IMNDA
CARE AND RESEARCH

CONNECT

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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.
Email pr@imnda.ie / info@imnda.ie or
Freefone 1800 403 403

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

www.facebook.com/irishmnd2011

@IMNDA

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:

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

A NOTE FROM OUR CEO

On behalf of the IMNDA, I would like to welcome you to the first Edition of the Connect Magazine for 2016.

We kicked off 2016 with our Sponsored Silence Campaign; this was our second year running the campaign. The aim of the campaign was to show people what it would be like if you could not communicate which unfortunately is a fate which many people with MND face. This year we saw many schools take up the challenge and I would like to extend my personal thanks to Padge Kelly and Esther Tracey who bravely fronted our Silence. Esther did a very powerful interview on RTE's Today Show with Maura and Daithí. In studio Esther spoke about the difficulties, with the aid of her iPad, that she faces living with MND on a daily basis. These real life stories are so important and valuable in raising awareness of the realities of living with MND and we couldn't do it without the support of our families. Thanks to this support from Padge and Esther over €25,000 was raised from the Silence!

As you are aware we welcomed our third MND nurse, Katie Kinsella to the team in May 2015. This position came about due to the Ice Bucket Challenge funds and our families are definitely seeing the benefits. In 2015 our three MND nurses carried out 554 home visits to people with MND across Ireland compared to 481 in 2014. The funding for this position comes to end in April 2017 and we are launching a Direct Marketing Campaign in the coming months to ensure the sustainability of the nursing service in the future.

Personally, 2016 is going be a very busy year for me as I am in the midst of planning the 27th International Symposium on ALS/MND which will take place in the Convention Centre from the 4th – 9th December 2016. The International Symposium is the largest medical and scientific conference on MND/ALS. It is the premier event in the MND research calendar, attracting over 800 delegates, representing the energy and dynamism of the global MND research community. There will be a lunch and Ask the Experts session hosted on the afternoon on the 5th of December and this will be specifically for people living with MND and their families. We will release registration details on the IMNDA website in the coming weeks.

As always we will be launching our National Awareness Drink Tea for MND campaign in June, we will also be launching a new radio advert. We are always amazed each year at the amount of Drink Tea events that happen throughout the country and we are so appreciative of the continued support and we hope this year will be no different.

And finally I would just like to thank everyone for their continued support; awareness of MND is at an all-time high and we thank each and every one of you for helping us to make that happen. Let's hope that we can continue doing that and fulfill our vision, a world free from MND. Together I believe that someday this may become a reality.

Aisling Farrell

Aisling Farrell
CEO

2016 CALENDAR OF EVENTS

MEMBERSHIP MAY

- Become a member of the Association for just €20 a year
- Buy your IMNDA Performance top from the office or online for just €10 in preparation for your summer run, cycle or walk!

AWARENESS JUNE

- *Drink Tea for MND* during June – tea packs available from the IMNDA
- Treat yourself to Afternoon Tea with the IMNDA: Details TBA
- MND National Awareness Day is 21st June; tell your story
- Monday 6th June@ 2pm: VHI Women's Mini Marathon
- Saturday 11th June: the Dunleer to Kilkenny D2K Cycle
- Saturday 25th June: The June Ball at the Double Tree Hilton, Dublin 4. A night of indulgence not to be missed!

D-FEET JULY

- Saturday 16th July: Walk to D-Feet MND in the beautiful grounds of Castletown House, Celbridge, Co Kildare OR organise a walk in your local area

ACTIVE AUGUST

- 20K, your way! Active 20 – cycle / run / walk / swim 20km in one go or do 5k a week. Contact us to find out some of our suggested routes.
- Getting married this month? Donate to the IMNDA in lieu of wedding favours!

SEMINAR SEPTEMBER

- IMNDA's AGM, Annual Conference and Patient & Carer Respite Weekend - Date & Location TBC
- Help your Employer to choose their 2017 Charity Partner and nominate the IMNDA!

ADVENTURE OCTOBER

- Saturday 8th October: Abseil off the roof of Croke Park's famous Hogan Stand, 100ft from top to bottom!
- Sunday 30th October: Run the Dublin City Marathon

DRINK TEA FOR MND!

IMNDA
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> *“I am 33 and soon I won’t be able to lift a cup of tea.*
>
> *Will you lift a cup of tea for me, and help support people with Motor Neurone Disease?*
>
> *This disease is going to rob me of the rest of my life. I will gradually lose the ability to walk, talk and even breathe”*

Andrew Brennan Living with MND

Support the Irish Motor Neurone Disease Association (IMNDA) this June and organise a Tea Party

Please contact the IMNDA for your free ‘Tea Pack’ sponsored by SuperValu

SuperValu

Join Andrew’s fight against Motor Neurone Disease

Text MND to 50300
to donate €2

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

www.imnda.ie

Some network providers charge VAT, meaning a minimum of €1.63 will go to IMNDA.
Service Provider LIKECHARITY 0766805278
Charity No. 8510

Grants for Making Adaptations to Your Home

As your condition progresses you may find it more difficult to get around your home or to get into the bath/shower. You may have to start planning changes to your house to make it more accessible. There are grants available through the Local Authority towards the cost of making these changes. There are two different grants and an overview of each is given below.

There is only a certain amount of funding available for these grants each year, so there is a limit on the number of grants that can be made in any particular year. However, if your grant application is received after this limit has been reached, the local authority will process the application the following year.

Housing Adaptation Grant for People with a Disability

The Housing Adaptation Grant is available from local authorities where changes need to be made to a home to make it suitable for a person with a physical, sensory or intellectual disability or a mental health difficulty.

This grant is means tested – your total household income is assessed to find out if you qualify for the grant and, if so, the amount payable. The maximum annual income threshold is currently €60,000. In addition, applications for the Housing Adaptation Grant are prioritised by the local authority on medical need.

The grant can help you make changes and adaptations to your home, for example, making it wheelchair accessible, extending it to add a ground-floor bathroom or bedroom.

An Occupational Therapist's (OT) assessment is required before a Housing Adaptation Grant can be approved. The local authority can arrange for an OT assessment, or you can hire an OT privately to carry out the assessment and recoup the cost of the private assessment up to €200 as part of the total grant. The grant will not be paid if you start work before the local authority gives written approval. However, it is expected that the work will start within 6 months of your grant approval.

The grant can be paid to people living in:

- Owner-occupied housing
- Houses being purchased from a local authority under the Tenant Purchase Scheme
- Private rented accommodation (the duration of your tenancy can affect grant approval)
- Accommodation provided under the voluntary housing Capital Assistance and Rental Subsidy schemes
- Accommodation occupied by persons living in communal residences

Means Test

Your total household income is assessed to find out if you qualify for the grant and, if so, the amount payable. Household income is:

- The property owner's (or tenant's) annual gross income, together with their spouse's or partner's annual gross income in the previous tax year
- The income of any other adults living in the household who are aged over 23 years if in full-time education or over 18 years if not in full-time education

The following is not taken into account when calculating household income:

- €5,000 for each member of the household up to age 18 years
- €5,000 for each member of the household aged between 18 and 23 years and in full –time education or on a SOLAS apprenticeship
- €5,000 for where the person with a disability (to whom the grant application relates) is being cared for by a relative on a full-time basis
- Child Benefit
- Family income Supplement
- Domiciliary Care Allowance

- Respite Care Grant
- Carer's Benefit and Carer's Allowance (if the carer's payment is made is respect of the person to whom the grant application relates)

Tax Information

When applying for the grant, you must provide:

- Your tax reference number (or PPS number if you are in receipt of social welfare payments)
- Details of your tax district
- A statement that, to the best of your knowledge, your tax affairs are in order

If the value of your grant application adds up to €10,000 or more, you must make a valid Tax Clearance Certificate available to the local authority. You must also provide evidence that the Local Property Tax on the house has been paid. For payments over €650 you must provide the local authority with the following details in respect of each contractor:

- Name, address, tax reference number and tax district
- C2/tax clearance number and
- Expiry date of the C2/Tax Clearance Certificate

For all grant payments totalling €10,000 and over, contractors must either produce a valid C2/Tax Clearance Certificate or authorise the local authority to confirm their tax clearance status electronically.

Amount of Grant

Under the Housing Adaptation Grant Scheme for People with a Disability, if your household income is less than €30,000, you may qualify for 95% of the cost of the works (up to the maximum grant amount of €30,000). The proportion of the costs to be grant aided tapers from 95% to 30% depending on your income. If your income is between €50,000 and €60,000, the maximum grant available is €9,000.

If your house is less than 12 months old, the grant will generally not exceed €14,500.

You may also be able to claim under the scheme of VAT refunds on aids and appliances for people with disabilities, which can also apply to adaptation and installation work being carried out to make a home more accessible. To apply for the VAT refund, you need to fill in claim form VAT 61A, which is available on the Revenue website: www.revenue.ie

You should contact the Housing Department of your Local Authority for details on how to apply for the Housing Adaptation Grant for People with a Disability.

Mobility Aids Grant Scheme

The Mobility Aids Grant Scheme provides grants for works designed to address mobility problems in the home, such as the purchase and installation of grab rails, a level access shower or access ramps.

The grant is available to people with a maximum household income of less than €30,000. Applications for the scheme are prioritised on medical need. The highest priority is given to a person where alterations or adaptations to the home would facilitate discharge from hospital or the continuance of care in their own home. The maximum grant available is €6,000.

The grant can be paid to people living in:

- Owner-occupied housing
- Houses being purchased from a local authority under the Tenant Purchase Scheme
- Private rented accommodation (the duration of your tenancy can affect grant approval)
- Accommodation provided under the voluntary housing Capital Assistance and Rental Subsidy schemes
- Accommodation occupied by persons living in communal residences

When the local authority receives your application, it may request for an OT assessment. The local authority can arrange for the assessment, but you can employ an OT to carry out an assessment and recoup the cost of the private assessment up to €200 as part of the total grant. The grant will not be paid if you start work before the local authority gives written approval. However, it is expected that the work will start within 6 months of your grant approval.

Means Test

Your total household income is assessed to find out if you qualify for the grant and, if so, the amount payable. Household income is:

- The property owner's (or tenant's) annual gross income, together with their spouse's or partner's annual gross income in the previous tax year
- The income of any other adults living in the household who are aged over 23 years if in full-time education or over 18 years if not in full-time education

The following is not taken into account when calculating household income:

- €5,000 for each member of the household up to age 18 years
- €5,000 for each member of the household aged between 18 and 23 years and in full –time education or on a SOLAS apprenticeship
- €5,000 for where the person with a disability (to whom the grant application relates) is being cared for by a relative on a full-time basis
- Child Benefit
- Family income Supplement
- Domiciliary Care Allowance
- Respite Care Grant
- Carer's Benefit and Carer's Allowance (if the carer's payment is made is respect of the person to whom the grant application relates)

Tax Information

When applying for the grant, you must provide:

- Your tax reference number (or PPS number if you are in receipt of social welfare payments)
- Details of your tax district
- A statement that, to the best of your knowledge, your tax affairs are in order

Amount of Grant

The maximum grant available under the scheme is €6,000. This can cover up to 100% of the cost of the works completed.

You should contact the Housing Department of your local authority for more details on how to apply for a Mobility Aids Housing Grant under this scheme.

26th international symposium on ALS/MND Orlando 11-13 December 2015

With much anticipation I crossed the Atlantic and took the connecting flight from JFK to Orlando for my first international symposium on ALS/MND. I arrived on a Wednesday evening, tired but excited about the four days that lay ahead. I was not disappointed as what followed was four days packed with discussion, research and problem sharing, all evidence based. The symposium gave great insight into best practice in neurology centres throughout the world and provided a forum for open discussion and questions. It also allowed access to the leading clinicians and specialists in the field of ALS/MND. Current and emerging research was presented and discussed.

Thursday 10th December Allied Professionals Forum

Day one started for me with attending the Allied Professional Forum, a day of presentations from members of the multi-disciplinary team such as Physiotherapists, Clinical Nurse Specialists, Social Workers, Occupational Therapists and Speech and Language Therapists. Each presenting data from their own practice and centres.

A topic which generated much discussion was "*Communicating with PALS/MND that have Dementia*" by Tammy Soukup USA. This is an area of the disease that health care professionals are shedding more light on which is beneficial as it is leading to advancements in better coping strategies for both carers and professionals. I found the framework that they out lined for communicating with people with dementia very helpful.

Leading on from Tammy's presentation we were brought through "*Transitioning a research tool into clinical practice: Use of the Edinburgh cognitive and behavioural ALS/MND screen in ALS/MND clinic*" by Judy Lyter USA. This was useful as we as nurses would be familiar with this concept as it is a tool that is used in Professor Hardiman's clinic in Beaumont.

The presentation on "*Parental disclosure of familial ALS diagnosis and mutation status to children: Perceptions of young-adult offspring*" by Samantha Neumann USA facilitated a discussion into a controversial and complicated element of some client's disease course and journey. It is often during these difficult lectures, that us as medical professional's learn the most, knowing that others in our fields are also experiencing difficulties and seeing how they are managing.

Laurie Fieldman from the USA facilitated a fascinating discussion on PDA (Personal Death Awareness). She was very persuasive and gave the whole room 'pause to thought' on our own mortality and views on death.

Following this was Jennifer Armstrong and her topic '*What ALS health professionals need to know about today's respiratory therapies?* Jennifer gave a valuable understanding and explanation into the respiratory assistance available currently. This proved reassuring as it demonstrated that the therapies available in the USA are of an equivalent standard in Ireland.

This examination of current respiratory therapies by Jennifer was definitely the outstanding highlight for me from the Allied Professional Forum as I found the practical application to my work most relevant. I also found Tammy Soukups discussions on communicating with PLS/MND with dementia very informative and it gave a useful insight into coping with a difficult and distressing symptom of the disease.

Friday 11th December

Friday started with a discussion on how health departments and governments cope with neurological disease internationally. Addressing the audience on *The Burden of Neurodegenerative Disease: A Global Challenge* was Dr Raad Shakir from the UK.

The symposium programme was split into two lectures halls, I have discussed my highlights below but the full programme is available at:

www.mndassociation.org/research/international-symposium/programme

I most enjoyed Session 3B on Holistic Care as I found it dealt with a sensitive area of the disease and enabled us to see how fellow health care professionals deal with delivering diagnosis, prognosis and balancing these with realism and hope. This session also investigated the factors that most cause burden to carers of ALS/MND. Session 2B focused on Clinical Management; Professors Orla Hardmian discussed her findings that attendance at a specialist MND clinic and access to the Multi-disciplinary team will improve outcomes for the person with ALS/MND. The management of excessive salvia was discussed by two clinicians from USA.

Saturday 12 December 2015

An interesting and educational session on Saturday was the Genetic Counselling Session that included the presentation by Professor Chris Shaw from London on his experience and protocol for Genetic Counselling for those at risk of familial ALS/MND. Dr. Ger Foley from TCD Dublin also demonstrated that patients too feel the burden of family decision making in the ALS/MND journey. Saturday also included a session on Respiratory Support. These presentations provided us with understanding into how other countries and clinics deal with respiratory support, assisted ventilation, mechanical ventilation, by taking us through the protocols used to initiate and withdraw these services as appropriate.

Sunday 13 December 2015

Highlight of the closing day for me was the on Session Clinical Trials, including the presentation of the Phase 2 trial on Edaravone from Japan which is very topical here in Ireland currently. The Edaravone trial in oral formula is expected to be roled out in Europe in 2016 and is eagerly anticipated. Phase 2 studies indicated a decrease in disease progression in a specific group of ALS patients early in their disease course. The session on Cognitive Change was a valuable forum for discussion and knowledge sharing into an emerging and poorly understood facet of the disease.

Irelands strong Voice at 26th International Symposium on ALS/MND

Ireland was well represented at the symposium with several presentations and six posters from Professor Orla Hardiman's group and Dr. Ger Foley TCD.

Being surrounded by scientists, neurologists, and people with ALS it was exciting to hear about clinical progress to treat motor neuron disease. Attendees pondered the preliminary, but positive, results of gene therapy trials in spinal muscular atrophy—may open the door for similar gene therapy in ALS. We heard news of completed and ongoing trials of edaravone, a drug that may slow ALS in certain people, and about therapeutics that relieve distressing problems with speech and swallowing. Basic science also made a showing. A better understanding of how pathogenic proteins travel from cell to cell emerged and researchers debuted new genetic variants to explain some inherited ALS risk. To find out more on this at:

www.alzforum.org/news/conference-coverage/26th-international-symposium-alsmotor-neurone-disease

This brought to a close a busy but fascinating symposium. The symposium reiterated to me the importance of an international drive and global commitment to better understand the ALS/MND disease process and the importance of a collective focus on minimizing symptom impact and maximizing quality of life with ALS/MND. The main goal of our MND community is that one day we will hopefully see a world free of MND.

Katie Kinsella, MND Nurse

27th Annual International Symposium for ALS/MND is coming to Dublin!

The International Alliance holds the **Annual Alliance Meeting** to provide a forum for member associations to meet and share advances in supporting people living with ALS/MND. It is an excellent opportunity for representatives of ALS/MND associations to discuss organisational development and planning, patient care, and funding, as well as the role and activities of the International Alliance and its Board of Directors. This year the 27th International Symposium on ALS/MND will be held in the Dublin Convention Centre, from 7th – 9th December 2016.

As an addendum to the Alliance Meeting, the IMNDA as the host association are organising a free, open **Ask The Experts** event, which allows local people living with ALS/MND and their carers attend an afternoon of presentations by ALS/MND experts and then participate in a question and answer session. Ask The Experts takes places on the afternoon of the second day of the Alliance Meeting.

- **Allied Health Professionals Forum**

The International Alliance also holds the annual **Allied Health Professionals Forum**. The **APF** functions as an educational and training forum for healthcare professionals who work with ALS/MND. This forum offers health care providers from around the world an opportunity to share ideas on good practice in the daily management of people with ALS/MND. Every year, this meeting is generously supported by **The ALS Hope Foundation**.

- **International Symposium on ALS/MND**

Both the Annual Alliance Meeting and the APF coincide with the **International Symposium on ALS/MND**, an annual event organised by our colleagues at the **MND Association of England, Wales and Northern Ireland**. The Symposium is the single largest medical and scientific conference on ALS/MND.

For more information, visit www.mndassociation.org/symposium.

The 2016 Alliance Meeting, Allied Health Professionals Forum and Symposium will be held at the Convention Centre in Dublin, Ireland. This year's meetings are hosted by the Irish Motor Neurone Disease Association (IMNDA). It will take part in the Convention Centre Dublin on Spencer Dock, North Wall Quay, Dublin 1.

For a full list of suitable hotels for the symposium please see the MND Association's website: www.mndassociation.org/research/international-symposium/hotel-information/

Please note that hotel rooms are available on a first come, first served basis. Book early to guarantee your spot!

- **24th Annual Alliance Meeting**

Registration for the 2016 Meeting will open soon. The **Annual Meeting of the International Alliance of ALS/MND Associations** brings together ALS/MND associations from around the world to share initiatives and develop strategies for fighting ALS/MND and serving people who live with the disease. Attendance is encouraged for all Alliance members, and people living with ALS/MND are welcomed as participants or observers.

The **Ask The Experts** session will be organised by the IMNDA, and information can be found here or on our website www.imnda.ie as soon as the experts are confirmed.

The Alliance Meeting immediately precedes the 14th Allied Health Professionals Forum and the 27th International Symposium on ALS/MND. The Alliance Meeting schedule is as follows:

- 3 December 2016 – Alliance Board of Directors Meeting (Board of Directors only)
- 4 December 2016 – Annual General Meeting – for Alliance members only
- 4-5 December 2016 – Annual Alliance Meeting – for Alliance members only
- 5 December 2016 (afternoon) – Ask The Experts – for the general public

- **14th Annual Allied Health Professionals Forum (APF) 6th Dec**

Registration for the 2016 APF will open in June. The Allied Health Professionals Forum is focused on practice and experience for health professionals in the care and support of people living with ALS/MND. During the APF, health professionals from around the globe come together to share their practical knowledge and experiences, with a mission to improve the quality of care for people living with ALS/MND worldwide.

- **27th Annual International Symposium on ALS/MND 7th–9th Dec**

The 27th Annual International Symposium on ALS/MND is organised by the MND Association of England, Wales and Northern Ireland in cooperation with the International Alliance of ALS/MND Associations.

The International Symposium on ALS/MND is a unique annual event which brings together leading international researchers as well as health and social care professionals to present and debate key innovations in their respective fields.

The Symposium is planned as two parallel meetings, one on biomedical science and the other on research and advances in the care and management of people affected by ALS/MND. Joint sessions consider issues of mutual concern, challenging current views and practice.

For information about the Symposium, or to learn about submitting an abstract, visit the Motor Neurone Disease Association's website: www.mndassociation.org/research/International+Symposium/

Burden of Care by Dr Geraldine Foley

The ice-bucket challenge in 2014 brought the daily adversities encountered by people with MND and their family caregivers, to worldwide attention. Research had already shown that family caregivers of people with MND experience physical and emotional strain in their care-giving role.

New insights on carer burden in MND have been reported in a study undertaken by Assistant Professor of Occupational Therapy, Dr Geraldine Foley, of Trinity College Dublin. Funded by the Health Research Board of Ireland (HRB) and conducted in collaboration with Professor Orla Hardiman (Academic Unit of Neurology TCD & Beaumont Hospital Dublin), Dr Foley's study identified that the caring process between MND patients and their family caregivers is reciprocal, leading in some cases to the patient experiencing carer burden. In-depth interviews with 34 people with MND explored their experiences of receiving care from family and from healthcare providers. The study revealed that people with MND provide strong emotional support to their family even when they are resigned to become dependent on their family. Dr Foley identified that MND patients shared a strong sense of obligation towards their family and made decisions about care in accordance with best interests of family.

A primary aim of the study had been to identify from the patient perspective, key factors that shape how people with MND engage with health and social care services. The study found that participants' concerns about their family's wellbeing, impacted greatly on how they made decisions about care. Participants were keen to alleviate family distress and invariably accepted and/or declined services at the request of their family even when they differed from family caregivers in their preferences for care. Dr Foley identified that participants themselves were very much attuned to the losses and limitations encountered by their family caregivers. Participants agreed to family caregivers' preferences for symptomatic, supportive and even life-sustaining interventions in order to help their family caregivers adjust to loss. Notwithstanding participants' accounts of the practical and emotional support provided to them by their family, the study revealed that participants were also rendering support to their family. Indeed, in some cases, participants had been primary providers of emotional support to family.

The study found that MND patients' anxieties about end-of-life care can be heightened by their concerns about the impact of end-of-life care on their families. Participants shared openly their fears about the future with MND and many spoke about how they envisaged end-of-life-care. Anxieties about the future with MND and about the impact of end-of-life care on family were most evident among participants who were parents of young and adolescent children. Indeed, those who were parents of young and adult children struggled between their perceived need to "be there" for their dependents and their desire to alleviate distress encountered by their dependents. Most participants struggled with the notion of becoming a burden on their family. Speaking about the significance of this research, Dr Geraldine Foley states that "the term 'carer burden' in MND, and in other illnesses, has traditionally focused on the experiences of family carers rather than the experiences of people who have become dependent on their family. The physical limitations arising from MND means that in most cases, it's not possible for MND patients to provide physical care to family. Nonetheless, people with MND continue to provide substantial emotional support to their family."

In conclusion, although burden of care for families of MND patients is high, the obligation that MND patients feel towards family means that MND patients themselves maintain a care-giving role within their family. Healthcare professionals have a key role in supporting MND patients to negotiate family obligation in the decision-making processes of care.

Behavioural Changes in MND: What Families Need to Know

The Irish Motor Neurone Disease Research Group at Beaumont Hospital and Trinity College is developing an educational programme for families of people with MND and health care professionals working with them.

The purpose is to help those affected by MND to recognize the thinking, behaviour and personality changes that can occur as part of the condition, to identify how best to understand these, to help those affected by these changes to manage problems that might arise, and to take care of their own health and wellbeing.

It is now recognized that up to 30% of people with MND experience changes in thinking and behaviour and some people may also experience a dementia-like syndrome.

Research by the Irish Motor Neurone Disease Research Group at Beaumont and Trinity College Dublin has shown that these changes can increase the burden of care for families. There is a lot of evidence to suggest that this burden may be under-reported by families and under-recognized by healthcare professionals.

Over the coming months, the Trinity /Beaumont research team will develop an educational programme for families of those with MND and seminars for Healthcare Professionals around the cognitive, behavioural and personality changes that can occur in MND, how to recognize and better manage them. By doing this, they hope to help families and health care professionals recognize the increased burden associated with thinking and personality changes.

This will be achieved by hosting a series of "town meetings" for families of people with MND.

During the meeting the Research Team will give some examples drawn from real life of the types of thinking and behavioural changes that can happen with MND, and will provide information on how to better manage them.

The team will then provide an opportunity for families to share information about their own experiences and any other comments they may have regarding cognitive and behaviour changes.

The information provided during these sessions will form the basis of a question and answer booklet that will be available online through the IMNDA website.

Dates and Locations of the Family Meetings are as follows:

Meeting 1 Dublin

Date: Saturday 16th April

Time: 1pm – 4pm

Location: Radisson Blu Hotel Dublin Airport

Meeting 2 Athlone

Date: Saturday 30th April

Time: 1pm – 4pm

Location: Hodson Bay Hotel

Meeting 3 Cork

Date: Saturday 18th June

Time: 1pm – 4pm

Location: Clayton Hotel Silver Springs

Please register if you would like to attend one of these events. To register or for further information see www.mnd.ie and www.imnda.ie or phone 089 470 8675

MND Research Update

Mr. Tom Burke, who is researching aspects of thinking and behaviour in Motor Neurone Disease under the supervision of Professor Niall Pender and Professor Orla Hardiman, recently presented an aspect of his work to the Psychological Society of Ireland, which investigated visual and verbal short-term memory processes in motor neurone disease. In recognition of his work, Tom was presented with the Deirdre McMackin Memorial Medal for Excellence in the Field of Neuropsychological Research, alongside an honorarium.

Dr Bahman Nasseroleslami works with the EEG (electroencephalography) research team in the Trinity MND group, researching the use of measurements of brain activity to allow early and accurate diagnosis of MND. Dr Nasseroleslami was awarded an Irish Research Council Postdoctoral Research Fellowship (€91,790) to study a new potential diagnosis for MND. The new study uses both EEG and EMG (which measure the activity of the brain and muscles) to study their impaired communication in MND.

Dr Russell McLaughlin's research focuses on the genetic contributions to motor neurone disease. He is working to answer the question of what rare inherited mutations may cause MND, which is critical information for the development of effective treatments. Dr McLaughlin was recently awarded an MND Association Junior Non-clinical Fellowship (€380,000) to further develop his ideas in the genetics of MND. This has placed the Irish MND Research Group in a very strong position to make meaningful progress in understanding the underlying causes of the disease and to build towards better diagnosis, management and treatments.

project MinE
Make it yours

Professor Orla Hardiman and long-time collaborator Professor Dan Bradley in the Smurfit Institute of Genetics were also awarded €820,000 from Science Foundation Ireland's Strategic Partnership Programme to conduct fine-grained genetic analysis of the Irish MND population. These funds will go towards whole-genome sequencing as part of a larger international initiative called Project MinE, which is the largest genetic analysis project in the history of MND research. The results from this project will help us to better understand the underlying causes of MND, which is vital for the development of effective treatments. For further information on this project go to projectmine.com and select the Ireland page.

Professor Orla Hardiman, Dr. Niall Pender, Principal Clinical Neuropsychologist at Beaumont Hospital, and Ms. Marta Pinto-Grau, PhD candidate, have recently been awarded a three year 'PhD Studentship' from the MND Association in the UK in order to investigate the prevalence, nature and progression of language changes in Motor Neurone Disease, as well as its relationship with changes in other cognitive, behavioural and social cognitive processes.

LIVING WITH MND

deterMND

> *Anto Finnegan is the former member of the Antrim Gaelic football team. He played for the Saffrons for eleven years and was captain on two occasions during this time.*

In 2012 at the age of 39 I was diagnosed with Motor Neurone Disease. It was a huge shock to me at the time, and even now 3.5 years on it is still hard to believe.

Before being diagnosed I knew very little about the condition, so when I was told I had MND I don't think my wife and I fully comprehended how it would impact on us as a young family. To discover there was no cure at this time was difficult to accept.

When we started sharing the diagnosis with friends and family, it became evident that the people we spoke to knew very little or nothing about the condition. After a couple of months Alison and I decided that we would try to do something positive on the back of this negative in our lives.

We established the deterMND trust with two simple objectives:

1. **Raise awareness of MND**
2. **Raise funds for research into finding a cure**

Since establishing the deterMND trust in 2013 we have raised around £150,000. The money was raised through numerous events, from a Valentines ball, organised by friends to community quizzes and everything in between. Our biggest event to date was the 'Game for Anto' in November 2014 when Dublin GAA footballers took on an Ulster All-Star select in a challenge game at Kingspan stadium in Belfast, the home of Ulster rugby. There were almost 7000 spectators and all the Northern Ireland political parties were represented at the game. The match was also shown live on Setanta TV.

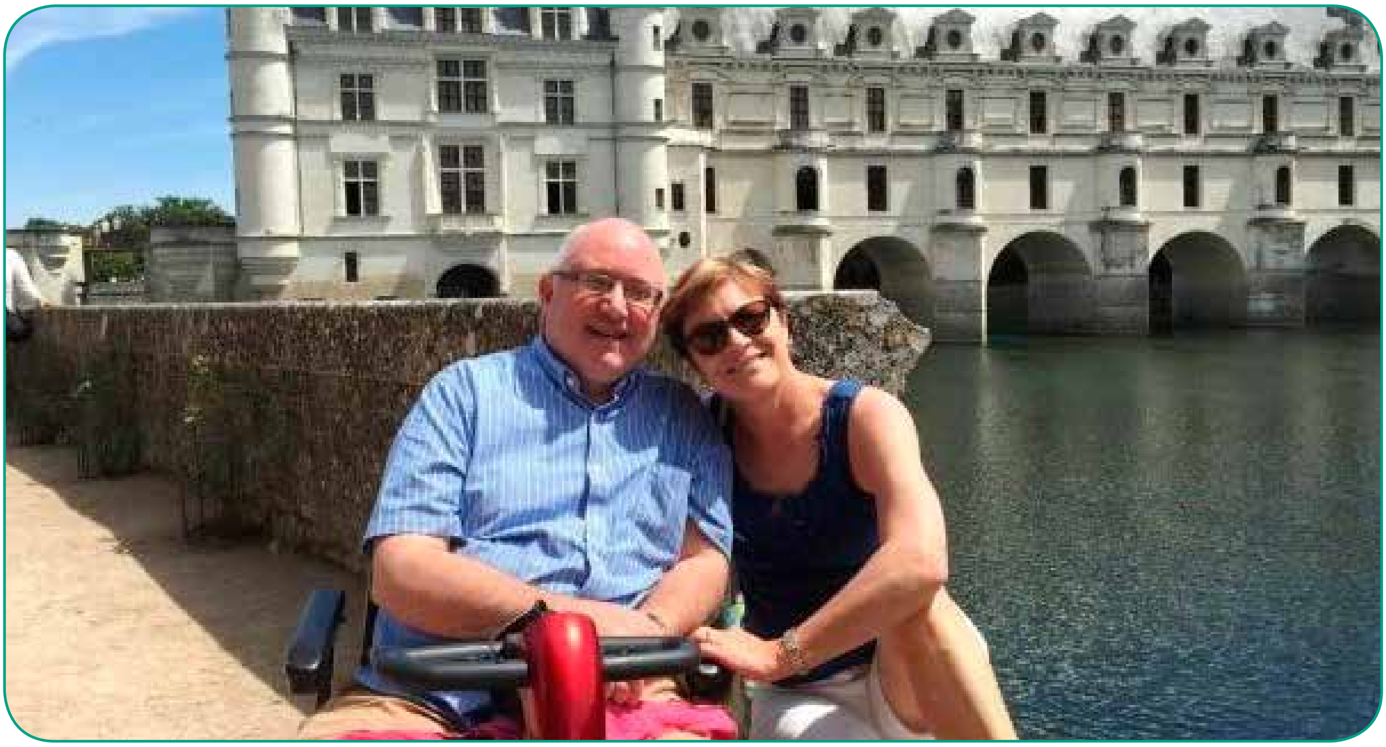
In May 2014 we made a donation to Project MinE in Dublin, a project that is sequencing the DNA of thousands of MND patients across the world in order to try and identify causes of MND. It is hoped that this work will lead to eventual treatments. We are in the process of identifying other research work that fits within the trust objectives, that we can make a donation to in 2016.

We continue to raise awareness and research funds in order to continue the fight against MND. In March 2016 we have teamed up with Aisling events for the Belfast Spar Craic 10K which takes place on St Patrick's Day. More information on deterMND can be found at www.deterMND.com.

To find out more about us we are also on Twitter @deterMND and facebook www.facebook.com/deterMND

Motoring to the Med – with MND

A special French beach station with hoists, sea-going wheelchairs and helpers transforms the holiday.



Kevin Dawson with his wife, Brianóg, on holiday in the Loire Valley, France.

> “At the foot of an aircraft in Carcassonne in July 2014, awaiting the special chair that would pull me up the steps, I said goodbye to France.”

My wife, Brianóg, and I had made many trips since the mid-1980s and three more since my diagnosis with Motor Neuron disease (MND) in summer 2011. Now, while my illness was slow, I could barely walk or stand, even with crutches. By another summer I would be weaker still. A progressive illness schools you in the act of letting go. So, not *à bientôt* then. Goodbye.

Dwelling on the loss of summer holidays amid illness may seem a frivolity. It isn't. Staying sane and steady puts a premium on precious moments, on both planting positives on the path ahead and enjoying them to the full as they come.

The travel door seemed closed for good in 2014. Yet in the spring of 2015 we decided to give it one more go. I still felt able – just about.

It required a lot more logistical planning, and no flying. We would need our own vehicle: a VW Caddy with multiple adaptations including rear-ramp entry and hand controls. The car can be driven from the driver's seat or from a powered wheelchair, steered up the ramp and locked in the driver's place. I use a mechanised driver seat which brings me back into the centre of the car and then turns. Then I slide onto my small scooter – a nimble little thing that gives great range and freedom.

July came. We hadn't taken the ferry in nearly 20 years, since the kids were small but Rosslare to Cherbourg proves a good experience for us. Irish Ferries' staff had been ultra-helpful on pre-travel inquiries and are great on board when it comes to parking and lift access. Restaurants are accessible, as is the outside deck via a portable ramp. The accessible cabin also works, though handgrips around the fold-down bed would be an asset.

Suitable hotels

We could reach Provence in one overnight but opt for a gentler meander. Finding suitable hotels was hard work. In a country as organised as France, one might expect a core website detailing every properly-equipped hotel. It was a lengthier trawl.

TripAdvisor proved helpful with searches filtered for reduced mobility room, not just wheelchair access. Even then, it's wise to contact hotels to ask more specific questions: turning room, height of bed or toilet seat – both crucial if transferring from a scooter seat with no leg power. On-site parking is important.

At Honfleur in Normandy there are several good options. We settled on L'Absinthe close to the quay; old French charm with good modern mobility features. Then two nights in the Loire. There are modern hotels like the Ibis Comfort in Tours, but we went for old charm again at Biencourt in Azay-le-Rideau. It's our most elegant mobility-adapted hotel room.

Then came two longer drives, first southeast to Lyon and the basic but pleasant Hotel Lyon-Sud near the A7, facing south.

The final stage south is a crawl through French holiday traffic, with some nervous anticipation. Even more than the hotel search, trying to find a well-adapted house in a nice setting is a needle-in-haystack job. We tried filtered searches on the main accommodation sites, direct conversations with a few specialists, and plain old Google searches using keywords for features I need.

We found an English couple, with a pretty-looking mobility-adapted bungalow in the village of Lorgues, inland from the coast at Fréjus. There's a pool, though without a ramp or hoist. However, I've invested in a special buoyant pool wheelchair, convinced that this may allow me to take cooling dips.

Mixed results

On arrival, the picture is mixed. House and garden are lovely. There are two fig trees laden with fruit. However, several of the owners' own mobility fittings don't quite suit me. Worse, it quickly becomes clear that the buoyant (and costly) pool wheelchair will not work safely for us. It's 38 degrees and I can only stare at the blue water. After all the planning, careful choices and long drives, our Provençal stay looks like being hot, sticky and frustrating.

Then the picture changes. A visit to the mobility store in nearby Draguignan, where I've rented a powered wheelchair to augment the scooter, produces a few simple pieces of kit that solve the in-house problems. France is dotted with such stores and the range for hire or sale is extensive. But there's also information of a beach facility nearby and it transforms our holiday.

And so, 50 minutes away at Fréjus, we encounter the *Handi-Plage*. It is a special beach station with hoists, big buoyant seagoing wheelchairs, a ramp across the sand, and a small team of trained lifeguards whose mission is to get you safely in and out of the water, whatever your condition.

They have me in the Mediterranean within minutes. It's my first time in the sea in three years and is an immensely liberating experience. There's a freshwater shower and iced drinks. It's all free, and is replicated at numerous resorts all round the coast. So French and so wonderful.

The *Handi-Plage* unlocks our holiday. We are in the sea every second day, lunching afterward in Fréjus port or back at base. With all this flows the sense of deeper reward: of having given it a go. What a wonderful thing it is to have done the research and attempted the journey, and now to be able to look up from our Kindles in the morning shade and say: "*Will we head into Nice for lunch?*"

This year? Like last year, it's another country. But where there's a will and a little time and (above all) a supportive and able partner, there can still be a way. Goodbye, la belle France? Maybe – just maybe – it's *à bientôt*.

The Irish Motor Neurone Disease Association:
www.imnda.ie

A map of the French beaches with facilities described is available at: www.handiplage.fr/spip.php?rubrique1

I found my tribe at the cove in Greystones

> “My house is full of strangers because my husband has motor neuron disease, but my secret all-year swim club saves me,”
> Ruth Fitzmaurice

*This article was written by Ruth and was first published in The Irish Times on Monday 4th of January.

Three-year-old Sadie says that Dadda talks with his eyes. An eye-gaze computer sounds less romantic. “I’ll ask his eyes,” she says when she wants something. “He loves me!” she exclaims like a surprise present. Love like a present is the gift we share from him. I hold it fiercely. His magnificent heart.

My husband is a wonder to me but he is hard to find. I search for him in our home. He breathes through a pipe in his throat. He feels everything but cannot move a muscle. I lie on his chest counting mechanical breaths. I hold his hand but he doesn’t hold back. His darting eyes are the only windows left. I won’t stop searching. My soul demands it and so does his. Simon has motor neuron disease, but that’s not the dilemma, at least not today. Be brave.

I am sitting in my car in Wicklow town, looking out on the harbour. I’m watching these yacht masts dancing. Their heads are swaying to and fro, warbling with Joni Mitchell on the radio.

Wicklow harbour is nice. It’s vast and full of blue. It has a higher, wider reach than the Greystones view. I can’t breathe in Greystones right now, so this is good. Maybe Greystones is like all great loves. You either marvel at every familiar dancing step and soak it into your bones or, like today, the familiar edges trip you up and annoy the shit out of you. Too claustrophobic, a rat in a cage, a lift with no panic button.

Here’s the dilemma. My house is full of strangers. I have painted it bright colours and surrounded it with love, but strangers step through it at an alarming rate. Well- meaning Muhammads make tea. So many Helens and Marys and Jackies and Michaels and Deirdres and Claires and Sams and Franks and Graces smile and leave mops in weird places. I sidestep them in the hall and at the dishwasher. Our house is filled with nurses and carers and they are hurting me. It’s not their fault.

Some stay a while, but most are passing through. Some stay a while. I grow to love them and then they break my heart and leave anyway. It’s nobody’s fault. This is agency work. Some wear overbearing perfume. It attacks olfactory emotions I didn’t even know I had. I feel irrational hatred towards them because they make my house smell like *them*. Most of them smoke but I don’t mind the smell of that. At least it’s a universal smell, like fire or Fairy Liquid or Persil Automatic or petrol. A lot of them try and turn our home into a hospital, and I fight like a tiger against that and bare pointy teeth.

They all leave eventually, except for Marian. Marian believes in angels and blood moons. She lives purely through her emotions, and a good day always starts with this night nurse and a sleepy, chatty cup of tea. I wish I believed in angels. We drink tea together on dark mornings. Marian believes everything happens for a reason and that people have colours and swirly energies around them, positive or negative.

If you hang out with her for long enough, you could be laughing or crying or both and you can almost see a pencil outline on the walls of angel wings in the shadows. She is, of course, my angel. “I’m not going anywhere,” she said to me once. “I’m here for you.” I look into her eyes and I believe her.

There was a blood moon last night and the sea is agitated. My soul is agitated. A blood moon. We are 90 per cent water, Marian says, and that is why the moon and the tides affect us. That is why I jump in the sea, I say. I am trying to find a home, make a home, be a home for my five children. Sometimes I succeed and sometimes I fail.

Some people understand that the small things make a difference. A nice pen to write with that slides perfectly on the page. Hot coffee in a particular cup. These things matter when your soul is on the edge. It fills you full of holes, this life.

This is my cove

I have to tell you a secret. This is *my* cove. No really, it's actually mine. So says an old lady who rolls up on a flowery purple push-bike one day. We are standing in swimming hats, my friend and I. Two ladies at Ladies' Cove, the steps that lead into the sea at Greystones, Co Wicklow. We are standing, turning slightly blue on a sunny April day. The air is warm but those in the secret all-year swim club know that the sun is deceptive. The sea is bloody freezing this time of year. Colder than Christmas.

We are trying to be brave. It's my cove, says the old lady, and hitches a foot to the ground, leaning her purple bike into a chat. We don't want to chat, we want to dive, but she isn't going anywhere. She is lonely and wants to talk to us and that's that. I aspire to be this old lady some day. I would feel lucky to grow old like her, on her purple, flowery bike, wind in her hair, stopping to chat when she feels like it and when she needs it. Some old ladies are great like that. I aspire to be her, because obviously, it's not her cove at all. It's mine.

I collect stones on the beach of my precious cove. My favourite stones are the grey ones full of holes. The sea made these holes, but each one is different and beautiful. I rattle them home in my pocket and arrange them on windowsills.

My swimming friend has a cousin who is one of those calm people who are healing to be around. A drink of tea with her in summer garden sunshine brings me the revelation that I am not a calm person. I yearn for her serenity. We were talking about a first-world problem, maybe a universal problem: the dilemma of where to live.

We have love in the nucleus of our family, but where do you put roots down with that love? An affordable bigger house in the countryside, or a commutable distant town? Or stay where you know people, in a smaller house bursting at the seams? My friend's calm cousin cuts through the bullshit. "Find your tribe," she says. Finding your people is more important than what kind of house you live in. Decide whether you've found your tribe and go from there. I believe her.

Find your tribe, she said, but maybe the cove is my tribe and the cove is mine. My babies stand with soggy shoes and noses on the shore, skidding on wet stones and cheer as their Momma plunges to her salvation. Yes, this is my cove and the sea is my salvation. It shocks my body back to life, as rain darts on the sea surface on a misty, romantic day.

On other days I need to weep. When your body breaks down in a parked car, it is embarrassing. A man walked by on the footpath at the precise moment my face crumbled, and I turned away sharply. Oh, the shame. The horror that someone should witness this pain in the safe routine of the school run.

On this day I can't escape the feeling of being robbed in a ransacked house full of strangers. I cry for all the things we have lost, my husband and I, for the pain of lost things in a ransacked house. I thought of stepping out of the car in the rain. Step out and walk in the rain to the sea, to the steps down to the cove. To just step into the waters and struggle in my winter jacket and not come back up.

I could never do that because of the five snoring beauties in my public space of a house. My five beautiful children. The sweep of Sadie's curls are the closest I've come to a God.

They're just American

Some people took over our cove one day, a group of tourists who announced they were jumping in with their clothes on. I stared at this lady in horror with her big winter coat and remembered I had thought of jumping in myself not so long ago. But this was no tragic, stones-in-her- pockets, Emily Dickinson endeavour. They were whooping and laughing.

"Are they drunk?" I muttered to my swimming friend.

"No, I think they're just American," she said honestly, and we both got a fit of the giggles. They had rolled up from the YMCA. A religious cleansing? I just kept eyeing the American woman's puffy winter jacket and imagined her swirling under with the seaweed. They marched in from the shore, arms raised in triumph, and emerged John the Baptist-style.

But on another day I stood at the edge of the sea and wept. My feet were submerged on the bottom step and I wiggled my red toenails and sobbed. My sea-swimming friend was there to hug me. Today the sea was choppier but my soul was calmer and refreshed and content when I climbed back up the steps. We are 90 per cent water, says Marian, and my emotions are as mysterious to me as the swell of the sea. All I know is that I could never leave this place. The cove is my tribe and the sea saves me.

We have lost many things. But sometimes I find my husband: lips on the curve of his temple, a crawl space in the crook of his arm. Some things are lost and found again. I email him words of love, and he emails back. A mad moon tidal wave. Screen to screen, we're holding hands at last. Two souls. It's a marvellous, familiar dance. Great loves are for the brave.

Speech Impairment in MND

The prospect of losing one's ability to speak is a terrifying one. We not only want to make our basic needs known but also share information with others and express our opinions and feelings. While not everyone with MND will experience these difficulties, when muscles in the mouth and throat weaken, our ability to communicate is changed. Living with this change becomes a major challenge. But communication is so much more than just speech. How many times has a change in someone's facial expression said more than many words could ever have? How much information is exchanged each day by writing, texting and emailing? While there aren't any exercises that will work to strengthen the muscles or reduce the speech impairment, we can maximise the person's ability to communicate in other ways.

Changes to Speech

- Weakness in the tongue and lips can make pronunciation less precise making speech sound slurred
- Weakness in the palate can mean too much air escaping through the nose during speech making the words sound 'nasal'. Sounds that need lots of air pressure are particularly difficult to produce clearly (e.g 'b' can sound like 'm') making words more difficult to understand
- Changes to the vocal cords result in changes to the sound of the voice. The voice may become hoarse, breathy or even strained with changes in pitch.
- There might be changes to breathing which is the support system for speaking. The voice may be quieter or the speaker may run out of breath more quickly, making longer conversations or even longer sentences more difficult

USING Changed Speech

It is important that the person with speech difficulties is given the opportunity to use his/her speech. With some extra effort from both the listener & speaker it is possible to get the message across using speech.

FOR THE SPEAKER	**FOR THE LISTENER**
Exaggerate speech sounds, particularly those sounds at the beginning and end of each word. Break up words with multiple syllables. This makes it easier to distinguish one word from the next. Take extra breaks during sentences. This will help slow down the rate of speech making it easier to understand. It's very helpful to introduce the topic first as predictable messages are more easily understood than unpredictable ones. Ask for extra time, particularly when speaking to people who aren't familiar with your speech (e.g. in shops, on the phone). It's easier for both you and your listener if this is indicated at the start of the conversation ("It takes me a bit longer to talk but let me finish what I have to say") Talking in groups (even small groups of 2-3 people) can be particularly challenging as it generally involves quick paced exchanges. It's helpful to position yourself so that everyone can see you and clearly signal when you want to speak. Sometime this signal might be with body language (e.g. lifting a finger, raising your head)	Ensure quiet surroundings: mute the TV, turn off the radio, move closer to the speaker. Clearly indicate if you do not understand. It is better to do this earlier in the conversation. The need to repeat an entire message not only is frustrating but also very tiring for the speaker and can often result in them withdrawing from the conversation. Work out some signals with the speaker to alert when you haven't understood. A non-verbal signal if often most suitable (raise your eyebrows). When there is a breakdown, repeat what you have understood. The speaker can then re-attempt it or try to rephrase only the mis-understood part, not the entire message. Allow extra time for the speaker Use questions that will generate a Yes/No answer

AIDS to Communication

There are a variety of aids available which can be used to supplement or replace speech. Broadly speaking they can be divided into lo-tech and hi-tech systems.

Lo-tech communication aids (non-electronic) might be less flashy but can work really well to help get messages across. After all, the key goal is for the person to have their message understood using whatever tools work. These more simple solutions include pen & paper, mini-whiteboards, magnetic sketch boards, letter charts or personalised word charts/books. These can be particularly useful for supplementing poorly intelligible speech e.g. by setting the topic or confirming key words with the listener. Sometimes a variety of these aids will be used in different settings or with different listeners

The hi-tech systems are electronic devices which will have buttons or touchscreens for the person to input their message. The device will use an electronic voice to "speak" the message. These systems offer lots of opportunities to speed up the process of inputting words by storing frequently used vocabulary & phrases and have the capability to predict words frequently used. For people with limb weakness, where hand control is problematic, there are different types of switches available to activate the screen (e.g. by using head control to touch a switch). There are also sophisticated eye-gaze systems available which track eye movements (usually preserved in MND). With the ever expanding range of technology, lots of everyday electronic devices with special software such as personal computers, tablets and smartphones are being used as communication aids. This has meant more readily available devices, now commonplace in everyday life, can be applied to assist with impaired speech.

There is no one single aid or system which is best. Each will have its advantages and disadvantages. Your Speech & Language Therapist will provide specialist advice on the options available and which might work best for an individual and their changing needs over time.

Fiona Rodgers
Senior Speech & Language Therapist
University Hospital Galway

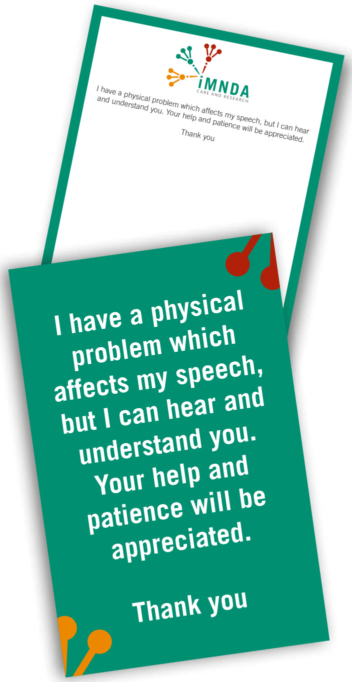
My Voice is Affected by MND

Although not everyone with MND will notice a change in their speech, 85-90% of people with MND will experience some loss of speech. MND can affect the speech in a number of ways:

- Difficulty articulating certain consonant sounds
- Limited movement of the soft palate causing "nasal" quality speech
- Impaired movement of the vocal cords resulting in hoarseness
- Shortness of breath when speaking

Each of these changes can impact on how well a person's speech is understood in conversation. You may not realise how your voice sounds to others. Although people close to you are more likely to understand what you're saying, people who are less well known to you may find it difficult to understand you. Strangers may think that you are drunk, which can be hurtful and embarrassing, or that you have a hearing impairment.

It can be difficult and frustrating continually having to explain the reason you have difficulties with your speech. The IMNDA have produced a small card which explains that your speech difficulties are due to MND. We hope this will make things a little easier.



I have a physical problem which affects my speech, but I can hear and understand you. Your help and patience will be appreciated.

Thank you

I have a physical problem which affects my speech, but I can hear and understand you. Your help and patience will be appreciated.

Thank you

While a lot of people now communicate by texting on a mobile phone or tablet device, quite a few still prefer to use pen & paper. We have designed a small notepad (with explanation) which can be used to write short notes to help with communication.

Both of these items are available from the IMNDA office by emailing services@imnda.ie or by giving us a call on Freefone 1800 403403.

MND Global Awareness Day 21st June

This coming summer, we are once again launching our National Awareness Campaign in the run up to 'MND Global Awareness Day' 21st June. We will be airing an infomercial on national radio stations with one of our clients Andrew Brennan. Andrew has bravely agreed to get involved with our radio campaign for 2016 to help raise awareness of motor neurone disease.

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

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

Andrew Brennan is 33 years old. Two years ago, he and his wife renovated an old school house into their family home. Andrew helped rebuild the school house brick by brick. He was there every day with the builders down in the dirt. They were building a house for life.

At 9.15am on the 26th February last year, Andrew was delivered the devastating news that he had MND. His youngest daughter was just 5 months old and the eldest was 19 months old.

Andrew and Yvonne are now building an extension to the house they so lovingly restored. They again are planning for the future, for the day quite soon when Andrew will no longer be able to go upstairs to go to the bathroom or to kiss his daughters goodnight. This is Andrew's story.

> *The first few months after my diagnosis were a bit of a blur. I was lost, we all were. My attitude was that this can't happen to me, they have it wrong, sure I'm fine, I'm young and fit, very fit in fact, I had quit smoking and could do a 100km cycle without so much as getting off the bike for a break.*
>
> *But I wasn't fine, my right hand and arm was getting thinner and weaker. I couldn't do the most easy, straight forward tasks.*
>
> *I'd lie in bed at night unable to sleep, all the muscles in my arms and legs were twitching and cramping involuntary, I'd look over at my wife and wonder what lies ahead for us.*
>
> *Would I save my wife, my kids and my family a lot of grief if I refused to go through this, if I didn't let them see me go through this, if I took a different path.*
>
> *I'll never fully accept this but one day I came to a point where I said to hell with this, I'm not going to let this get in the way of me enjoying my life, I'm going to grab this condition by the scruff of its neck and drag it into the future, I won't live with it, it'll live with me while I'll enjoy the time I have left.*
>
> *I have plenty of things that I want to do, my greatest achievement was marrying my beautiful wife Yvonne and having two wonderful daughters. We've restored a 200 year old house and I'd like to finish it and I want to spend time with my family and watch my girls grow up.*
>
> *So for anyone who has this condition I'd like to say it's never over and to anyone who hasn't I'd ask them to enjoy every day as tomorrow it could all change.*

Two years ago Andrew lifted and laid the blocks for his house, now he can barely lift a cup of tea. Please help us spread the word about MND.

We want to commend and thank Andrew and his family for agreeing to take part in our national awareness campaign in June to mark MND Global Day 21st June. It is not an easy undertaking to put yourself out there and open up your doors to let people in. Please keep an ear out on the radio in early June for more on Andrew's Story. Let's Drink Tea for MND and together we will beat Motor Neurone Disease!

For more information or to hold a tea day, visit our website www.imnda.ie or check out the Drink Tea article in the Fundraising Section.

Thanks for your support!!

Liz's MND Blog

In previous editions of Connect we have shared blog posts from people living with MND in Ireland. We were recently contacted by Alan Ogg in Scotland to let us know about his wife Liz, she has decided to share her journey of MND in a blog.

Liz has just turned 67 and three years ago she noticed she was having difficulties with her speech. Six months later, after a number of months of tests, she was diagnosed with MND. It was identified as being Progressive Bulbar Palsy (PBP). This affects about a quarter of people diagnosed, and involves both the upper and lower motor neurones. Symptoms may include slurring of speech and difficulty swallowing.

"*I'm not quite sure why I want to post this Ogg-blog on the website. Despite the bad times, (and there are some) my husband and I try to remain positive and make the very best of what we have. It's not always easy, but it's the only way.*" said Liz.

We have included some of her blog posts below. To read more about Liz, you can get her blog on lizmnd.blogspot.ie

Blog Post 3 – Jan 25th 2016

Movement

Ah, how I remember Friday nights, after a couple of glasses of Bordeaux, when I would get out the inflatable hurdles and hurtle round the lounge, my husband shouting encouragement! But I'm afraid these days are long gone. Yes, the theme of this blog is difficulty with movement and it's clearly one of the most common symptoms of the disease.

When first diagnosed over 30 months ago with bulbar MND, my ability to walk was only slightly affected. After our first few weeks of emotional trauma following the final diagnosis, when we frankly didn't feel like doing much, we tentatively began to make plans again. I'm not a great fan of the "bucket list" concept - we simply decided to splurge some found money and saved-up Avios points on visits to some of our favourite European cities. Looking back, these were wonderful days, but gradually over time, such holidays became more difficult and finally out of the question. We still go on short breaks when we can, but now mainly to Fife or our beloved Kintyre, in Scotland. Now necessary equipment takes up more and more boot space. EasyJet or Ryanair would make a fortune from me!

In the beginning, I naively thought that my limbs would remain unaffected for longer. Ah the innocence of ignorance!

In an attempt at a logical approach, let's start at the top of my body and work down.

Smiling

Smiling in social situations is tricky, particularly when you are dealing with the excess saliva at the same time. Since I can't participate nearly as much in general chat, at times I just have to sit, listen and practise the social smile. But after a short time, the smiling becomes more difficult and my mouth and jaw muscles become tighter and more uncomfortable. Any photos have to capture the first attempt at a smile; otherwise, I can look as if I really don't want to be there. For this reason, I tend to limit social interaction to around two hours. Any longer, much as I would love to linger, I can get too tired. And tired facial muscles make eating difficult. MND also makes you yawn, sometimes noisily. So between the smile that has slipped and the noisy yawning, I may not always look like someone having a good time!

Sleep position

We've been experimenting with a pillow lift, as moving in bed is increasingly awkward. It sounds an excellent idea – an electrically controlled inflatable cushion under the pillows, that raises and lowers the upper body. The inflation is disconcertingly accompanied by sounds like a tyrannosaurus rex with severe flatulence. Disturbing for The Boy (code from now on for husband) should I decide to raise my pillows at 3am. Nonetheless, we've been inflating and deflating to our heart's content, to see if I can get into that desirable final sleeping position, but I'm afraid without success so far. We'll keep trying.

Walking

Walking has now become more difficult, with a definite weakness on the left side. I can still walk around the house a bit, unaided, although holding on to surfaces, just in case. I sway alarmingly without warning, and that's without the drink. And my left foot follows the rest of me with a two-second gap and doesn't always clear the ground. The Boy and I now sometimes take romantic walks together, arm in arm, from room to room. We particularly enjoy the stroll from kitchen to dining table and back. Reliving our youth together? - well, not quite!

Exercise

I now have an exercise bike, to encourage muscle retention and strength and to increase my circulation. Of course it's not a normal bike, but a small floor model which I can use while seated in a chair. The Boy has bought me a bicycle bell to encourage me to use it, but exercise and I are strangers...as all my friends would readily agree. See photo for proof of said activity!

Glacial hands and feet have become an issue. I used to try and sneak my feet over to The Boy's side of the bed, but being sneaky requires stealth and speed, two skills I no longer possess. However, I have a small furry animal, not real I hasten to add, which after a couple of minutes in the microwave, restores some semblance of heat.

Fingerless gloves are a good ploy for during the day and still allow some movement. I also have therapeutic putty, a kind of adult playdough which keeps the circulation moving in my hands. It would be more efficient if I used it more often!

Out and About

In the end, I gave in to the inevitable and now use a wheelchair to get around outside. Measuring your length indoors and on a carpet is one thing. Doing so in public, another matter altogether, not to mention more dangerous. Although The Boy is a good car driver of many years' standing, I am less convinced about his wheelchair skills. This probably dates from the day when he rammed my feet into the door of the hospital lift and blamed it on the lift! He's definitely improving - according to him - but I still fear the backwards lunge as we come off, or mount, pavements. Not too sure either about reversing into lifts. And despite all, I just don't like the "wheelies" he insists on doing in the broad fruit and veg aisles of the supermarket.

I also feel a bit like a Russian tank, once the wheelchair trolley is clipped on in front, although it is damned effective at running up the heels of the ladies who invariably occupy the middle of the aisle, chatting. The Boy does this with panache and apparently an apologetic smile that astounds. And it's not until you are in a wheelchair, that you realise how inaccessible shelves are. The hand signals I spoke of in an earlier blog become increasingly frantic and much less polite, as we speed past items not on the list. If it's not on the list, no chance!

Oh, and a serious complaint: when will people stop parking in disabled carpark spaces, when they are fully able-bodied? Or there is no disabled parking permit to be seen. I have noted it's very often large 4x4s in particular. It incenses me and I would propose corporal punishment, public stocks or even car-impounding – for starters...

Going Up

Chairlift, Lift, Skiing, Gondola we've also installed a stair lift, which, according to The Boy, will allow me to continue to mess up the whole house! It has certainly given me back a great deal of independence, where the stairs had begun to take on the challenge of the Eiger. It's also useful for sending piles of ironing upstairs. Again I can hear friends' hollow laughter! The grandchildren call it the "chairlift" and were quite disappointed that it didn't swing precariously over the stairwell. However, offering to sell them tickets for the lift has thankfully dissuaded them from overuse of gran's 'stair taxi'.

So all in all, we lead life at a more sedate pace than before.

As someone once said "Stop being afraid of what could go wrong and start being positive about what could go right"

Keep reading and keep well.
Liz

FUNDRAISING

The difference we make together

To all of our amazing supporters and fundraisers, please accept our sincere thanks. It is because of you that all of us here at the IMNDA can continue our vital work in supporting the MND community. We are so grateful to have such wonderful support throughout the year. To those who aren't specifically mentioned here, please accept our sincere thanks.

Thank you to...

Afternoon Tea

The ever popular tea and coffee mornings proved once again a timeless treat. A huge thanks to the 3rd year BA in Event Management Students in Dundalk Institute of Technology on organising their "1916 Afternoon Tea" and raising €1,136.50 for the IMNDA. Roxanne Wall, Laura Woods, Christina White and Rachel Curran deserve special mention for all their hard work and for making the event come together. Well done girls.

A big thanks also to Ms. O'Donnell and the fifth class students in Newport NS who raised a fabulous €175 in their cake sale and raffle.

Fishing for Answers

Margaret Murphy, who held a table quiz in her local golf club and raised a brilliant €350. Sharon Lynch and the students at Meanscoil Lughaidh Naofa in Monaghan also put their heads together and their quiz raised a clever €200.

Fun-raising!

A huge thanks to Declan O'Shaughnessy who rounded up his work colleagues and made them grow a Tash for Cash! An amazing €2,645 was raised – thanks guys! Declan Carey did the opposite and shaved his head for a hair-raising €2,110. Unbelievable Declan!!

Sarah Walsh and all the staff at the Classic Movieplex cinema in Listowel held a special Christmas screening of The Theory of Everything Charity Movie Screening in aid of IMNDA and raised a fantastic €2,338. Thank you so much to you all!!!

A special thanks to Miriam O'Callaghan and all the fabulous 6th year students in Santa Sabina Dominican College, Sutton who raised over €1,100 in their sleepover fundraiser.

We also have to say a big thanks to the students of Gaelscoil Riabhach in Co na Gaillimh who went to school in their pyjamas' and raised a brilliant €217.50!!

Well done to Aaron Nolan and Dan Meijer. The duo held a bag pack and a few other events for the IMNDA and managed to raise a hefty €1,967. Well done guys!

Everyone loves a bit of drama and the Church Hill Players put on a show that Twink would have been proud of. Their Variety Show raised €5,000. Special thanks to Veronica Kelly and all who took part.

Frances and James Murphy held a Charity Shop Fundraiser through November until Christmas. The industrious pair raised over €3,000 from their efforts. Well done guys! Brian O'Flaherty went on the dry for January and collected over €500 for the IMNDA – cheers Brian.

A huge thank you to Irene Crampton and Stephanie Moody. The Rathangan Parish banded together and raised nearly €15,000 from a raffle in the village. Phenomenal fundraising guys!

Music Moments

A massive thank you to Alan O' Conchubhair and Good Works Opera in association with Opera at Castalia, who presented a stunning performance of G.F. Handel's Messiah in Castalia Hall, Ballytobin, Callan, Co. Kilkenny and raised a fantastic €1,800!!

Opera was all the rage this year as Mary Troy and Kate Callaghan also organised an Opera Gala Night in Castleknock. It was a great affair and a celestial €4,260 was raised.

Geraldine Collins and her choir went carol singing in Dundrum this Christmas and collected a brilliant €440 for the IMNDA. Thanks to all the singers!!

Dances & Festivals

A huge thanks to Ballinalee, Killoe and Newtownforbes Friends of Motor Neurone raising an amazing sum of €19,000 through a tractor run, barn dance, raffle tickets and bucket collections. A cheque presentation ceremony was held in Rawle's pub in Ballinalee where the proceeds were divided between the IMNDA and RMN. We are truly overwhelmed by this great event in it's fourth year and the amounts raised have been amazing. Without people like this we could not provide the equipment and services we do. Thank you so much.

Niamh Ní Dhrisceoil and all from Cape Clear Island held their family fun day and raised a fantastic €2,015. Thanks to everyone who helped to make the event such a great success

A special thanks to Frank Brennan and the Ballyouskill community who raised an amazing €2,400 in the Ballyouskill Vintage Festival, lots of fun was had with bouncing castles, a vintage display, tractor run, cabaret and auction!!

A special thank you to Frank Whitney and Vincent & Una Brennan who organised a fantastic fundraiser in the Leitrim Gaels Club house for Joe Brennan with the amazing proceeds of over €14,000 being kindly donated to IMNDA. A huge thank you to all those who attended and donated both near and far. Sadly Joe passed away shortly after the event and he will be sorely missed by all in his community.

The IMNDA would just like to congratulate and thank once again the June Ball Committee. Last year's extravaganza raised over €73,000 for Motor Neurone Disease!! This is an unbelievable amount, incredible work guys!!

A huge thanks to the Irish Travel Agents Association (ITAA) for nominating the IMNDA to benefit from the Charity Raffle which took place on the night of the ITAA 2016 Awards Ceremony in the Mansion House, Dublin on the 21st January 2016. The IMNDA were chosen as a very well-known colleague, Ray Tracey passed away from MND in April 2015. The raffle raised an amazing €9,105.83.

Witches and Ghosts

Collette Nugent organised a ghoulish Halloween and fancy dress party in the Market Bar, Drogheda and raised a fantastic €645. Thanks Collette!!

A big thanks to everyone who attended and to all those who donated fantastic raffle prizes to the Seven Arches, Laghey Halloween Party Fundraiser. The total raised in memory of the late John Given was a brilliant €610.

Corporate Donations

A special thanks to Arthur Cox solicitors who have nominated us as one of their chosen charities of the year, we are absolutely thrilled!! Huge thanks for the phenomenal Christmas donation of €20,000.

A massive thank you to everyone at Intel!! The IMNDA and St. Luke's Hospice were the Intel 2015 charities of the year along. The Intel staff were unwavering in their support - organising countless events throughout the year including a charity cycle, midnight and 5k runs, bake sales and The Intel Premiership Survivor competition all of which raised an incredible €29,716.46!! We were so honoured to be chosen!!

An absolutely massive thank you to Diageo, who so generously presented us with 8 IPads in memory of Matt Murphy. A massive thank you to Jane Murphy and Rosemary for putting us forward. We are deeply grateful for this fantastic contribution so thank you to everyone in Diageo!

The fabulous Fitness league of Ireland gang who were overwhelmingly supportive during our Christmas fundraising campaign! A huge thanks to you all for raising over €7,000 during our Christmas fundraising campaign

The IMNDA were thrilled to have been selected by the students union in IT Carlow as one of the beneficiaries of their RAG week 2016. The students raised an impressive €3,500.

The IMNDA would also like to make a special mention about the Saturday Hospital Fund. They selected us as one of the lucky beneficiaries of the Hospital Saturday Fund and for the very generous donation of €4,000. This is deeply appreciated. This money will be put to great use, buying much needed communication aids for people living with Motor Neurone Disease (MND).

AOIFA

On the 23rd March, the Chairman of **Association of Irish Floral Artists** (AOIFA) Brid Coonan, presented a cheque for €71,794, on behalf of the Association of Irish Floral Artists to Marie Reavey, IMNDA Regional Development Officer.

AOIFA selects a charity every two years and holds various fundraising events, including a National Festival of Flowers during this period. Individual affiliated Clubs also hold fundraising events throughout the two year term e.g. Floral Art Demonstrations, Floral Art sales tables etc. These events are organised on a purely voluntary basis and our sincere thanks and appreciation to all AOIFA members around the country who through their generosity and wonderful work helped to raise this remarkable sum of money.

Brid acknowledged the incredible work of the Irish Motor Neurone Disease Association and stated that AOIFA were delighted to help and support the Association on this occasion. Besides raising vital funds it had also helped to raise awareness of MND among AOIFA members, families and friends. Brid wished the IMNDA continued success and good luck in all their future endeavours and said it was a privilege to have worked with the IMNDA over the last two years.

Egg-stra Egg-stra!

We just want to say thanks to everyone who took an Easter Hamper this year and raffled it off in local bars, cafés and shops across the country. The campaign did brilliant once again and it is thanks to you. We would be lost without our treasured dedicated supporters! Another egg-citing year with an egg-cellent amount raised!

Speaking of all things egg-cellent, Glenn and Conor Cullen are 16 and 14 years old. They have an egg sale business and from every box of eggs they sell from their Galtee Free Range Eggs they have been donating 50c to the IMNDA. They sell their eggs around Tipperary so please support the guys. Well done Glenn and Conor.

Balls in 2016

SUMMER GALA BALL

A small group of local people in the North East area whose families have been affected by Motor Neurone Disease are planning a Gala Ball on the 3rd June 2016 to raise much needed funds for Irish Motor Neurone Disease Association.

The venue for the Summer Gala Ball is **"The Millhouse"**, Slane, Co. Meath. The evening commences with a prosecco reception at 7.30pm followed by dinner. Ronan Collins from RTE Radio 1 will MC the evening and his band will also be providing the music. There will be a raffle and auction with lots of lovely spot prizes.

We invite everybody to come along to this fabulous event in beautiful surroundings and support a fantastic organisation. This is also an ideal opportunity to use the event for a family celebration, company reward, or just a group of friends having an evening out whilst supporting IMNDA. Tickets only €75 per person.

For ticket bookings and/or table reservations contact;
Micky 086 360 1338 / **John 087 224 8503** or www.imnda.ie

Summer Gala Ball
in aid of the
Irish Motor Neurone Disease Association
in The Millhouse, Slane
on Friday 3rd June 2016 at 7.30 p.m.

Prosecco Reception
followed by Dinner

M.C. and Music by:
Ronan Collins & his Band

Raffle and Auction
on the night

Ticket - €75.00

Formal Dress

Tickets can be purchased from
www.imnda.ie - Micky 086 3601338 or John 087 2248503

THE JUNE BALL

The June Ball in aid of the IMNDA returns to the Double Tree by Hilton Hotel (Burlington Road, Donnybrook, Dublin) on Saturday 25th June 2016 for the third year running.

The June Ball 2016 promises to be an amazing night packed full of fun and entertainment, so dust off your best ball gowns and tuxedos, get a group of your friends and family on board and secure your tickets for what will be the night of the Summer 2016!

Last year's event proved to be a massive success with over 600 guests attending an incredible evening, which, with your help, we will be aiming to surpass!

If you would like to donate a prize (or prizes!) for the raffle or auction on the night, or know of any friends or businesses who would like to make a donation or sponsor a prize, we would love to hear from you.

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

For any queries in relation to the event, please email us at **thejuneball@gmail.com**

Thank you for getting active for your Association!

Pedal Power!

A very big and sincere thank you to all who took part, the sponsors, Gordon Brett AIT, Taoiseach Enda Kenny and all who contributed to the amazing success of the 'Friends of Nicky McFadden Cycle. The 40k greenway from Mullingar to Athlone raised a fantastic €3,500 for IMNDA. A very special thanks to Gabrielle McFadden for organising the event. Despite the weather there was a great turn out and spirts were high. As the comedian Pat Shortt once said "It would be a great country if we could roof it!!"

The Irish Distillers also organised a very successful Charity Cycle and raised just under €7,000!! They cycled all the way from Cork to the Jameson Whiskey Distillery in Dublin. I say they needed a stiff dink after that! Thanks to all who pedaled the miles – great achievement!

Taking the scenic route was the aim of our next cycle. Ken Lenihan organised a Coastal Cycle in Kerry. The event was a fundraiser for the Fenit School but they also gave a very generous donation of €1,000 to the IMNDA. This is deeply appreciated! Thanks to all in Fenit and Kate Brosnan for attending on the day.

Ryan Willmott and a few friends had a mission. Their mission was to cycle from Galway to Cork for Motor Neurone Disease in 5 days! To say they were saddle sore by the end of it is probably an underestimation but they guys were thrilled to complete it and raise over €2,000. They travelled over 700 miles on their bikes and while they were a bit battered and bruised when they arrived in Cork, they were floored by the generosity they met along the way so from all at the IMNDA we would just like to thank everyone who offered a kind word or a free drink, you helped keep this plucky crew sustained. We are very grateful for the cheer you showed these guys!

On Your Marks!

A big thanks to all of you who put on your trainers and ran, jogged or walked for IMNDA!

A huge thank you to Paddy Butler and all Moorefield GAA Club who organised the Croke Park to Moorefield Walk for Paddy Butler and the IMNDA which was held on 28th September 2015, raising an unbelievable €10,000. Sadly Paddy passed away a short time ago so our thoughts are with his family and all his friends in Moorefield GAA.

Thanks to Kevin Maguire whose 5K walk collected €700. Áine Hanley took on the dizzying task of completed three peaks including Ben Nevis and Noel Quinn who climbed Croagh Patrick Climb for nearly €400.

We would also like to make a special mention of Bernard Bannon. Bernard climbed Croagh Patrick in aid of the IMNDA with his son-in-law Pat. Bernard is 78 years old and the pair tackled the mountain in 8 hours. Congrats Guys!!! Brilliant job!!

A massive congratulations and thank you to Niamh Murphy and Kirsty Moran, our two brilliant 16 year old supporters from Wexford who raised an amazing €4,895 from a Colour Fun Run in Kilmore, Wexford, which they so brilliantly organised. Niamh was inspired to raise money for the charity as she was touched by the passing of a man close to her friend's family.

To all the amazing ladies who took part in the Cork Women's Mini Marathon, thank you! Rose Keating and all her friends raised over €1,100 as did Dymphna O'Connor and her gang! Irene O'Flynn and her troop raised almost €1,900, Lisa Murphy raised a fabulous €612, Mary Nolan a brilliant €90 and Noelle Higgins an amazing €300.

A huge thanks to the Carlow Lions Club who organised 'Run with the Lions' event in memory of Mark Attride who sadly passed away from MND late last year. Over 400 people took part and the event raised a fantastic €4,211.35 for the IMNDA. A great day was had by all.

Thanks to all the fabulous runners who took part in the Dublin City Marathon including Donal Spellman, Marie Clancy, Amy Looney, Eoghan Barry and Tanya Healy - collectively €18,000 was raised. A massive thank you to you all!!

A huge thanks to Annmarie Connell who raised €1,500 in the New York City Marathon, to Elizabeth Duffy who raised over €400 in the Frank Duffy Half Marathon

Running was all the rage last year with countless people taking part in marathons at home and abroad. Alan Brett was a running machine and he took on the Killarney Marathon for the IMNDA while Jenny Dowswell demolished a Triathlon Sprint in Scotland. Paul Bohen chanced the windy city of Chicago to run his marathon with Simon Delaney heading to Canada to do the Vancouver Marathon. Annemarie Connell also went stateside competing in the New York Marathon. Julianne Deane and Tess Healy kept it local and took part in the Munster Ladies Charity Mini Marathon just over €600.

Not content with just running, the adventure race proved ever more popular. We had loads of hellraisers taking on Hell & Back, Tough Mudder and Runamuck. Thanks to people's bravery, nearly €4,000 was raised from these mighty mud filled runs.

The Good Run

On Good Friday, more than 800 walkers, joggers and runners descended on St. Anne's Park on Dublin's Northside for the second Good Run. A massive thank you to Olivia Tracey and family for organising this exciting fun run to raise funds to support the fight against Motor Neurone Disease. The atmosphere was electric and everyone had a brilliant time. All funds raised will be divided between the IMNDA and Project MinE. We just want to thank everyone involved, the turnout was terrific and the day was an unbelievable success.

Strawberries and Cream!

Betty Hogan held her second Tennis Tournament in Offaly and raised a smashing €620. Thanks to everyone for participating and playing in the event.

Abseil

An overwhelming thank you to all our amazing supporters who climbed onto the roof of the Hogan Stand in Croke Park in October and abseiled the 100ft to the pitch! We were absolutely blown away by the incredible fundraising efforts you all made. Over €48,000 was raised!!!

Hole in One

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

Olivia Kearns County Louth Golf Classic was a swinging success raising €3,375. Elieen Darcy held a Classic 3 Ball scramble in Ballinasloe and Martin Fahy organised a Golf Competition all in aid of the IMNDA.

Dance the Night Away

St. Kierans Dance Club in Cloughjordan danced the night away to the sum of €2,000. Thanks to Willie Wolfe and all in the dance club who organised the night.

The Dance Society in DCU held an event called "DCU's Best Dance Crew", which sees the other societies learn a dance routine and perform it in front of judges and an audience in an effort to be crowned DCU's Best Dance Crew. This year the IMNDA were the lucky charity chosen to benefit. Special thank you to Eimear MacCarrick for all her hard work. It certainly paid off as the students raised over €1,000.

Other Challenges

The IMNDA would like to say a huge thank you to Sinead Denby, Garrycastle Ladies GAA club, Garrycastle Lotto committee and the Molloy family who held a mum's V's daughters match on Saturday 24th October and raised a fantastic €1,400!! Thank you all so much!

Peter Walsh kindly donated the proceeds of his yoga classes for a week to IMNDA. After a lot of downward facing dogs, warrior poses and shavasana's Peter raised an amazing €522.75.

Taking a dip to a new level, Fintan Lambe and his brave comrades did a chilly Christmas Day Swim. The ice water didn't dampen donations as they raised a n-ice €1,105.

We were bowled over by the success once again of Brian Daly's Bowling Classic in memory of Paul Magee. This annual event went down a storm and roped in a golden €2,600.

The IMNDA would like to thank John Lee, Niall and Tom Kirwan and all from the ICPSA Leinster Sporting League. They held a clay pigeon shooting league competition involving the Bray Clay Pigeon Club, Fingal Sporting Club, Cedarbrook Clay Target Club, Ballivor Clay Target Club and Lakelands Clay Target Club. The clubs raised a whopping €1,950. Thank you to everyone who made this happen.

Motoring for Motor Neurone Disease

A big thanks to Hilary Cleary and the Thatch Vintage Club who raised a brilliant €700. The North East Vintage Car Club also held a Vintage Car Rally and raised an amazing €2,000.

We also want to thank Louisa O'Callaghan and all from the 10th Annual Eireball Run for raising an incredible €4,850. The Eireball Run is a gruelling week long sponsored drive. Each year a challenging route is set and a convoy of classic Volkswagens winds its way around the island of Ireland. We just want to say thanks to all in the convoy who motored for MND!!!

The Sky is the Limits!

Not content with their feet on solid ground Gerard Murphy and Sarah Ennis took to the skies! This daring duo both took part in skive dives. We admire your gusto guys!

The very best of luck to all our active fundraisers who are taking part in this year's many marathons – full, mini and half – walks, swims, cycles. ENJOY!

Walk to D-Feet MND

On **Saturday 16th July at 12.00pm**, the IMNDA is hosting its 4th 'Walk to D-Feet MND'. Last year over 100 people came together with friends and family on for a beautiful 5k walk (or run!) in the stunning grounds of **Castletown House, Celbridge, Co Kildare** in aid of Motor Neurone Disease.

Register online - just **€20 per person** at www.imnda.ie or alternatively complete the below form and return it to us with payment. Walkers will also be able to pay on the day. The IMNDA will be based in front of the house and registration opens at 11.30am on the 16th. All children under the age of 12 go free. All walkers receive an IMNDA t-shirt and light refreshments. The route is fully wheelchair & buggy accessible.

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

Can't make Castletown on the 16th July? Why not organise your own Walk to D-Feet MND in your local area this summer! We'd love to have as many walks taking place across Ireland as possible in conjunction with our own so we can spread the message further afield. Get in touch to discuss your walk and we will provide you with some tips and practical information. Freefone **1800 403 403** or email **fundraising@imnda.ie**

Together, let's take steps to D-Feet MND.

Your details: (Please use BLOCK CAPITALS)

First Name:____________________ Surname:____________________

Address:____

____

Phone:____________________ Email:____________________

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

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

Total payment amount due: €________

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

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

☐☐☐☐ ☐☐☐☐ ☐☐☐☐ ☐☐☐☐

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

Cardholders Name: ____________________ Cardholders Signature:____________________

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

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

____

IMNDA
CARE AND RESEARCH

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

Walk to D-FEET MND

SATURDAY 16TH JULY, 12 NOON

CASTLETOWN HOUSE , CELBRIDGE, CO KILDARE

- Register online for **€20 per person** at www.imnda.ie. Walkers will also be able to pay on the day.
- Come together with friends and family (kids & pets welcome!) for a **5K WALK** in aid of Motor Neurone Disease.
- Every step makes a difference. We walk for hope, we walk in support, we walk in memory and we walk so that one day we will see a world free of Motor Neurone Disease. TOGETHER, LET'S TAKE STEPS TO D-FEET MND.

Under 12's walk for free & all walkers receive an IMNDA t-shirt and light refreshments. The route is fully wheelchair & buggy accessible.
Can't make Castletown on the 16th July? Why not organise your own Walk to D-Feet MND in your local area!
Freefone 1800 403 403 or email fundraising@imnda.ie for more information.

www.imnda.ie

Charity No. 8510

Drink Tea for MND!!!

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

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

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

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

As we have already mentioned in the Living with MND section, this year Andrew Brennan is fronting our National Awareness campaign and he is also encouraging people to Drink Tea for MND!

"I am 33 and soon I won't be able to lift a cup of tea. Will you lift a cup of tea for me, and help support people with Motor Neurone Disease?"

Drink Tea for MND is a great way to gather round some friends and raise funds for people just like Andrew. Everyone loves a cuppa especially in Ireland so why not organise an afternoon tea / coffee morning in your home, local pub, restaurant, GAA club, workplace, community centre, garden... anywhere in fact!

We want as many people as possible drinking tea for MND throughout June. Tea packs, which have been sponsored by SuperValu, are available from the IMNDA office so call **1800 403 403** or email **fundraising@imnda.ie** to get yours today.

Let's Drink Tea for MND!!

Sometimes Silence Speaks Volumes

Imagine an hour...a day...a week without speech. Imagine not being able to say 'I love you' on Valentine's Day. Unfortunately that is the fate met by most people living with Motor Neurone Disease (MND).

To create awareness around this fact Esther Tracey and Padge Kelly bravely fronted our Sponsored Silence 2016. We asked people to take on a sponsored silence during the month of February to experience what it would be like to not be able to communicate.

Patrick (Padge) Kelly is 28 years old from Lucan in Dublin. Padge was diagnosed with MND in 2003 when he was 17. When he was in sixth year in school he noticed that his hand writing had become very messy and that he wasn't as fast when he played football. One day when he was walking home from the shops with his Gran he found he couldn't carry the bags for her.

"*I went from a limp to needing a crutch to a wheelchair. I can't move my arms or hands. The worst of all is that my tongue, mouth and diaphragm has also been affected which robbed me of my speech. I could deal with being disabled but not being able to communicate with family and friends was difficult to come to terms with*", said Padge.

Esther Tracey is 58 years old and was diagnosed with MND in 2013. Esther is an amazing cook, and runs her kitchen with the precision of a professional. She may have lost her swallow and speech to MND but that hasn't dampened her appetite for life.

"The progressive symptoms which have left me without speech and swallow were daunting but with help from my family and friends I can communicate very well. Every challenging step along the way has consistently brought out the fighter in me and the support of the IMNDA has helped me to maintain a positive attitude to keep fighting this", said Esther.

People took on the challenge at home, in work and in their communities. We had a great response from families, work colleagues and schools coming together to take on our silent challenge. They took sponsor cards and donated by texting MND to 50300 to donate €2. The length people stayed quiet for ranged from 30 minutes right up to a few hours to a few days! One woman did our silence for 2 full days proving that sometimes silence does speak when words can't.

Thanks to Padge and Esther championing the campaign it was a tremendous success. Sponsor cards flew out the door and the awareness created through the media was brilliant. There were full articles in the Irish Sun, the Irish Mirror and the Irish Independent. Esther and her daughter Emma went in to studio on RTE 1 on the Today show with Maura and Daithí.

More people took on the challenge than last year. More people quit speaking and stayed quiet for MND. Thank you to absolutely everyone for taking part - the word is now out, now our silence shouts!

VHI Women's Mini Marathon 2016

Ireland's favourite 10k run returns on Monday 6th June and we need you to run the race to make a difference for the IMNDA!

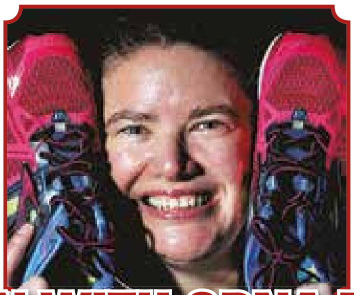
Registration opens from the 17th February and sponsorship packs are available by emailing fundraising@imnda.ie. Remember places go quickly so make sure to register today.

As always our base will be in Toner's Pub on Lower Baggot Street and we can't wait to see you all there!

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

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

For your sponsorship pack:
Email: fundraising@imnda.ie
Phone: 01 873 0422 or
Visit: www.imnda.ie



RUN WITH ORNA FOR MOTOR NEURONE DISEASE

Orna O'Beirne has taken part in the VHI Women's Mini Marathon for 4 years now. She runs the race to make a difference as her mum sadly passed away from Motor Neurone Disease (MND) in early 2015.

The Irish Motor Neurone Disease Association (IMNDA) is the primary support organisation for families affected by Motor Neurone Disease.

"I feel passionately about encouraging others to participate for the IMNDA. The support we received was invaluable. The IMNDA help carry some of the burden and they also offer that glimmer of light in what is a stark reality. Through participating and raising vital funds for the IMNDA more support can be offered to people with MND and their families," said Orna.

To Run with Orna please contact the IMNDA for your VHI Women's Mini Marathon sponsor pack.

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

IMNDA
CARE AND RESEARCH

EDITORS DESK

In Remembrance

Those We Love Remain With Us

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

Those we love can never be more
than a thought apart,
For as long as there is memory,
they'll live on in the heart.

Mary Patricia O'Sullivan
Stephen Melia
Dominic Byrne
Mary Hourihan
Paul O'Shaughnessy
James O'Brien
Padraig Kevane
Mary Elliott
Maura Gillick
Mark Attride
Peter Geraghty
Liam Gaynor
James Mordaunt
Ann Rowland
Michael Mitchell
Eileen Flynn
Ellen Coogan
David Hand
Kathleen Kerrigan
Tim Sheehy
Aidan Roche
Teresa Cullen
Tom Dundas
Stephen O'Dwyer
Wieslawa Geisler
Michael Kelly
George Cooke
Joseph Brennan
Denis Keogh
John Brennan
Patrick O'Sullivan
Hugh Moynihan
John Nugent
Patrick Butler
John Tremlett
John Hernon
Tommy Kelleher
Teresa McGauley
Kieran Gleeson
Mary Tierney
Eileen Loughnane
Anthony Reilly
Morgan Finn
Michael Joyce
Laurence Kenny
Alan Kidd
Tom Sweeney
Robert Deinum
Bernadette Lyda
Joachim Bird
Maura Doyle
Patrick Halloran
Mary O'Connor
Mary Mannion
Frank Dunne
Kathleen Lawlor
Joseph Hallinan
Ronan McGee
John McGing
Maura Breen
Sean O'Donovan
Denis Kiely
Edward Orr

Staff Updates

IMNDA Corporate Partners Update

This year we have been blessed to have been chosen by two companies, Equifax and Arthur Cox, as their charity partners. Working with companies is very important for a small charity like us as not only does it help raising vital funds but it is also very beneficial for raising awareness about the impact of MND.

Equifax

Our first Charity Partner is Equifax Commercial Services Ltd. They are based in Wexford and have chosen to support us for 2016. The company will be organizing various events throughout the year. So far they have already done a fantastic bake sale and are set to hold a 24 hour snooker marathon.

This partnership came about thanks to Margaret O'Rourke who nominated the IMNDA. Sadly Margaret's mother passed away from MND. "Each year our team chooses a charity and then work together to raise money while having some fun,' said Margaret.

Again many thanks to Margaret and all at Equifax, we are delighted to have been chosen and we wish them the best of luck with all their fundraising through the year.

Arthur Cox Charity Partner

Like many other organisations around the world, in 2014 Arthur Cox took part in the Motor Neurone Disease Ice Bucket Challenge. But for the staff in Arthur Cox, there was a more poignant reason for participating. Inspired by a personal battle with MND of one of their colleagues, Loretto Dempsey, who was diagnosed with MND in March 2014, Arthur Cox wanted to do something more – they wanted to make a real difference in the fight against Motor Neurone Disease (MND).

The firm supported Loretto at a personal level in her work environment, but they also wanted to partner with a charity that could make a real difference in the battle against this debilitating disease. As part of their CSR programme, the firm asks the staff which charities it would like the firm to support on their behalf. Not surprisingly in 2015 the results came in overwhelmingly in favour of the Irish Motor Neurone Disease Association (IMNDA) as their number one charity of choice.

IMNDA was selected by Arthur Cox staff for support because they had seen first-hand how debilitating MND can be. In 2015, Loretto, acted as an ambassador for IMNDA and featured in both print and broadcast media campaigns talking about her struggle with the disease.

Arthur Cox wanted to acknowledge and support Loretto and the excellent work that she has done for IMNDA. However they also wanted to provide a legacy of support for others suffering with MND by assisting with the services that IMNDA provides day to day. It was decided that Arthur Cox would provide IMNDA with additional support through the sponsorship of a job placement at the charity to address this need. The placement has been named the Loretto Dempsey Placement in recognition of their colleague who continues to bravely fight the disease.

Arthur Cox's partnership with IMNDA means a commitment to supporting the organisation both practically and financially for the next two years. This ensures that the organisation can function more efficiently day do day, but ultimately, and most importantly, it can concentrate on helping more people living with MND in their fight against the disease.

Arthur Cox's commitment helps to ease the day to day pressures of IMNDA's staff by providing additional practical support. In late March the Loretto Dempsey Placement began and Jackie Martin started work with the IMNDA team.

"After only being with the IMNDA for a short time, I can really see the difference this wonderful association make for the MND community. I'm delighted to have been given the opportunity to join such a lovely team for 12 months as part of the 'Loretto Dempsey Placement' and help towards changing the lives of people with MND and their families"

said Jackie

"Provision of such incredible support like this from Arthur Cox really goes above and beyond anything experienced thus far by the IMNDA. We wish to extend our deepest thanks to all at Arthur Cox and welcome Jackie to the team. 2016 is going to be busy but promises to be rewarding working with wonderful partners like Arthur Cox and Equifax – together we will beat Motor Neurone Disease!"
said Aisling Farrell, CEO IMNDA

New Services Assistant

Along with the edition of Jackie to our team, we are delighted to welcome Sarah Nevin. She will be joining Tracy in the services team and looks forward to dealing with all your queries and assisting you in any way she can. Welcome on board Sarah!

Online Fundraising

Online Fundraising Pages – www.everydayhero.ie and www.idonate.ie

Fundraising online has always been a convenient way of collecting money instead of or as well as traditional methods like bucket collecting or using sponsorship cards.

The IMNDA has been registered with **www.mycharity.ie** for many years and it is now becoming **www.everydayhero.ie**

Everydayhero is an online fundraising platform just like MyCharity.ie, allowing people to raise money for their favourite causes or to give donations directly to them. Over the coming months you will see MyChairty.ie evolving into everydayhero – as it becomes the brand new version of MyCharity.ie – and now fully mobile optimised to work on your smart phone and including a range of engaging features for fundraisers to post photos, blog posts and even share their training effort with their friends and family.

Everyday Hero is a much more interactive, user friendly and fresher site and will no doubt inspire people to sponsor you for your heroic efforts!!!

After a few requests from our fundraisers the IMNDA has also recently registered with the online fundraising platform **www.idonate.ie** which works very much like Everydayhero.

It's very easy to create your fundraising page following the step by step instructions. Be sure to select the IMNDA as your charity and check if we have the event that you are taking part in created already (options will come up when you select us), if not you can create your own thing but please make it clear as to what it is and the date it is happening. The more information the better; make your page reach out to people by telling your story and why you are doing what you are doing for the IMNDA. People are always much more likely to give...or give more!!!

Now you just e-mail the link for your page to everyone that you think might like to sponsor you and don't forget to share it on your Facebook and Twitter pages. It takes less than 5 minutes, and hey presto your fundraising page is live for all to see and donate to.

Now you can just sit back and watch the sponsorship roll in!! The monies raised will be transferred straight through to the IMNDA's bank account.

The benefits to you are:

- Minimal effort for you – 5 minutes to set up the fundraising page and send out the e-mail
- You can keep letting your friends and family know how you are getting on
- No sponsorship cards
- No counting cash

- No chasing cash from sponsors
- No storing or lodging of cash
- Ability to reach sponsors overseas
- Ability to over achieve on your fundraising target – your page is still there for potential sponsors when you have stopped actively fundraising, or even after your event!!
- By online fundraising you are also helping the IMNDA because:
- Fees can be incurred by the donor at their choice, most choose to do this!!!
- Funds raised by you go directly into the IMNDA's bank account
- It's more efficient because the IMNDA can track your fundraising income in real time online
- It's time friendly as we don't need to count money and lodge to our bank account

Regional IMNDA Ambassadors

Community Ambassadors

The IMNDA are currently looking for inspiring volunteers throughout Ireland to become IMNDA Ambassadors in their local communities.

The IMNDA Community Ambassador will play a vital role in representing the IMNDA at local events and functions, attending cheque presentations on behalf of the IMNDA. On occasion you may be asked to speak on behalf of the IMNDA.

If you are interested in becoming an IMNDA Community Ambassador, please contact our Regional Development Officer, Marie Reavey on 1800 403 403 or email mreavey@imnda.ie for more details.

IMNDA Ambassador – Seamus Bonner Dublin

It is an honour for me to be nominated as an IMNDA Ambassador. My job is to represent the IMNDA at various functions, to explain the aims of the IMNDA, its hopes and its aspirations. And to raise awareness of the disease whenever possible.

The IMNDA is a fantastic organisation. The people who work for it – mostly volunteers – work with dedication and enthusiasm. Their hope would be that someday that there will be a cure for MND.

My involvement with IMNDA started about 10 years' ago, when I discovered there was such an association which helped people with MND. But, my own knowledge of the disease goes right back to my 'teen years, when mother contracted it. In this regards, I am going back to the early '70's when it was relatively unknown. Many times I had to explain to people what the disease was, what its nature was and what the symptoms were.

I urge all of you to consider becoming Ambassadors for IMNDA and help raise awareness of the disease in your community. It's the seemingly small bits each of us does that all add up and make a great job of work done.

Thank you
Seamus Bonner

iMNDA
CARE AND RESEARCH

THE IRISH MOTOR NEURONE DISEASE ASSOCIATION

DARES *YOU* TO TAKE PART IN THE

CROKE PARK

ABSEIL

The IMNDA is looking for people to abseil from the roof of Croke Park Stadium, Dublin.

100FT FROM TOP TO BOTTOM!

ARE YOU GAME?

Then contact the IMNDA today
Freefone: **1800 403 403** Email: **fundraising@Imnda.ie**
www.imnda.ie

Over 18's only / No experience necessary / Full training provided on the day.
Event ran in association with **www.adventure.ie**

Places are limited; a non-refundable deposit of €100 and fundraising is required of all participants. All proceeds raised will go directly to supporting people affected by Motor Neurone Disease; a progressive, incurable and terminal condition.
Charity No. 8510

adventure.ie
The Adventure Agency