kinirons for completing the Copenhagen Marathon. Special thanks to Melanie Hacking for undertaking the South Coast Triathlon.

Pauline Kinsella and Mary Sweeney O'Reilly and family organised their second 5K Rosie Run. The event was another success; we would just like to thank all those who supported the run in Loch Gowna in memory of their mother Rosie. Thanks also to Jim Lawton who took part in the Ballycotton 10 Mile and to Liam O'Neill who ran the Ballybunion 10K. (PHOTO I)

This year we were one of the chosen charities for the Waterford Viking Marathon Marathon. Some of our brave and brilliant supporters from Waterford took up the challenge. These fantastic ladies included Sharon Barry, Bernie Walsh, Eileen Boland, Fran Sheehan, Fiona Ryan, Anita Norris and Aileen Boland. Eileen Boland is 73 and Fran Sheehan is 83 years old. They walked the quarter marathon in just over 2 hours.
Well done women!!! (PHOTO J)

HOLE IN ONE

Rory McIroy wasn't the only one winning this year. Joe Gaffney, Mary Kennedy and Marguerite O'Brien all played off the green and organised tee-tastic golf events for the association. Thanks to all the golf societies who assisted their efforts as collectively they raised over €4,000 for the IMNDA. (PHOTO K)

FOOTIE FANS!

Ashwood FC lent their grounds for an Astro Football Tournament in aid of the IMNDA. The event raised over €2,400. Thanks to Robert McGuinness an all at Ashwood FC. (PHOTO L)

BOWLING BONUS

We were bowled over by the success of Brian Daly's annual bowling tournament in memory of Paul Magee. This year's event raised over €3,000. Well done Brian!

MAKING A SPLASH

Patrick Curran took on a sponsored swim to raise money for the IMNDA. Patrick certainly made waves as he raised a brilliant €800. Go raibh maith agat!

THANK YOU FOR GETTING ACTIVE FOR YOUR ASSOCIATION!...Cont.

LIVE YOUR LIFE CYCLE 2014

Live Your Life Cycle is a cycle run from Ballincollig Rugby Club, Cork to Allihies at the tip of the beautiful Beara Peninsula by the O'Sullivan "Rue" family in memory of our late mother, Betty "Rue" O'Sullivan in aid of the IMNDA. There is also a half cycle from Ballylickey to Allihies. Betty lost her battle with Motor Neurone Disease on the 26th of July 2012. This year was the second year of the cycle. A large sum of €50,000 was handed over from the cycle and other fundraising in 2013. This memorable event took place again this year with an increase in numbers from 309 cyclists to 440 cyclists. The event was a testament to our late mother Betty Rue who was fondly remembered with the large number of local and not so local cyclists for their first time and second time who took part in this sporting event. Betty looked down on us all by keeping the rain away as we left the Rugby Club in Ballincollig with reports of flooding behind us as we cycled west getting a sun tan. The people of Beara came out in force to welcome the cyclists along the way, with none warmer than the welcome for the cyclists into Allihies Village, Ballincollig RFC gave their facilities for free and offered assistance as we set off on the morning of the 19th July. This was attended by our charity ambassador Ronan O'Gara accompanied by a number of celebrities, including GAA stars Graham Canty, Paddy Kelly and Kerrys Thomas O'Shea. The cyclists were also met by Jennifer Bonus who again wore her heart on her sleeve as she did in this year's Operation Transformation. She travelled to Allihies with her daughter Tara who fitted in like they had been visiting for years. All the cyclists were given goodie bags sponsored by Gala & M+P O'Sullivan Cash and Carry. Barretts of Coppeen allowed us the use of their property again this year for a water stop and all the drinks and food were sponsored as by Scallys Super Valu, Blackrock, Cork. The half cycle set off from Cronins Supermarket, Ballylickey, who sponsored most of the food stop for the full cycle at the half way mark. Luckily again this year Denis from Bike n Beara was on hand to attend to any mechanical difficulties that had become the cyclists, Denis's good wife Vera was on hand (in Castletownbere) looking after the logistics firstly for the cyclists travelling from Beara to Ballincollig before kicking off on the morning of the cycle and again looking after them with water and fruit before they battled the last leg of the cycle to Allihies on the return journey on their bikes. Noel O'Leary famous former Cork Footballer met the cyclists on their arrival in Allihies. Unfortunately none of the beneficiaries of the IMNDA Committee were able to attend this event but they were represented by family and friends. This event has grown in momentum since last year. There has been a very personal feel to it with the cycle being led all the way to Allihies by our dad Oliver Rue O'Sullivan senior, Bettys family and friends were again all at hand offering their help at every juncture.

The amount of volunteers offering their help and support in the organising and the planning stages was again unbelievable, these include motorbike outriders, photographers, Cork Sports partnership and our Corporate Support Partner, Morgan McKinley Recruitment who looked after Graphic Design, Social Media and Registration, Wordhoard Communications who looked after the website and all the people who helped at water stops and road marshals. This year has given us the opportunity to meet other families who have been affected by Motor Neurone Disease and offer them the support by cycling with them on a common goal. To support these people along this journey in keeping the memory of our loving mother alive in our hearts and in the village she loved so dearly is comforting in her loss. This cycle isn't about TIME, speed or distance but it is about taking TIME to meet people on this journey who have had their own personal experience with dealing with the loss of or living with a loved one/or friend suffering MND or who simply were touched with our story and many others and wanted to be a part of this annual event. All funds raised goes to the IMNDA again this year and hopefully it will ease the suffering for someone in this unfortunate position.

THANK YOU FOR GETTING ACTIVE FOR YOUR ASSOCIATION!...Cont.

RING OF KERRY

In 2011, Kerry Friends of Motor Neurone was established to raise awareness of Motor Neurone Disease locally in Kerry and raise funds for the IMNDA. Since its foundation in 2010 the voluntary group have gone from strength to strength. This year they had the incredible honour and achievement of being selected for the Ring of Kerry Cycle. Christy and Mary Lehane from Kerry Friends of Motor Neurone have written a piece about the success of the cycle:

GREETINGS FROM KILLARNEY!

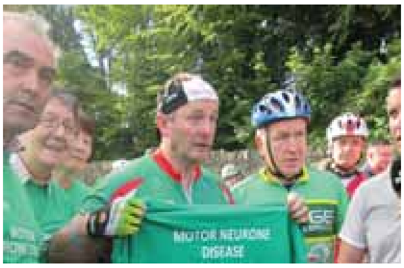
We the Kerry Friends of Motor Neurone were delighted to be selected as one of the major beneficiaries of the Ring of Kerry Charity Cycle 2014. The Ring of Kerry Cycle is one of the largest one day charity events to be held in Ireland and this year celebrated its 31st staging of the event with over 10,000 cyclists taking part. When Kerry Friends of Motor Neurone were selected to participate in the cycle we knew that it was a big call. Our Committee is very small, very spirited and hardworking and we enthusiastically faced the challenge ahead last January 2014. Some of the proceeds of the Ring of Kerry Cycle we are purchasing TOBII C12E - EYE GAZE communication devices for our Motor Neurone Disease sufferers so as to enable them to have conversation surf the net or send an e mail. We worked day and night to source cyclists from all parts and we were absolutely overwhelmed with the number of people who finally came on board to cycle the Ring for our Charity.

We were formed in 2011 and are based in East Kerry and we are committed to fundraising and raising awareness of this most awful disease. Some of our committee are people whose families have had first-hand experience of Motor Neurone Disease in the past while others are dealing with it presently. We received wonderful encouragement and support from Motor Neurone families and friends and this is where we draw our strength from.

Motor Neurone sufferer Patrick Carmody and his Wife Betty were wonderful ambassadors for our Charity contributing to many media articles. We are especially grateful to Motor Neurone sufferer Emma Fitzpatrick and her husband and family from Kinsale who invited us to their home and demonstrated for us the workings of the EYE GAZE technology. That evening in the company of the Fitzpatrick Family in Kinsale was a most inspiring experience.

We now would like to thank all the people who helped us in any way on this journey-- the cyclists -- the volunteers -- the sponsors --and all who helped and encouraged us.

From all at the IMNDA we would just like to repeat this sentiment but also thank and congratulate Christy and Mary and all the Kerry Friends of Motor Neurone Committee for their Trojan work this year, we really appreciate all they have done for Motor Neurone Disease and the IMNDA.



MND NATIONAL AWARENESS CAMPAIGN

"I HATE THE WAY MOTOR NEURONE DISEASE IS TAKING MY LIFE BIT BY BIT,"

Paul Lannon

21st June is Global Awareness Day. In January, Paul Lannon and Jan Battles, both of whom have Motor Neurone Disease (MND) recorded Radio Adverts that ran throughout June to raise awareness of Motor Neurone Disease and try draw people's attention to the difficulties they face every day.

Paul is 43 years old. In February 2011 he was diagnosed with MND. From once being able to lift two kegs of beer at a time, he can no longer lift the kettle. Dressing himself is now impossible and he has recently started to have difficulties with his speech and swallow. He can no longer work.

Jan is 42 years old. In March 2013, Jan was diagnosed with MND. Soon after diagnosis she was walking with a stick, then a rollator, now a wheelchair. Her arms have become very weak. Her right shoulder sometimes dislocates as the muscles are no longer strong enough to hold her arm bone in place. Since recording the advert in January, her speech has become slurred and she now has difficulty speaking.

"All you can do is try to cope with every challenge this illness throws at us and there are many. It is relentless," Jan Battles. Jan and Paul shared their stories about their terminal disease in the hope that greater awareness would generate increased support for those living with this degenerative condition.

The campaign ran throughout the month of June to mark Global MND/ALS Day on June 21st. Jan and Paul were encouraging people to Drink Tea for MND and organise Tea Days in their homes, communities and work places.

Thanks to Jan and Paul supporting the campaign and telling people what it means to them nearly 100 tea days across the country were held and over €70,000 raised.

We have run our Drink Tea for MND campaign since 2009 and never has it been so well supported. This is thanks to Jan, Paul, all our other clients who took to their regional airways, Insomnia and everyone from Dublin to Donegal, right across the country who held an event in their home. We can't thank everyone enough for their support and want you to know it truly has made an impact.

"It was an honour to be involved in the campaign, the IMNDA do so much for MND sufferers that I was happy to do my bit to raise awareness and also much needed funds. It was fantastic to hear the response from the media and the public to the ads and see the comments on social media from friends and strangers who heard them. MND traps us in our own little world as it progresses so to be able to reach so many people all over the country gives me a great lift," Paul's thoughts on the campaign.

Paul and Jan have touched our lives; their fight has spurred over 100 people to bake and brew, and countless more to act and support MND. We will leave you with Paul and Jan's powerful messages.

"At 42 I thought I had the job of my dreams, travelling all over the world meeting different people and cultures and leading a life I never thought I would; I was devastated when I had to give it up, Oh how I miss that life; if only I could still put on a smart suit and tie. Oh how I wish my hands still worked and I could dress myself; I hate the way Motor Neurone Disease is taking my life bit by bit," Paul Lannon

"A year ago I camped overnight to get to the front at a Gary Barlow concert. Now I need an entourage as big as him to get to a gig. Someone to dress me, someone to do my hair and makeup, someone to wheel my chair onto the disabled platform. That's because I have motor neurone disease,"
Jan Battles

Our last interview on the campaign was published in Woman's Way as they chose our courageous Jan to be their hero of the month. Jan not only helped us with this campaign but she also helped organise a Kodaline concert for us, as you will hear about later. This is Jan's inspirational Story.

Local hero

Jan Battles

***Woman's Way* had the honour to meet a truly inspirational woman**

Jan Battles is the definition of a hero. She has achieved so much for others in a short period of time, all while engaged in battle with her own body. Last year, at 42, Jan was diagnosed with Motor Neurone Disease.

Jan is a journalist originally from Dunmore East in Co Waterford. She has lived in Dublin since 1989 where she spent 15 years writing for *The Sunday Times* and in more recent years *The RTÉ Guide*.

Motor Neurone Disease (MND) is a progressive neurological condition that attacks nerves in the brain and spinal cord. This means messages gradually stop reaching the muscles, which leads to weakness and wasting. MND can affect how you walk, talk, eat, drink and breathe. There is currently no cure for this horrific disease.

But MND didn't factor in the fierce lady that is Jan Battles. She is a woman on a mission to raise awareness and funds, so that one day a cure to end this cruel disease will be found.

I meet Jan and her mother Breda in Jan's home where she lives with her husband Terry.

She tells me her story with a strength that she does not give herself credit for. She doesn't think she's brave and yet as I sit there I keep forgetting to take notes because I'm so in awe of her and all she has done to raise awareness about MND since her diagnosis.

Before she was diagnosed Jan's knowledge about MND was minimal. Jan says, "The only awareness I had of MND was that Stephen Hawking had it and he is a very unusual case and then other than that Colm Murray.

"I saw the documentary Colm did about it and I remember thinking what a horrible disease it was."

For Jan, the diagnosis came when she became aware of significant changes in her body. She had experienced a series of falls, and had noticed that she could not keep up with the pace of her friends like she used to. In March 2013, Jan first heard the words Motor Neuron Disease attached to her name.

> ***"This disease takes part of you away bit by bit"***

Jan's got her JB Army in support

"It was devastating news, we had to drive from the hospital down to my parents in Waterford to tell them, it's not the sort of news you can tell over the phone. That day marked the end of my life; this disease takes part of you away bit by bit."

Jan has not let it stop her and her wish to raise money to go towards helping others find a cure. As her condition has progressed Jan now uses a wheelchair. Her arms have weakened so that sometimes her right shoulder dislocates as her muscles are too weak to hold it in place. Her voice is weakening and I can see the physical effort she puts in when she talks.

And still Jan is a powerhouse; even as her body weakens she has not, not one bit. Since being diagnosed she has banded her family and friends together, otherwise known as the JB Army, and they have raised just over €34,000 for the Irish Motor Neurone Disease Association.

That is only the tip of the iceberg of what Jan has achieved. Ever the determined woman, last year, she set about getting in touch with Kodaline to ask would they play a gig in aid of the Irish Motor Neuron Disease Association.

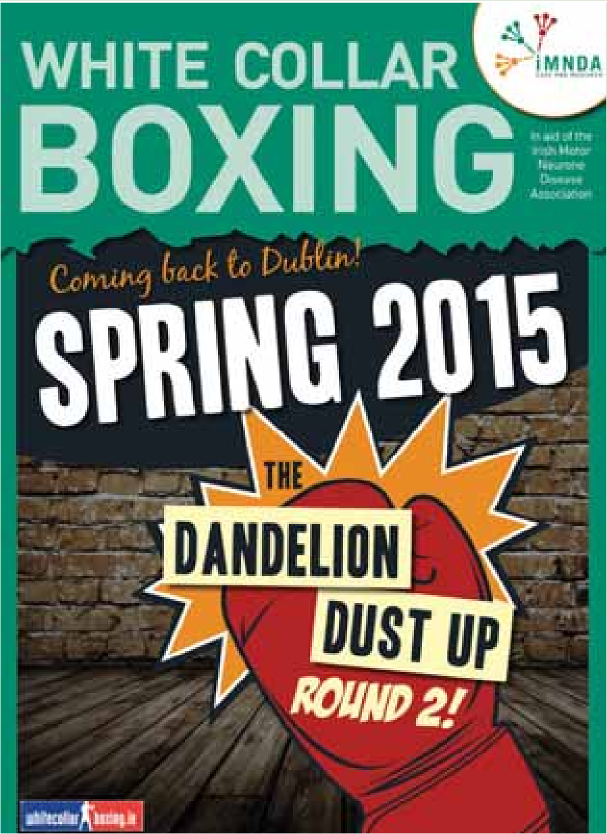
Kodaline not only agreed to do one gig, they did two. These gigs were held in Whelan's a few weeks ago. Jan attended both gigs and met the band and their families. These gigs raised €30,000 for IMNDA.

Jan says, "There may be things I can't do now but one of the things I can do is to raise awareness and let people know about the disease. I have to do it because people with MND don't really have a voice. Very soon I will lose my voice totally and it will be harder for me to do a lot of things so while I can, I feel it's my duty to do as much as possible."

I ask Jan if the support she has received from the general public has provided solace for her. Jan says, "The messages I'm getting, people tell me, 'My father has this disease it really helps talking about it', that's one of the things that keeps me going now."

Meeting Jan was a day *Woman's Way* won't forget. A woman like Jan is one in a million. Her ability to keep on going and thrust this little known illness into the limelight, so that others won't have to endure what she and her family have is selfless and awe- inspiring. Jan Battles is truly a force to be reckoned with, a hero. WW

We hope that readers will donate to Jan's page all proceeds which go to IMNDA at http://www.mycharity.ie/event/jb_mnd/ To find out more visit their website at www.imnda.ie



WHITE COLLAR BOXING IS RETURNING TO DUBLIN CITY CENTRE!!!

WE ARE LOOKING FOR BOXERS TO SIGN UP FOR OUR EAGERLY ANTICIPATED

“DANDELION DUST UP – ROUND 2!”

Think you have what it takes to join the Fight against MND!?

Wanted men and women of all ages and fitness levels to commit to 8 weeks of intensive boxing training by the best in the business.

No previous boxing experience necessary; the training will ensure you are ready to step into the ring on Fight Night!

Places are limited -
Email fundraising@imnda.ie or call 01 873 0422 to secure yours www.imnda.ie
Fundraising & ticket sales is required by all participants. This event is run in association with whitecollarboxing.ie

THE KODALINE CONCERT

he IMNDA were extremely lucky to hold two exclusive and intimate concerts this year in July with Kodaline and Special Guests in Whelans on Wexford Street. Tickets for both concerts, which took place on the 2nd and 3rd of July, sold out in less than ten minutes! The band decided to perform these exclusive concerts for the Irish Motor Neuron Disease Association because of their close relationship with Jan Battles.

We were treated to two very intimate nights where Kodaline performed all their hits including ‘High Hopes’, ‘Perfect World’ and dedicated “All I want” to Jan as it is her favourite. The sweat and tears were pouring down everyone’s faces and the rafters were nearly lifted clean off the roof as everyone came together for this surreal and heartfelt experience.

All in all both nights were a fantastic success and around €30k was raised. The IMNDA would like to extend its sincere thanks to Jan Battles, Kodaline, Paddy McPoland and MCD promotions, Whelans, Aoife Kelly from Sony Records, Duncan Ellis & Lewis Palmer from Scruffy Bird Management.

THE ICE BUCKET CHALLENGE

#THANKYOU

The Irish Motor Neurone Disease Association can reveal that the viral internet phenomenon the “Ice Bucket Challenge” has resulted in donations to the charity of over €1.5 million, with a final total to be released in the next few months. Based on the number of donations, it’s estimated that as many as half a million people across the island of Ireland deliberately drenched themselves in ice cold water to raise much needed funds for the association, which helps some 330 patients and their families deal with the challenges of motor neurone disease. Patients, staff and supporters have today put a “thank-you” video on-line, in acknowledgement of the effort made by donors.

This can be viewed on our website www.imnda.ie

Dr. Declan Mac Daid, chairman of IMNDA said, “We have been blown away by the generosity of the Irish public, and have watched on almost in disbelief as the total raised kept rising and rising, and people’s timelines kept filling and filling. We cannot thank people enough for what they did. The focus now is on how the money can best be spent to deal with the needs of those living with motor neurone disease, and their families.”

The money is to be used in a variety of ways to be outlined following a detailed consultation with the IMNDA’s clients, their families, their carers and supporters of IMNDA. A questionnaire is in the process of being prepared which will be sent to every patient and user of the IMNDA service across Ireland to identify where the need is greatest.

Dr Mac Daid says, “The only thing we know for certain is that at least 25% of the money raised will be given towards clinical research into causes and treatments for MND, led by Professor Orla Hardiman of Trinity College Dublin. This will be in addition to funding which the IMNDA already give regularly to support research.

Outside of that, we will spend the next few weeks getting feedback, and considering where investment is needed most. We look forward to investing in services and technology into the future, and we hope to use some of the money to establish a reserve fund to allow for the fact that the number of people being diagnosed with MND continues to rise. The number of patients has risen from 220 in 2009 to 330 today. Through the generosity of the Irish public, we are now in a better position to help those people who have yet to be diagnosed”.The IMNDA has also committed to ongoing openness and transparency about how the donations are used, with Dr Mac Daid concluding; “We will have a section on our website (IMNDA.ie) which will detail exactly how the ice bucket money has been spent. And, as we have always done, we will publish our annual report and finances online in full.” The Ice Bucket Challenge originated in America, with people challenging each other to be drenched in ice-cold water, before donating money and nominating three others to do the same. The whole idea behind dumping a bucket of ice on you is to freeze your whole body for a second to raise awareness about how the disease actually affects people. Even though it is for a split second it still gives the person some perspective on how an MND victim feels every day. MND can take your breath away and prevent you from moving – just like the shock of ice water to the body.

The Irish truly embraced the initiative after Daithi O’Se accepted the challenge on the first night of Rose of Tralee, before one of the biggest TV audiences of the year. Amongst the other celebrities who helped the IMNDA’s cause were Paul O’Connell, George Hook, Sharon Ni Bheolain and Amy Huberman. This remarkable campaign could not have happened without the support from ‘Like Charity’.

The ice bucket challenge marks the third viral campaign for the Dublin-based company that provides its text-donation service free of charge to Irish charities. If you are one of the few remaining people who hasn’t taken up the Ice Bucket Challenge there is still time!

Don’t forget to donate €2 by texting MND to 50300 (100% of text goes to IMNDA across most network providers. Some providers apply VAT which means a minimum of €1.63 will go to IMNDA. Service Provider: LIKECHARITY. Helpline (01) 4433890). Once again all from the IMNDA #thankyou!

NEW BOARD MEMBERS

ANGELA HOGAN; DIRECTOR

Angela Hogan has been working in Human Resources with the Mater Private Hospital since 1996. Her current responsibilities are around Learning and Development for the Mater Private (Dublin and Limerick).

Born and educated in North Tipperary she obtained her degree in Human Resources and Industrial Relations from National College of Ireland and is CIPD certified. She joined the IMNDA in late 2013 and also does some work with Catherine McAuley Nursing Home Board.

ALISON GRAY; TREASURER

Alison Gray completed her Bachelors Degree in Business Studies for Accounting in Dublin and started her career as a senior auditor. She is an audit Director in BCK, and has worked there since 2007. Alison has over 10 years' experience in the audit of small and large enterprises in many industry sectors. Working closely with clients, Alison has also provided valuable advice on internal controls and audit findings to support the business needs.

Alison is a seasoned business networker. Through the various network groups Alison has been involved with, she has supported BCK in building excellent relationships with SME's in Dublin city and joined the board of the Irish Motor Neuron Disease Association, as the treasurer in July 2014.

Alison is also part of the JHI international network, of which BCK is a member and has attended and presented at the annual audit & tax school conferences held by JHI. Through JHI, she has been able to make numerous international contacts, enabling her to gain access to tax and accountancy law worldwide.

NEW STAFF MEMBER

We would like to welcome a new staff member Hamufari Mtamiri to the Association. She joined us in June of this year and took up the position as Accounts Technician; she is a qualified accountant and ACCA member with tremendous experience. She hails from Zimbabwe and has been living in Ireland since 2002. She lives with her husband and her daughter in Monasterevin in Co Kildare.

LEAVE A LEGACY

A SMALL GIFT CAN MAKE A BIG DIFFERENCE

Leave a legacy and make life more manageable for someone with Motor Neurone Disease.

Until our vision of A World Free from Motor Neurone Disease is realised, the Irish Motor Neurone Disease Association (IMNDA) is committed to providing the best possible care and support for people affected by MND.

We cannot slow the progression of MND or change the outcome but we can alleviate the feelings of isolation and improve quality of life. We strive to ensure that each individual receives the care and support they require enabling them to live as active independent citizens in their own homes for as long as possible.

Leaving a gift in your will (a 'legacy') to the IMNDA offers much needed financial security on a long term basis and will ensure families affected by this incurable disease have access to our vital services regardless of their location or means.

WHY GIFTS ARE SO IMPORTANT TO THE IMNDA

It costs approximately €1.5 million for the IMNDA to operate each year. On average we receive only 14% of our funds from the government.

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

Since 2000 legacies have brought the IMNDA nearly half a million euro making a real difference to the thousands of people we have provided support to over the years.

"One saving grace we can be thankful for is the Irish Motor Neurone Disease Association. At first I was sick to my stomach calling this organisation to explain that MND had entered our lives.

LEAVE A LEGACY...Cont.

They immediately put in place a plan that would include emotional support in the form of counselling and have continued to support us through each and every stage of the disease." Shane Kelly, Carer

Legacies of all values help to sustain our vital services; this is what your contribution can help to fund:

- Home visits by our two MND Nurses
- Financial assistance towards home care
- Provision of specialised medical equipment
- Funding counselling
- Funding towards research

TYPES OF LEGACY

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

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

YOUR LEGACY OPTIONS

Once you have made provisions for your nearest and dearest you might choose to leave the remainder, or part of the remainder of your estate to one or more preferred charities. Your solicitor may find the following wording helpful if you would like to remember the IMNDA in your will:

For a gift of the residue of an estate (a residuary bequest):

To leave a portion, or all, of the residue of your estate:

"I give, devise and bequeath all (or a fraction or a percentage) of the residue of my estate of whatsoever nature and wheresoever situate to the Irish Motor Neurone Disease Association, registered charity number CHY8510 (Ireland), and I direct that the receipt of the Treasurer or other proper officer for the time being of the said Association can be relied upon as proof of full discharge of same".

For a gift of a specific sum of money:

You may like to state a specific sum of money in your Will that you would like to go to a particular charity, or charities of your choice.

"I give, devise and bequeath the sum of €xxx to the Irish Motor Neurone Disease Association, registered charity number CHY8510(Ireland), and I direct that the receipt of the Treasurer or other proper officer for the time being of the said Association can be relied upon as proof of full discharge of same".

For a gift of a specific item:

To leave a specific item or property:

"I give, devise and bequeath <insert specific item or property here> to the Irish Motor Neurone Disease Association, registered charity number CHY8510(Ireland), and I direct that the receipt of the Treasurer or other proper officer for the time being of the said Association can be relied upon as proof of full discharge of same ".

Leaving a legacy to benefit others in the future is an extremely thoughtful and generous act.

What if I already have a Will?

If you already have a will, it's easy to amend it to include a gift to the IMNDA. Minor changes like this do not require a new will, as an existing will can be amended by completing a codicil (a document that amends an existing will), which your solicitor will help you draw up.

How do I make a Will?

Simply contact a solicitor and let them know you would like to make out a Will which includes a legacy to the IMNDA. They will advise you on how to do this in order to best suit your needs and wishes. For the purposes of making a Will, you will require our registered charity number, which is CHY 8510. Please let us know if you are leaving a gift to us, we would like to say thank you!

Best Will in the World Week

Best Will in the World Week takes place from 20th to 24th October this year and highlights the importance of making a will. During Best Will in the World Week, solicitors across the country offer will consultations for a fee of €50. People interested in making their will, or updating an existing will, are also asked to consider leaving a gift to their favourite charity once loved ones have been taken care of.

Check out www.bestwill.ie for a list of participating solicitors in your area. Thank you for considering leaving a gift to the IMNDA.

much loved

The online tribute charity

GIVING IN MEMORY OF SOMEONE SPECIAL

The memorial website Much Loved provides the facility for people to set up a Tribute Page in memory of their loved one. This free service helps you to express your feelings about your loved one in words, pictures, music and even video. It can also help all those affected by the loss to come together, sharing memories & supporting each other.

Creating a tribute page is very easy to do and only takes a couple of minutes. You can personalise the design, add memories as well as invite friends & family to visit and contribute to the Irish Motor Neurone Disease Association in memory of your loved one. At all times you retain total control over privacy and postings, plus your site is hosted online in perpetuity so that you can keep it as both a loving and a lasting tribute.

We hope that it helps you to remember & commemorate.

- Simply go to www.muchloved.com and click on Create A Tribute.
- You can then add as little or as much information about your loved one as you like
- You can make the page private or public
- You will be asked if you'd like visitors to the page to make a donation to a charity, if you select Yes you will be able to select the IMNDA as your chosen charity. Simply type Irish Motor Neurone Disease Association in the search box when asked.
- You can then personalise your page with photos, music, words and anything you else you feel is a fitting tribute to your loved one.

Alternatively one of the IMNDA fundraising team can set a page up for you and then hand it over for you to update.

Please contact us if you'd like us to help:
email fundraising@Imnda.ie or call 01 873 0422.

The tributes are here to help you as you try to cope with the pain of loss. They help you and your family and friends to express your grief, share your special memories and commemorate your loved one together, regardless of the time of day or where you live.

Much Loved believes that there is often a sense of reserve that accompanies death which can make grieving worse. It is almost as though death is unnatural, something best forgotten. We reject such a taboo and believe that positive recognition of loss and mutual support are key parts of grieving.

THROUGH SETTING UP A TRIBUTE PAGE ON MUCH LOVED:-

~You can cherish and express your feelings about your loved one using words, pictures, music and video.

~You can use your website to enable family and friends to send their thoughts and you can invite them to contribute as well, maybe by adding a lovely picture you've never seen or a special story you've never heard.

~You can keep your tribute access totally private to just you and selected family and friends, or choose to allow public access. The privacy of your site is completely handed over to you.

~You can record and keep your own private bereavement diary and listen to your own personal music play list.

~You can use your website to pass on information about the death, the funeral, anniversaries or other important occasions to your family & friends.

~You can use your website to collect and display donations to the IMNDA on their anniversary / birthday at Christmas or throughout the year in memory of your loved one.

~You can develop and keep a beautiful lasting record and legacy for your family and future generations.

www.muchloved.com/g_home.aspx

Christmas Cards

Spread a little bit of IMNDA festive spirit this Christmas by purchasing a pack of our charming Christmas cards! The cards are €10 per pack of 12 cards (including postage) and each pack has 6 different designs (2 of each design).

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

or

freefone 1800 403 403.

This pack contains 6 designs (12 cards)
€10 per pack

IMNDA
Coleraine House, Coleraine Street, Dublin 7
Phone: 01 873 0422 | Fax: 01 873 1409 | Freefone: 1800 403 403
www.imnda.ie | info@imnda.ie
CHY: 8510

The purchase of these cards directly supports our services, thank you.

IN REMEMBRANCE

Dan Boohan
Paul O'Connor
Mary B O'Sullivan
Marie Hughes
Mary Harty
Vincent Flood
Bridget Coughlan
Paddy McCabe
Bernard Martin
Tony Walsh
Enda McLoughlin
Therese King
Rosarie Coughlan
Raymond O'Donnell
Stephen Raftery
Philomena Doyle
Brendan Comiskey

Brendan Carroll
Bridget O'Rourke
Nicholas Caulfield
Captain John E Bukley
Kathleen Horan
Mary Walsh
Cathal Oliver
June Culliton
Pat Long
Abdul Kafeel Faruqi
Delia McGuinness
Elizabeth O'Brien
John Claffey
Lone Roe
Peggy Whittington
Conn Ryan
Alice Flynn
Kathleen Kidd

Eamonn Gibney
Donal Deasy
Mabel Davidson
James Leamy
Thomas Byrne
Thomas Brosnan
Denis Kavanagh
Rita Aitchison
Orla Roe
Desmond McGroarty
Philomena McCarthy
Brian Fahy
Patrick Currid
Martin Queally
Mary Hughes
Abdolrazagh Azad
Michael Jones
Joan France

Catherine Rhatigan
Martin Freedman
Pauline Hogan
Michael Stafford
Dolores Monaghan
Mary O'Dea
Seamus Finnegan
Nicky McFadden
Marnie Lopez
Ann Graham
John Mahon
James O'Connell
Noreen O'Leary
Dermot Perry
Bridget Meagher
Thomas Culhane
Marie O'Connell
Michael Garbutt

TIME WILL EASE THE HURT

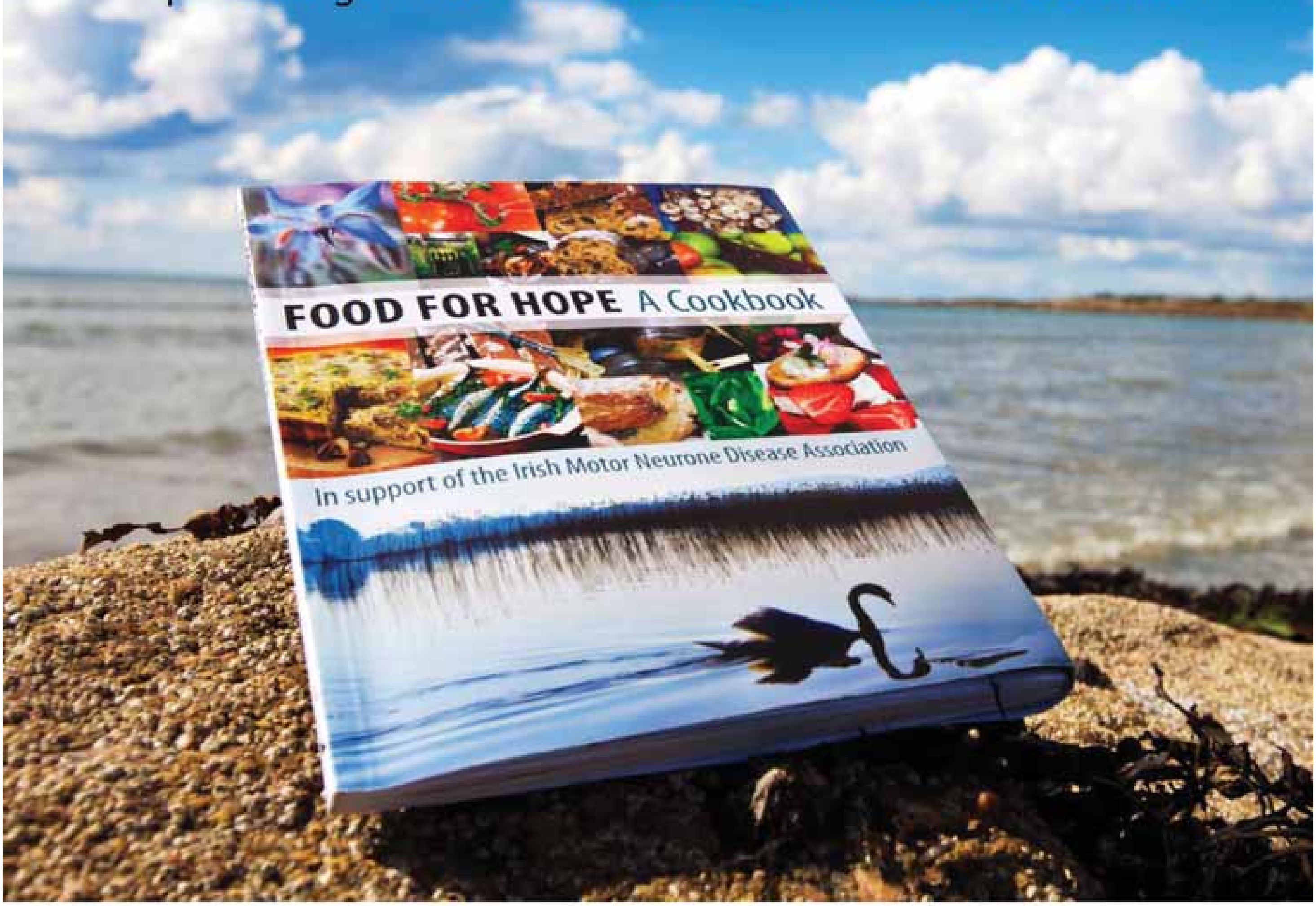
The sadness of the present days
is locked and set in time,
and moving to the future
is a slow and painful climb.
But all the feelings that are now
so vivid and so real
can't hold their fresh intensity
as time begins to heal.
No wound so deep will ever go
entirely away
yet every hurt becomes
a little less from day to day.
Nothing can erase the painful
imprints on your mind
but there are softer memories
that time will let you find.
Though your heart won't let the sadness
simply slide away
the echoes will diminish
even though the memories stay
Anon

Support People with Motor Neurone Disease by purchasing the IMNDA Charity Cookbook for just €12

FOOD FOR HOPE A Cookbook

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

All proceeds go to the Irish Motor Neurone Disease Association



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info@imnda.ie

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IMNDA
CARE AND RESEARCH