30 YEARS
iMNDA
CARE AND RESEARCH
1985-2015

CONNECT

ISSUE 15

Autumn 2015

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CONTRIBUTIONS TO THE NEXT EDITION OF CONNECT:

If you would like to submit a story, photo or anything else you would like to share please email pr@imnda.ie / info@imnda.ie or Freefone 1800 403 403.

A NOTE FROM OUR CEO

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

This year has been a big year for the IMNDA.

We successfully marked 30 years of the IMNDA with a whole host events that included a ceremonial visit to Áras an Uachtaráin to meet with our President Mr Michael D. Higgins. I would like to extend my personal thanks to him and Sabina for the memorable day. It was a highlight for the staff, board and clients. It was a very special way to honour 30 years of providing vital services for our MND community. I feel very proud of the quality of the service that we have been able to provide this year and right across our 30 years.

2015 heralded the arrival of our third nurse Katie Kinsella. Her appointment was only made possible by the generosity of the Irish public during the Ice Bucket Challenge in 2014. Katie is a superb and much needed edition to the IMNDA team. She is looking after the Munster Region and hopefully we will be able to continue having a third nurse well in to the future.

2015 also saw a few more arrivals! I would like to extend my exuberant congratulations to Derbhla Wynne and Gemma Watts on the births of their baby girls. Gayle Cummins also started with the IMNDA as maternity cover for Gemma's position and we were blessed to benefit from her enthusiasm and expertise.

We had another highly successful Drink Tea for MND this year with just over €60,000 being raised from our annual campaign. While €60,000 is quite a significant sum, it is priceless compared to the excellent awareness generated thanks to Loretto Dempsey and countless MND families across Ireland who gave national and regional interviews. Truly you were amazing and we can't thank you enough.

And finally I would just like to thank everyone for their continued support, Motor Neurone Disease has finally come to the fore front in the public's eye and we thank each and every one of you for helping us to make that happen. Let's hope that we can continue doing that and fulfil our vision, a world free from MND. I have never felt more confident that someday this may become a reality.

Aisling Farrell
CEO

DIARY DATES – DO SOMETHING SPECIAL IN 2015

10th OCT	**CROKE PARK ABSEILS** Hogan Stand, Croke Park Stadium, Dublin 10th October 2015 (back up date 17th October)
25th OCT	**LIMERICK WOMEN'S MINI MARATHON** Limerick City - 25th October 2015 www.limerickminimarathon.com
26th OCT	**DUBLIN CITY MARATHON** Dublin City - 26th October 2015 www.dublinmarathon.ie
28th NOV	**30TH ANNIVERSARY MEMORIAL SERVICE** The Law Society of Ireland, Blackhall Place, Dublin 7 28th November 2015
09th DEC	**ANNUAL GRAND RAFFLE DRAW & CHRISTMAS COFFEE MORNING** Richmond Room, Carmichael House, North Brunswick St, Dublin 7 Wednesday 9th December @ 11:30am

Registering your Fundraising Event

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

To register and receive promo items / lodgement slip etc:

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

Thank you for your support and co-operation.

iMNDA
CARE AND RESEARCH

Irish Motor Neurone Disease Association
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www.facebook.com/irishmnd2011

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IMNDA Bank Account details:

'Motor Neurone Disease Association'
AIB, Capel Street
Sort Code: 93-13-14 **Acc No.** 07725002
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BIC/SWIFT: AIBKIE2D

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NEWS & RESEARCH

AGM / Patient & Carer Weekend Charleville 2015

In September of this year, the IMNDA's 30th Anniversary AGM, Annual Conference and Patient & Carer weekend took place at the Charleville Park Hotel in Cork. The event was well attended with around 100 delegates coming along. The business part of the weekend took place on Saturday morning where the IMNDA's Board of Directors reviewed the operations and financial performance of the organisation in 2014.

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

First up was **Aisling Farrell**, the IMNDA's CEO. She welcomed everyone to the conference and thanked people for their generosity and support throughout the year. She made special mention of Loretto Dempsey who did a masterful job being the face and voice of the IMNDA's National Awareness Campaign 2015.

Dr Sinead Maguire was next up. Sinead is the Neurology Research Registrar in Beaumont Hospital and the Academic Unit of Neurology in Trinity College Dublin. Sinead spoke extensively about the updates in MND research and what exact research projects the Ice Bucket Challenge money will fund. She also delivered a presentation on developing a framework for early intervention in palliative care in MND.

She explained that the Ice Bucket funds were set aside for four specific projects which were carefully chosen as cutting edge research initiatives. She laid out each research topic and described exactly what each initiative aimed to achieve.

The four projects discussed detailed are:

1. Irish ALS/MND Register
2. Neuropsychiatric Diseases
3. Genomics of MND
4. Multidisciplinary Care and Health Services Research

The **Irish ALS/MND Register** is the longest running population based register in the world. The register has over 2,100 patients from Republic of Ireland over 20 years with 1,050 DNA samples stored in the DNA bank. This is pivotal as it provides insights into the basic demographics and core Clinical Details from which a lot of research is derived. The register examines disease prevalence, incidence and survival. The funds permit a high level capture of data and will fund a dedicated research manager.

The second project is to look comprehensively at **Neuropsychiatric Diseases**. These diseases include conditions such as Schizophrenia, Obsessive Compulsive Disorder, Autism and Bipolar Disorder. The reason this section of study has been selected as it has been observed that neuropsychiatric conditions can occur with higher than expected frequency among some MND families. This observation implies that the genetic basis to some forms of MND is shared with some forms of psychiatric disease. This study will aim to identify new pathways from which new drugs could be developed to slow disease progression.

The third area selected is that of **Genomics**. Effectively it is a study to look at the genetic makeup of ALS/MND to try and determine the genetic reasons for ALS/MND to discover potential treatments. This international project is called **Project MinE**. 22,500 genomes or full DNA profiles, will be sequenced by research groups from at least 13 different countries. Ireland's contribution is 1,050 genomes and will cost approximately €2 million.

The last research topic is Multidisciplinary Care and Health Services Research. The involvement of a Multidisciplinary Team support at a MND clinic is known to improve survival. The research team want to look at this further to try and understand why this is so and to what extent. They also want to enhance patient and carer experience and satisfaction.

Sinead then went on to speak about her specific area of research which involves determining how best to provide access to palliative care for MND. She stressed how early intervention has been proven to be beneficial and that Palliative Care should be a part of the ongoing management of MND. She concluded that there is often the perception that palliative care occurs traditionally at the "end stage" of the disease but really it is about symptom management, maximising quality of life and minimising the burden of the disease.

Next to speak was **Dr Aisling Ryan**. Dr Ryan is a Consultant Neurologist in Cork University Hospital and also Clinical Senior Lecturer in UCC. As well as establishing and leading the specialist MND clinic in CUH, Aisling has been medical patron of IMNDA since 2013. She delivered a presentation on an update on MND in Ireland.

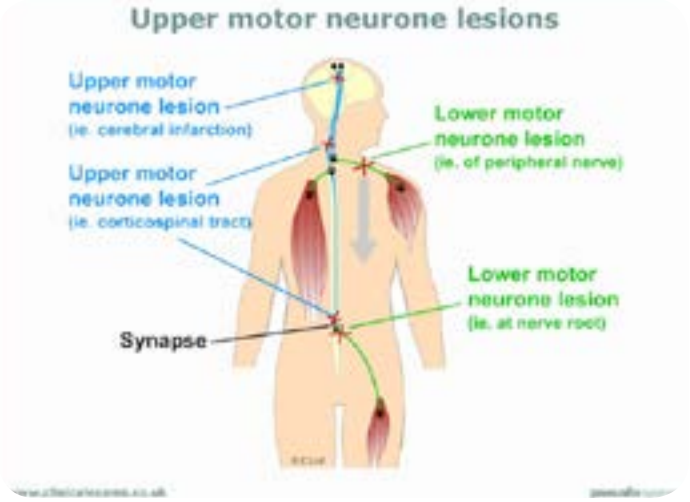
She started by explaining the important role of the Multidisciplinary team in the clinic and their role in patient care. Research has shown that by interacting with a Multidisciplinary team helps you live better, and maybe longer, with MND. It has also shown that the health professionals can give you better care and advice when they are knowledgeable about MND and have a coordinated, multidisciplinary approach to care. It allows the medical team to ensure maintenance of quality of life despite deterioration in strength and function. Both MND patient and professional are better informed and approaches to care can be individually tailored as changes in patient wellbeing are more closely monitored.

She spoke about common questions she is often asked in the clinic. A recurrent question that is often put before her is, "What type of MND do I have?"

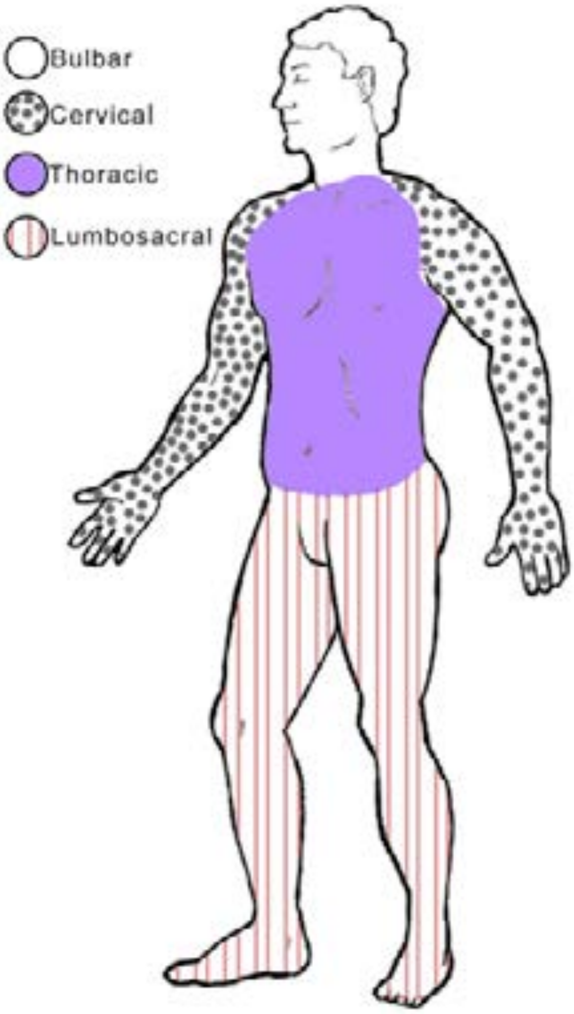
She outlined the 4 main types of MND:

- Classical MND
- Primary Lateral Sclerosis
- Progressive Muscular Atrophy
- Progressive Bulbar Palsy
- Familial MND

Classical MND is the most common form of this syndrome and is often called ALS, Amyotrophic Lateral Sclerosis. The individual experiences a progressive deterioration of the nerve cells and experience loss of motor function in hands, feet, arms, and legs, in addition to difficulty chewing, speaking, and swallowing.



She showed diagrammatically what regions in the body were involved.



Primary Lateral Sclerosis (PLS) is a progressive degeneration of the upper motor neurones and is characterised by progressive spasticity. This is a very slow progressing form of MND and is very rare. It is a clinical diagnosis made by exclusion of other known disorders. People can live upwards of 20 years with PLS.

Progressive Muscular Atrophy (PMA) is again characterised by progressive degeneration of the lower motor neurones. Early symptoms may be noticed as weakness or clumsiness of the hand. Most people will live for more than five years with PMA. Common symptoms include weakness, muscle wasting, weight loss and fatigue. About 5-7% percent of people with MND have PMA. More men are affected by PMA than women and the average age at which PMA manifests is less than 50 years old. PMA generally has a longer life expectancy than classical MND.

Progressive bulbar palsy (PBP) affects about a quarter of people diagnosed, and involves both the upper and lower motor neurones. Symptoms may include slurring of speech or difficulty swallowing. Life expectancy is between six months and three years from onset of symptoms.

Another common question that Dr Ryan is often asked, **"Is MND genetic?"**

She explained that most cases of MND occur with no apparent family history. About 10% of cases may have a family history, this is often referred to as familial MND and through research several genes have been identified that cause MND. One such gene is C9ORF72 and it has been revealed to cause about 40% of familial cases. They have also discovered a clinical, genetic and pathological overlap between MND and frontotemporal degeneration (FTD).

One of the ways we are investigating the genetics of ALS in Ireland is by harnessing a principle called identity-by-descent. Using enormous datasets already generated in previous projects, we are able to tell which portions of the genome have been inherited from the same ancestor in any given pair of patients. We have observed that, interestingly, there is some level of hidden relatedness for many pairs of patients previously thought to be unrelated, and it is possible that this shared ancestry has led to increased ALS risk. Ireland is the ideal place for such studies, with a small population and large family sizes. These findings help us to reconstruct the family structures of ALS patients which are immensely useful in the design of our genome sequencing projects. The ultimate goal is to determine the genetic cause of ALS in every case in Ireland. This is necessary if effective therapies are to be developed, tested and ultimately administered to patients.

Dr Aisling Ryan then went on to discuss possible treatments. Currently there is on one proven therapy to date, a glutamate-release antagonist called Rilutek (Riluzole). There have been many agents tried and that are in trial at the moment. She spoke about Edavarone. This drug has recently been approved for use in ALS in Japan but not approved for use in other countries as during trials it failed to demonstrate efficacy of Edaravone to delay the progression of ALS. Another drug mentioned was GM604. This has shown in Pre-clinical studies in ALS animal models to have neuroprotective properties. This drug still requires further testing in larger scale clinical trials; however, with this should hopefully come some positive outcomes. She concluded that there is hope on the horizon and is adamant that with the worldwide collaborative research effort that we will eventually identify safe and effective therapies for MND.

Grattan Donnelly was our next speaker and he has written a piece below on **Mindfulness and Acceptance**.

Picture the scene. Roughly 70 people sitting in the main hall at the IMNDA 2015 conference Annual Conference, with their eyes closed. No, they weren't sleeping, they were doing mindfulness training.

What is mindfulness?

Trying to convey what mindfulness is in language often leaves more questions than answers. Understanding comes best through the experience and practice of mindfulness - which is the key reason I invited the audience to try it for themselves. And with regular practice, as mindfulness is often subtle and personal, people's understanding shifts and deepens.

Jon Kabat-Zinn, widely recognised as the person who has done most to bring mindfulness to western audiences, describes mindfulness as ***"paying attention, on purpose, in the present moment, non-judgementally, as if your life depended on it. Actually, mindfulness is what comes from paying attention on purpose in the present moment, non-judgementally, as if your life depended on it. Which is nothing more than awareness, something we are intimately familiar with, yet complete strangers to."***

This definition may capture some of the nuance of what mindfulness is. Put simply, mindfulness is a meditation practice – based on ancient eastern traditions going back 2,500 years - that through focusing on the breath develops our muscle of attention and enables us to be more in the present moment. As we exercise our muscle of attention and it becomes stronger, our awareness widens, and how we perceive things changes too.

Mindfulness training helps us to be more in the present moment, and not be lost in our thoughts. Very often, our mind wanders and it is usually to thoughts worrying about the future, recalling things from our past or evaluating what's happening now. With mindfulness, we can learn to recognise these are just thoughts, and we can return our focus to our breath, and the present moment. Thoughts are like clouds in the sky, constantly coming and going.

What are the benefits of mindfulness?

Practicing mindfulness helps shift us from 'autopilot' – living in our heads – to 'manual' where we learn to 'be', just being in the present moment. Research has shown that regular mindfulness training can help people to feel less stressed, less anxious and more calm. It can also improve sleep, enhance your immune systems and help people to have a better quality of life.

Six or eight-week MBSR (Mindfulness Based Stress Reduction) Programmes are widely available throughout Ireland. You can also find free online MBSR programmes (e.g. http://palousemindfulness.com/selfguidedMBSR_week0.html), and if you choose to do this, I recommend you contact the programme provider before you undertake the programme.

What has mindfulness got to do with acceptance?

With mindfulness we can cultivate the ability to be with whatever thoughts, feelings, emotions, sensations, or pain are present. Acceptance is the ability to be with whatever is there, and to not to make bad things worse. Not adding to the pain or negative emotions and thoughts calls for wise action. It also calls for great patience, something that can also be developed with mindfulness. Acceptance then is also an act of courage, of recognising and facing reality, rather than fighting it or running from it.

Some audience members shared stories of how acceptance was the key difference in how they came to terms with having MND. Andy McGovern shared how once he accepted he had MND, it changed how he lived his life. He now lives for each day, enjoys the simple pleasures of life, including a few pints.

For the month of October there is a mindfulness summit, perhaps a good way to find out more about mindfulness. You can visit the website at: http://themindfulnesssummit.com.

Grattan Donnelly is a Senior Trainer with The Potential Project and delivered a Mindfulness @ Work programme for the staff of the IMNDA. This was recognised as an important initiative, providing care for the carers. Please feel free to contact Grattan directly if you have any questions related to mindfulness call 086-2252737 or email grattan.donnelly@potentialproject.com

The final speaker on the bill was **Rabi Panda**, Senior Occupational Therapist (OT) at Cork University Hospital. He spoke about the role of Occupational Therapy in MND.

An occupational therapist (OT) helps to maintain mobility, function and independence. OTs can advise on different ways of performing tasks and the selection, acquisition and adaptation of disability aids. Occupational therapists can visit private homes to advice on equipment or home alterations. They enable people to lead a more productive, satisfying, and independent life.

The Occupational Therapy intervention begins with an assessment of the person's ability to do the daily activities of life and the home and social set up. A person diagnosed with MND may have difficulty, in doing their daily activities of life, due to a decrease in the physical ability associated with the MND.

Following the assessment, the Therapist will then analyse the person's physical skills and home environmental set up and then an Occupational Therapy Treatment plan is advised which may include any of the following.

1. **Remedial treatment (Improving Performance Skills)**

- Functional ADL Practice
- Upper limb and Hand Rehabilitation
- Coping Skills and Cognitive Strategies
- Fatigue Management

2. Compensatory treatment (Aids, Appliances and modifying environment)

- Assistive Aids to improve independence in self-care ADLs
- Provision of Mobility Aids such as wheelchair or the Mobility scooters or Power Wheelchair to compensate for the loss of mobility
- Adapted Aids and Devices to improve Instrumental ADLs which includes Kitchen task, Communication (such as use of Phone), Transport, Shopping and other Community activities
- Home and Environment Modification
- Facilitating returning to Driving and work

Last to speak was **Noel Noonan**. Noel spoke from a carer's perspective and about the lessons he learned when he took care of his wife Denise, who sadly passed away from MND in August 2011. Noel wrote an article in the 2013 Autumn Edition of the Connect Newsletter and he read it out loud for our conference audience.

"Being a full time carer for someone you love who is seriously ill is possibly the hardest thing anyone could take on in their life. To watch a partner or family member that you are caring for with MND and who is losing all their movement slowly but surely is very difficult. In hindsight for me the toughest part of all was the realisation that every night when everyone had gone home and Denise was asleep, I was on my own. It was then my brain started to go into overdrive with mostly negative thoughts. As a carer, to deal with this situation is very difficult. The trick here is to accept your situation. However this is not easy. I think the carer has to live with this.

We had a great marriage. However our relationship changed on the day Denise was diagnosed. From that second everything changed for our family. In hindsight everything I did from that day was for Denise. While she struggled in the early days to come to terms with MND, I had to step in and try to sort out the daily routine with the family. This marked the beginning of my time as a carer. Life moved along for two years. All was grand but then Denise became too sick to work, her speech was almost gone she was losing power in her hands and legs. What I learned at that stage however was that every obstacle can be overcome no matter how enormous, providing both people agree that they are in this together and we did that. It was never discussed that was just how it was. Going to the loo, periods etc [I thought at that point I was going to give up and run away]. I learnt though from the Home Help staff that these little challenges were nothing. I was making mountains out of molehills. Denise and Alice [H.H.] used to have a great laugh at me. These issues proved to be trivial because we worked as a team to get through them.

Another important lesson that I have learnt as an MND carer is as follows. Accept your mistakes and move on. My behaviour at times was not always what it should have been. The pressure was always on big time. The illness, the kids and my job all added to very high stress levels; right up to the end the stress levels were impossible. The most important thing I can say to other carers who may be in this very difficult position right now or who may be coming into the most difficult stage is that MND will never let up, it will never give you a break it keeps on getting tougher and tougher even impossible. However you are entitled to make mistakes, to get mad or even break a mug now and again. The situation entitles a person to, on occasion, let off steam. They were times that I wanted it all to end. I prayed for Denise to pass away, I hoped that this might end the constant pressure. Occasionally I used to get into a temper over little things, for example on one occasion I could not get Denise's pillow just right and Denise could not tell me the right position. We were both upset. I got mad. As usual though, Denise in the end won out. By looking in a different direction she let me know exactly what she thought of my behaviour. In the end her eye movement was all that she had left but by using only her eyes she would every time win all the debates and argument. However we made a pact. Denise would let me fly of the handle now again and when it was over she would give me a look that would say are you sorted now? I would say yes fine. She was amazing. This was a great trick between us; the air was cleared in an instant.

If I had to do it all again for Denise I would. Mistakes and all. I would never again complain. I still miss her. I miss the craic. She was my carer and I will never forget how she helped me to get through the toughest years in our marriage."

After the conference talks were over, Aisling Farrell CEO presented the Silver Pin Recognition Awards to people who contributed to the IMNDA over the last year. The association couldn’t function without the fantastic support received from so many people across the country. Each year at our AGM we like to select a small percentage of the people we feel dedicate their time and effort to our organisation. We like to acknowledge this by presenting them with an IMNDA Silver “Thumbs Up” pin and were delighted that so many of the recipients could attend and accept their award in person. Awards were given to Margaret Murphy, Sharon Friel, Paddy Butler, Loretto Dempsey, Niamh Ní Dhrisceoil, Claudia Fonteyne, Jerry Twomey, Kate Brosnan, Teresa Jordan, Rosemary Doherty and Francis Grisewood. These people truly went above and beyond for the IMNDA in 2015.

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

The evening entertainment resumed later that day when everyone spruced themselves up and met at a drinks reception followed by a delicious 3-course meal. Following dinner we had a lively Table Quiz and then were treated to some swing music.

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

Visit to Áras an Uachtaráin

In light of the special anniversary the IMNDA is marking this year, President Micheal D.Higgins and his wife Sabina invited 50 people involved with the association including our members, staff and board members, active fundraisers and dedicated volunteers who could make the journey to come along to the Áras an Uachtaráin.

We descended on the famous building in the Phoenix Park for a very pleasant afternoon in May where we eagerly awaited the arrival of the President. He spoke to each guest individually and mingled for some time whilst we enjoyed some presidential tea and cakes!

An enormous thank you to all the staff at the Aras especially the President for a very special afternoon for all who attended.

Equipment Tagging System

As most of you are aware, the IMNDA has a specialist equipment loan bank that is made available to all within the IMNDA community. Over our 30 years providing services to those living with MND, the IMNDA has purchased countless valuable and much needed pieces of specialised equipment that we loan out.

Unfortunately not all the equipment that we loan out is returned to our IMNDA stores. To stop this from happening we have upgraded our equipment database to a new online system called Salesforce. This is to ensure more accurate tracking of our stock. Now each piece of equipment is tagged before it leaves our stores and it means we have a complete stock of all our equipment. This tag should reduce the loss of equipment during repairs and removal.

In November 2014, the services team spent two full days in our stores in Co Wexford, tagging all large pieces of equipment and updating all details. These tags once put on can be scanned before leaving the stores and when the pieces are returned. This will update Salesforce automatically and helps keep track of all the equipment. These tags are small, green bands as pictured below. They are waterproof so will not be damaged when cleaning the equipment.

Nursing Service

Eithne, Katie and Fidelma are the IMNDA nurses, who work alongside the IMNDA and consultant neurologists throughout the country. As well as attending MND clinics, the nurses travel throughout the country providing nursing support to people who have been diagnosed with MND. They provide support to their families and carers by means of home visits, a help line and on-line contact. All three nurses have a vast level of experience working within the field of neurology and all three previously worked together on a neurological ward in Beaumont hospital.

Being nurses that specialise in Motor Neurone Disease means they play active roles in both patient and health care professional education to ensure the highest level of patient care is being delivered at all times.

The nursing service is active in its total approach to care, embracing physical, emotional, social and spiritual elements. It focuses on enhancement of quality of life for the client and support for the family and includes the management of distressing symptoms and provision of support and care throughout the journey of MND.

The MND nurses are central to the patient and family. They are also vital for links out to all of the services and health care professionals. They endeavour to co-ordinate a service that provides continuity of care for a case load of patients in collaboration with local health care professionals and carers, especially those with specific palliative care needs. The role applies to acute and community care settings. The nurse's act as an informed resource for health and social care professionals, involved in the care of the clients living with MND.

The nurses have designated areas to ensure a continuity of care and equitable service throughout the country.

Katie's Area

- Cork
- Kerry
- Waterford
- Wexford
- South Tipperary
- Carlow
- Kilkenny
- South Wicklow
- Laois

Eithne's area

- Sligo
- Roscommon
- Donegal
- Leitrim
- Longford
- Cavan
- Monaghan
- Kildare
- Louth

Fidelma's area:

- Mayo
- Galway
- Limerick
- Westmeath
- Meath
- Clare
- North Tipperary

Dublin is shared care by the three nurses.

Research Update

Ice Bucket Challenge Donations Fuel Significant Research Discovery

2015 saw round two of the MND/ALS Ice Bucket Challenge begin again. In the states Bridget Jones actor Renee Zellweger took on the icy challenge. Across the water Eddie Redmayne also got doused and many IMNDA supporters on our Fair Isle also filled up buckets to try beat MND one ice cube at a time – this August and every August until a cure.

But what was the result of all the money generated across the globe last year and why is funding still so pivotal? Well, researchers in Johns Hopkins have recently announced a significant research discovery relating to a protein called TDP-43. This discovery was made possible by MND/ALS Ice Bucket Challenge donations.

Cells in your body are constantly reading your DNA to make proteins. The TDP-43 protein is known to bind to and regulate RNA; this is the cellular messenger that converts genetic instructions into proteins. Most cases of ALS are characterized by accumulation of TDP-43 into clumps, or aggregates, which may indicate the protein is no longer able to carry out its normal function.

Researchers Jonathan Ling, Ph.D., Philip Wong, Ph.D., and colleagues at Johns Hopkins University in Baltimore, MD, showed that a specific function of TDP-43 is to bind to and repress cryptic exons, these are bits of genetic instruction that are not used to make protein under normal circumstances. The researchers showed that loss of TDP-43 increased the expression of cryptic exons, leading the cell to destroy messenger RNA containing them, thus reducing the amount of normal protein the cell made, and leading to cell death. They also found an abnormal increase in cryptic exon expression in the brains of people with ALS.

Dr. Jonathan Ling, a key researcher from this team explains more: ***'For nearly a decade, scientists have known that a protein called TDP-43 appears to clump together in the cells of almost every ALS patient. However, researchers have struggled to pinpoint its exact function. This month in the journal Science, our team here at Johns Hopkins has published a study that reveals a new function of TDP-43 that could explain exactly why TDP-43 is so important for cells. Specifically, we found that when TDP-43 was removed from a cell, stretches of DNA called 'cryptic exons' were being mistakenly used to create proteins. Without TDP-43, these cells eventually died. However, when we inserted a custom designed protein to suppress these cryptic exons, the cells remained healthy. If the neurons of ALS patients are dying because TDP-43 is no longer working properly, we may be able to fix this problem using a similar strategy!***

Currently, our lab is working hard to bring this to the clinic, although it will take years to complete proof of concept studies in mice and safety studies in higher order organisms. We are also working on developing new biomarkers for ALS based on the results of our work. With any luck, this will be a promising new direction for ALS research.'

In a recent "Ask Me Anything" (AMA) feature on Reddit, Dr. Ling commented: ***"All of your donations have been amazingly helpful and we have been working tirelessly to find a cure. With the amount of money that the ice bucket challenge raised, I feel that there's a lot of hope and optimism now for real, meaningful therapies. After all, the best medicines come from a full understanding of a disease and without the financial stability to do high risk, high reward research, none of this would be possible!"***

LIVING WITH MND

Walk with Eileen

“Always try to give more than you take is my motto. I was conscious that since the progression of my illness the reverse was usually the case. With the help of one friend initially – which increased and multiplied – we set out to rectify that.”

So says Eileen Finn who was diagnosed with Motor Neurone Disease in 2012 and who through her campaign “Walk with Eileen” raised over €70,000 for the Irish Motor Neurone Disease Association.

Eileen, a mother of four grown sons, who still continues to work as a lawyer, found the Irish Motor Neurone Disease Association to be a great support when she was diagnosed with her illness. “I was not entitled to any support from the State, so their services made a huge difference to me. I had to find a way to try to give something back.”

A friend, and Public Relations consultant, Ita Gibney, whom Eileen eloquently and aptly described as “somebody with a brass neck and a heart of gold”, sat down with her in March. Together they planned a three month campaign which was to culminate in walking (or more accurately pushing Eileen who is wheelchair bound) in the VHI Ladies Mini Marathon on 1st June. They set a target to raise €30,000 and initiated it on the mycharity.ie website.

“Eileen had run and walked many marathons in her day, and so we thought we could rally enough support around this event. I was also aware of the huge reserves of support out there for Eileen herself, who had borne her illness with such courage, good humour and grace under pressure. She had extraordinary support from family, a wide circle of friends, professional colleagues in the law and many many more who she had touched over the years. If they all came on board – well anything was possible,” said Ita.

The response was overwhelming. “People had cake sales, coffee mornings, raffles, a cheese & wine reception, and the donations came rolling in – large and small,” said Ita. “We organized the publication of an article by Eileen in The Irish Times, which seemed to set everyone on fire. ‘I am living with Motor Neurone Disease, as opposed to dying from it” ran the headline.

“A six year old boy brought his friends on a walk in Wicklow and raised 500euros. An 83 year old man gave a donation that was a large chunk out of his week’s pension. One of Ireland’s largest corporate law firms, William Fry Solicitors, chose Walk with Eileen as their charity for the coming year which will raise thousands more. People gave their time and their services for free. Messages of support as well as money poured in”, says Eileen, “We could not believe it.”

“People were touched and inspired as much by Eileen’s own spirit as by the cause. We reached our target of €30,000 a week before the Mini Marathon and so we raised the target to €50,000 and exceeded it on the day of the walk”, said Ita.

On June 1st 2015, an army of 50 women donned the IMNDA T shirts and outrageous hats, including Eileen herself, and set off in gale force wind and rain to a fast pace, pushing Eileen. Incidentally, Eileen’s award-winning hat was made by her carer and polish friend, Magda. Eileen had a bumpy ride but they completed the 10k in just over two hours. Celebrities tweeted Team Eileen along and a marching brass band, led by Eileen and her four sisters, played the small army over the finish line, straight into TV cameras and a host of supporters, including three of her sons and her two brothers. The footage made its way on to the main evening news bulletins, You Tube, and all the way to Australia, Florida and Columbia.

“It was an incredible day,” said Eileen. “Motor Neurone is deadly serious, but life can still be fun.”

Taking the Letters Back – Simon Fitzmaurice

Living with mnd you have all of the feelings, thoughts, joys and woes that everyone else has except some of your body doesn't work, and the longer you have it the more parts don't work. That's it.

Does it change your life? Like tectonic plates shifting in the earth. Yes it changes your life. How much? No one can map the human heart, however many claim otherwise.

Apart from the reductive generalisations above, I would not dare to speak of another's experience of mnd. I can only speak of my life.

The hardest thing about living with mnd is the distance it puts between me and those I love. The best thing about living with mnd is the living part. I love being alive.

You will notice that I choose to ignore the correct grammatical rule of capitalising the acronym MND. That may annoy some people (all letters on a postcard to the editor). Words have a powerful presence in my life. Those three letters and the words they represent shook me to my foundations.

It took me years to recover from the first earthquake they caused. And when I did get back my strength, they were never going to shout off the page at me again. Never. They are not the boss of me anymore. They know their place in the scheme of my life: mnd.

These three letters that shook my world would no longer define me. I would take the letters back:

- Make New Dreams
- Move New Directions
- Motivate Narrow-minded Doctors
- Miss Nice Dinners
- Millimetres Need Direction
- Movies Need Directors
- May Not Dance
- My Night and Day
- Mind Not Dead
- Mingle Near Dark
- Mission Not Decided
- Married Near Dundalk
- Much Needs Discussion
- Myopia Not Dementia
- Moles Navigate Darkness
- Maps Need Deciphering
- Meaning Necessitates Divination
- Must Not Die
- Mind Nesting Ducks
- Morning Nervous Dogs
- Monday Not Disastrous
- Molecular Nano Dimension
- Motorists Never Dally
- Mouth Not Dry
- Mother's Noodles Defend
- Motes of Nebulous Discovery
- Mountains North of Delhi
- Morning New Day
- Might Not Dip
- Might Not Die
- Might Near Distress
- Might Need Drugs
- Meet New Day
- My Nearest and Dearest
- My Nubile Darling
- My Nutcase Descendants
- My New Determination
- My Next Darkness
- My New Day
- My Nice Dog
- My New Direction
- Mind Nerves Dreams
- Move Nearer Darling
- Me Now Don't

Shape Shifting Emma Radio Documentary

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

"My body is crooked, twisted and unreliable but inside I am well thanks to this eye-gaze computer which allows me to express myself. I honestly think I wouldn't have made it this far if it wasn't for this amazing machine. I feel I am being true to myself in writing this blog," said Emma.

Before she sadly passed away on the February 2015, the eye gaze technology allowed Emma to upload posts to her blog. These posts gave an honest insight into Emma's life. Producer Jo Pickup had started making a radio documentary along with Emma's guidance before Emma died. Each episode consists of extracts from Emma's blog narrated by an actor (Orlaith McManus) interspersed with testimonies recorded with her family and friends. This five part radio documentary for UCC radio station's UCC 98.3FM is very powerful and you can listen to it online at: http://www.ucc.ie/en/983fm/documentaries/shapeshiftingemma/

We have previously printed pieces from Emma's blog and to reinforce the inspiration that she was we have included some very poignant posts from last year.

Like a Prayer – posted 10th October 2014

" I felt tiny wirey legs scuttle across my neck earlier. My carers looked as if they'd seen something repulsive. I was still waiting for an answer about the neck tickler when the tissue emerged hoping to squash the hairy little fella into oblivion. Poor little spider, "little? ", he was frickin massivo, I was told. Anyway, spiders are lucky for me and if a big one treaded on me well that's even luckier.

I could do with a bit of luck in the chest area overall as I've been experiencing difficulty with my breath. Nothing major though but it's a change and from where I'm sitting, change is frightening. I've spent a lot of days of endless crying over my mortality and furious with life for inflicting this on me. One afternoon I broke down seeing a mum loading shopping in her car and kids inside, just like I used to do, it's heartbreaking what I and so many other mums in my situation have been denied.

I find it so hard to write when I'm down. This week I feel much better especially since Lucy's' visit and wonderful laughter crept back into the house. Lucy's' a tonic for the soul and I love when she's here. I feel close to my lovely Dad when she's around as she shares the same quirky sense of humour as he had.

I want also to praise Jonnie because he's so amazing. I hear him getting up early each morning to meditate [he's been doing that for years]. Then coaxing kids from their cosy beds and getting them out the door on time. At weekends he rarely goes out as we've less help and it's full on with the kids. Rowan does rugby on Saturday mornings now and Kitty's started soccer. They look great in all the gear and the sound of them clunking into my bedroom on wooden floorboards to kiss me goodbye is adorable.

Every weekend Jonnie cooks a roast on Sundays. Roast spuds, mashed, veggies, gravy, the works! Often, a freshly baked cake too. Then there's the tidy up as anyone engaged in this activity on a regular basis knows. Every evening, Jonnie gets me ready for bed and does things no husband should ever have to do for his wife. My love for him has grown deeper than I ever could imagined. I respect him so much and appreciate everything he does to keep our family going as normally as possible. Our kids are happy and have lots of interests and thankfully good at doing their homework every afternoon.

Jonnie often reminds me of the importance of meditation in his life. Without the practice of being still and knowing that all will be ok, our family might not have made it to here. I don't practice regular meditation any more. I did it for years before I got MND. Perhaps it's the fact that I'm sitting down constantly and being still whether I like it or not, my life feels like some kind of meditation or prayer.

Freak-Heart – posted 17th November 2014

I was taken by ambulance Tuesday afternoon to Cork University Hospital with a heart racing at one hundred and seventy. That was before I was wheeled onto it. It has stayed normal between seventy and one hundred since then.

I'd been awake since half seven Tuesday morning with a heart thumping so fast I thought it would jump straight out of my chest. My doctor strongly recommended hospital and I shuddered at the thought.

Luckily Lucy and Tomas are back from France for a few months and are more than happy to stay with the kids. Jonnie stayed the two nights with me as I was released Thursday! They don't know why my heart was racing and after countless scans and twenty four hour observation, they let me go as all is normal again thankfully.

Some nurses and doctors in the hospital don't seem to know how to speak to me. They have a few different approaches;

1. They address Justine one of my carers instead of me.
2. They address me as if I'm retarded. [Excuse non pc word, its anger talking]
3. They shout at me as if my ears have been affected too by my illness.
4. They address me with overwhelming pity saying "creature, you poor unfortunate darling". And they often do this silly looking wave goodbye like you might do to a child.

What I want is to be treated like a normal human being. I believe it's my right. It's such a horrendous illness and it's hard enough to bear without being treated like some kind of freak. ”

Margaret Murphy - A Carer's Perspective

“Just over three years ago, our middle daughter Sharon was diagnosed with Motor Neurone Disease. We were devastated and still are. She was 38 years old, healthy, happily married with a three year old son and a successful career. Today Sharon cannot walk or talk and at 41 is permanently confined to a wheelchair. How life can change in such a short space of time. Our beautiful daughter is totally dependent on her carers. Her number one carer is her husband. He has a full time career and is such an amazing man. He provides Sharon with 24/7 love and care. He attends to every detail of her care, not to mention also looking after the normalities of any family life like shopping, cooking and cleaning. The parenting of their 7 year old son, Senan, as in any family, demands time and attention.

This involves taking him to school each day with a packed lunch, collecting him from after-school each evening, supervising his homework, involving him in after-school activities and having father- son playtime. These activities, which Sharon once enjoyed managing, can now be only viewed by her from her wheelchair.

As a mother, it breaks my heart to see life so restricted for Sharon. The loss of her voice is one of the hardest losses she has incurred. One of Sharon's great qualities was her ability to socialise. She loved nothing better than chatting with family, her wide range of friends and work colleagues. Despite what MND has stolen from Sharon she still displays her huge personality. Her sense of humour is still to the fore and never fails to entertain us all through the medium of her iPad. The inspiration that emanates from Sharon is incredible and she constantly astounds me. I continuously admire the strength, courage and the love she displays to us all. She is the one that keeps up our morale.

Sharon loves an afternoon shopping. How and where she creates the ideas for endless gifts never fails to baffle me. On the mention of a shopping expedition, we get our makeup on; hair sorted and be loaded up and down the motorway in her "Bingo Bus" in a wink of her eye! Such an event always results in the car packed on the return journey home. It's a privilege to spend such quality time with Sharon. Through this time we have developed a huge understanding between us and I have developed an inner strength. I focus on enjoying quality time with Sharon whether it be taking her to appointments, giving her a foot massage or cooking up something tasty for our lunch together. We share a similar sense of humour. Yes we shed tears together but we giggle a lot also.

I could never have envisaged how our family's lives could be changed so severely in such a short few years but we have all become closer and stronger. Her older sister, Niamh, who lives in LA with her family, comes home frequently sometimes taking her two young children. Our family get togethers at this time are particularly special for us. Grainne, her younger sister who lives relatively local, regularly collects Senan for sleepovers or adventures. Saturday morning could be visiting the local farmer for eggs, baking or building Lego towers. Sharon's Dad is our hands-on man. He loves nothing better than a challenge to modify equipment in order to assist or make life a little easier. He has equipped all our homes with wheelchair ramps for easier access in and out of doorways. As grandparents we get to spend lots of time with Senan taking him swimming or walking through the fields and much more fun activities.

Sharon's professional carers attend to her three times per day. Despite her horrendous illness her great sense of humour still shows and she never fails to entertain those working with her. She delights in telling us all how she has the A team in attendance. Senan, who has just turned seven is also on hand when the team arrive at night. He is the real super hero in our family. He has adapted so well to the situation that surrounds him and takes so much in his stride. His explanation of his Mum's condition is often so simple and uncomplicated thanks to the honest but simple way his Dad talks to him about it. He happily joins in to assist with the carers every night so as to participate in the fun and craic.

Carers come in every shape, make and creed. The privilege of being a carer has had a profound impact on me. I believe it has given me a greater insight into both the fragility and the beauty of life. It has also helped me today to appreciate and treasure the gems in my life. ”

Margaret Murphy

Kathleen & David Burkhill

This is our story....

“We retired from the UK to live in Malaysia in 2005. David was a Painter and Decorator who was sick and tired of cold wet winters, I was a nurse ready to retire. So with our cat in tow we headed off for Penang, Malaysia, under a retirement scheme called “Malaysia My Second Home”. Our life in the sun as X Pats started.

Three years later, November 2008, I noticed David’s upper arm muscles twitching which took us to see a Neurologist in Penang. He suggested going to see a Specialist in Kuala Lumpur, a Professor Goh at the University of Malaya, which we did. It was not until February 2010 that David was diagnosed with Motor Neurone Disease and commenced Riluteck 50mg twice daily.

2010 was a very hard year, David looked up Motor Neurone on the internet and had himself dead and buried within two years. I had nursed two people with this condition during my nursing career and knew a ‘little’ more about it but still found it very difficult to come to terms with it. We eventually pulled ourselves together and decided to take each day as it came.

David’s condition gradually deteriorated over time and what started with weakness in his arms and hands gradually went into both legs. He attended Physio and kept swimming until he started to fall and I was unable to lift him. It was then that we decided to come home to Ireland to be near family who live in Co. Longford.

April 28th 2013, with cat in tow, we arrived in Ireland. We had made contact from Penang with Professor Hardiman and had an appointment in June to see her and the team at Beaumont Hospital where we met the Motor Neurone Nurse Specialist, Eithne. She has been our Guardian Angel ever since.

Having lived and worked in UK longer than I lived in Ireland, it took some time to get to know the Irish System. Getting PPS numbers, medical cards and mobility was a challenge in itself but we got there in the end. Before we left Penang we had organised a property to rent near ‘home’ and had a list of properties to view with the intention of purchasing a bungalow suitable for David’s needs now and in the future. We found the perfect place and had it renovated into a ‘home’ for us. We moved into our new home in a new country in December 2013.

David is well, apart from MND. Thankfully his speech and swallowing are not affected. He is chair bound and needs full nursing care with all activities of daily living. He enjoys a glass or three of wine through a straw and likes a good meal out. He can use the up/down buttons on the lap top with one finger when his hands are propped on the table and reads the morning papers. He enjoys sport on the TV...cricket, F1 and rugby league. Thanks to the CRC for supplying him with a device that he can change channels himself. I have two intercom devices strategically placed which allows me to do some gardening and still listen out in case David wants anything. He has taught me to use an electric screw driver/drill, hang wall paper, paint fences and wash cars. He was always good at DIY but now it’s my turn! We make a good team.

We have a good life thanks to many people from family, medical professionals, friends and helpers, We thank you all sincerely. We have our affairs in order no matter what the future holds. We have no regrets.

Having bit his finger nails all his life, he now can’t...every cloud....!!!!!!!!!!!!!!!!!!!!”

FUNDRAISING

Drink Tea for MND

"Sometimes I think it is unfair that as well as dying young you have to waste away slowly,"
Loretto Dempsey

MND National Awareness Campaign

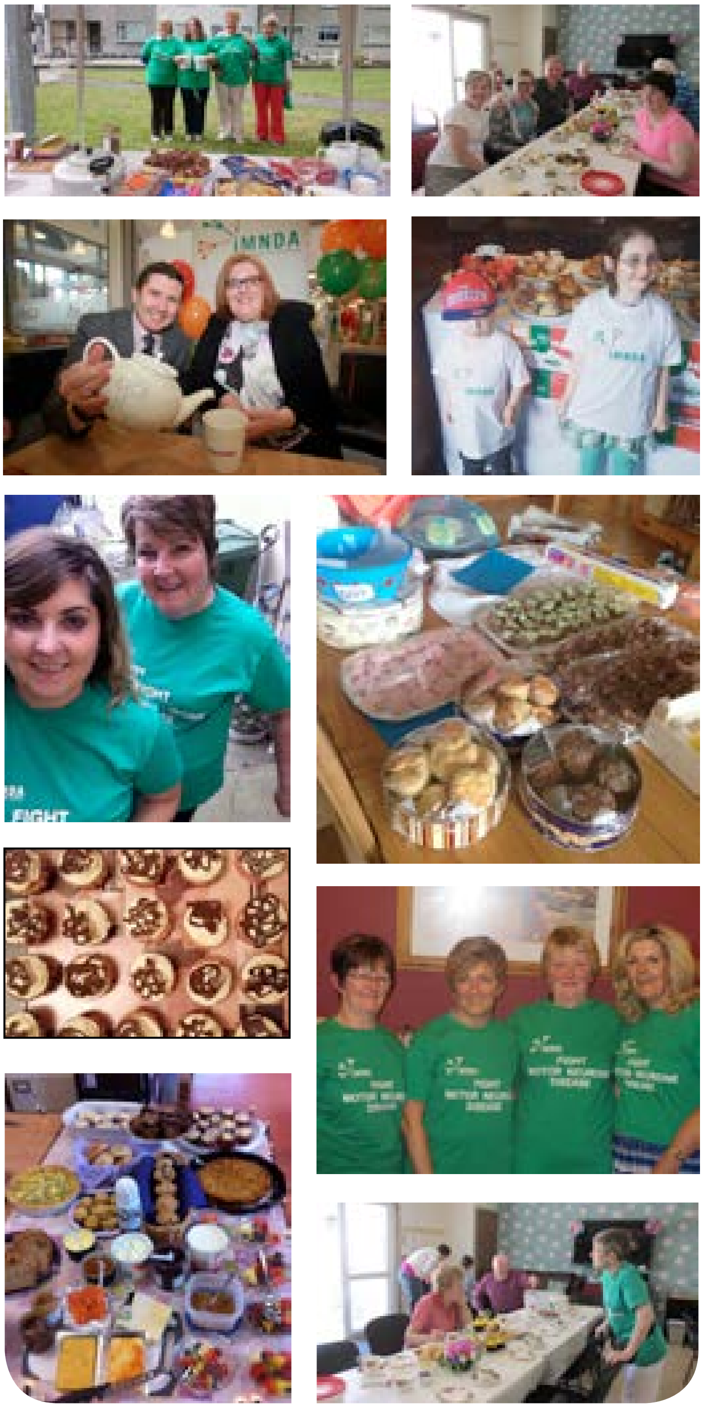
On the 21st June we mark Global Awareness Day. In April, Loretto Dempsey recorded Radio Adverts to raise awareness about MND and to draw people's attention to the difficulties she faces every day.

Loretto is 50 years old. In March 2014 she was diagnosed with MND. Loretto used to be a baker. She would spend all day in the kitchen, lifting bags of flour and making treats to feed an army. Now she can't move the fingers on her left hand and needs somebody to chop up her dinner and feed her.

"I am the same person I always was, I just know that I will be dead in a couple of years. Everyone has to die of something and if I had a heart attack I would be gone already. Just because I can't physically do things doesn't mean I can't still enjoy what I can do. You can't say "Actually I don't want MND. I want to give it back thanks, I kept the receipt", said Loretto.

Loretto shared her story about her terminal disease in the hope that greater awareness would generate increased support for those living with this degenerative condition. The campaign ran throughout the month of June to mark Global MND/ALS Day on June 21st. Loretto appealed to people to Drink Tea for MND and organise Tea Days in their homes, communities and work places.

Thanks to Loretto's encouragement, and Supervalu's sponsorship, over 125 people did just that, they baked and brewed and helped spread the word about MND. We can't thank Loretto and everyone enough for their support and want you to know it truly has made an impact. Tea days took place right across the country, from Donegal to Dublin, in Cavan and Cork! We had the whole of Ireland drinking our SuperValu tea bags and we raised a teatastic €56,632.55!!!



Getting Active for Your Association

Thank you for getting active for your Association!

ON YOUR BIKE

For the third year running Paul Lannon's D2K Cycle hit the roads on June 6th & 7th. The 180k cycle from Dunleer to Kilkenny hosted an amazing 120 riders and a whopping €39,020 was raised and divided between the IMNDA and Pauls Fight for Life. An absolutely amazing achievement – thank you so much Paul and Sandra!!!

A huge thanks to John Hynes and Panda Power for organising the fantastic East Meath Cycle. Hundreds descended on Stramullen GAA on August 16 to cycle 45k, 70k or 100k and raised almost €3,000!.

A massive thank you to Intel and the 220 employees who cycled routes of 40km, 80km and 160km, and arrived in Tayto Park on September 04. Well done guys - we really appreciate it!! Thanks also to Paul Lannon for welcoming all the cyclists in and for giving an inspiring speech. Great day and great achievement by everyone!!

A special thanks to Kevin McGrath for organising the Nenagh to Galway Cycle for a second time and raising a brilliant €3,426, Pearse Foley for raising a fantastic €1,230. in the Giro De Baille cycling event on August 02, Steven Bergin and all his friends for raising a brilliant €5,303 in the Mizen to Malin Cycle and Nicholas Geaney who took on the Ring of Kerry Cycle and raised a brilliant €300

ON YOUR MARKS, GET SET – RUN, JOG OR WALK!!

On Good Friday, more than 550 walkers, joggers and runners descended on St. Anne's Park on Dublin's Northside for the inaugural Good Run. A massive thank you to Olivia Tracey and family for organising this exciting new fun run to raise funds to support the fight against Motor Neurone Disease. An amazing €11,500 was raised and divided between the IMNDA and Project MinE. Also on Good Friday, the staff from Louch Rynn Castle organised a 10k walk/run and raised a fantastic €1,396!! Thanks to you all!!

A huge thank you to all involved with the Walk with Eileen fundraising campaign. The terrific troop who took on the VHI women's mini marathon with Eileen Finn raised an outstanding €72,418. The incredible sum is deeply appreciated, a phenomenal feat – well done ladies!

To all the brilliant ladies who took part in the VHI Womens Mini Marathon, you really do deserve your medal after braving the elements and raising over €30,000 for IMNDA.

Thanks to everyone who took park in half and full marathons this year - Paddy Clarke who took on the Clontarf Half Marathon, Simon Delaney who completed the Vancouver marathon, Tess Healy for completing the Munster Mini Marathon.

A massive thank you to everyone who joined us on our annual walk to D-Feet on July 18th in the beautiful surroundings of Castletown House in Celbridge, Co. Kildare. A special thanks to Paddy Butler and his family who joined us in the walk and made the day all the more significant. Over €5,000 was raised on the day.

A special mention must go to the O'Shaunghnessy family who organised the fantastic Lugnaquilla Walk and raised an unbelievable €19,141. Lugnaquilla is the highest mountain in Leinster and the 13th highest peak in Ireland so no mean feat!! Well done everyone and a huge thanks to all who took part and made donations.

Thanks also to Chloe Conlon who did the Camino de Santiago and raised almost €500!

FUN-raising

A massive thank you to Michael O'Mahony and all involved with the Tractor Run in Baltimore. The fantastic event raised €3,725. A BIG shout out to Pauline Breslin and all the crew who organised their tractor run in Longrod and raised a brilliant €2,482.

Well done to all the U12 players, mentors and supporters in St. Mary's Donore GAA for raising an incredible €1,200 from their 5k charity solo run. Phenomenal amount and great achievement!

A big thank you to the J Division of An Garda Siochana who raised a brilliant €280 through their football event, Kehoe's Craft butchers in Co. Tipperary who raised €345 by standing on a stool outside the butcher shop and Noel Quinn climbed Croagh Patrick and raised over €400!

A huge thanks Pat Leacy and all involved in the Ford Cortinas & Honda 50 Enthusiasts Clubs We really appreciate all your efforts to help raise €7,000.00 and awareness for the association.

Sean Allen organised the Comet Pub shaving event and brought in a fabulous €766.

STRICTLY COME DANCING

Nicola Maguire put her dancing shoes on and danced all the way to winning the Strictly Come Dancing competition whilst raising a fantastic €250 for IMNDA. Ali Davis and her Shakers Hip Hop Dance Club raised a brilliant €510 through the end of year show raffle.

GOLF

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

A special thanks to Leo Levans and Cathal Dervin for organising A Day for Ray in memory of the great Ray Treacy in Hollystown Golf Club on August 15 and raising a brilliant €4,250.

To all our fantastic lady golfers – thank you!! Mary Kennedy and all the ladies in Bellewstown Golf Club raised an amazing €3,180 at their 3 ball scramble competition, Yvonne Cloherty who organised the Connemara Golf Isles AM AM in July and raised a brilliant €400, Regina O'Regan organised her golf event in Esker Hill Golf Club and raised over €300.

HELL AND BACK

To all those who went through Hell to help support the IMNDA, thank you!! Brian Finnegan, Ann Comerford, Dwayne Bryne, Patricia O'Brien and Robert Barnwall!

Nearly 30 years of Fundraising by Anthony Martin

Anthony Martin has been running and fundraising for the IMNDA for nearly 30 years. This is Anthony's story and why he has pounded miles of pavements for Motor Neurone Disease.

"My name is Anthony Martin. I was born in Cavan in 1952 to Christine and Michael Martin. I had two sisters and three brothers. I am the youngest and was well cared for.

Near the end of 1988 my mammy Christine complained of her throat. She had no other complaints. But her throat got worse and worse by April 89 she was fading away. The doctors said it was motor neurone disease and this was the first I had ever heard of this disease. On the night mammy died she walked to the bathroom herself. Went to bed that evening it was 14 May 1989 mammy died aged 69. It was after mammy past we got talking about her father Patrick Reid Who died in 1935 from what doctors called a muscle wasting disease!

In 1995 my sister Kathleen started to trip over nothing and developed a limp. Soon after, she was diagnosed with Motor Neurone Disease. She had three young children. She lived in Cavan with her husband Hugh. The disease progressed through her; her husband was very good but could not do it alone. They got in touch with the Irish Motor Neurone Disease Association and received a tremendous help.

Kathleen fought on but life got harder as the Motor Neuron Disease took over. Sadly Kathleen's husband passed 11 February 2000 aged 60 from a heart attack. Without the help from the Irish Motor Neurone Disease Association, Kathleen would not have been able to attend the funeral. Kathleen passed 25 July 2000 aged 55 years leaving behind 3 children.

Late in 1998, my brother Jerry got a diagnosis of Motor Neurone Disease; it also started in his throat and progressed quickly. He went into the hospice in January 1999, where he received help and support from the Irish Motor Neurone Disease Association. Jerry passed on the 1 March 1999, aged 51.

In 2010 my brother Bernard got a feeling in his throat. He said it was like a piece of glass but doctors couldn't find anything wrong. Bernard had an uneasy feeling. By 2011 Bernard was showing other symptoms. In 2013 we got in touch with the Irish motor neuron disease Association. They were an immense support. Bernard did not want to go into hospital so with the help of his partner Breada and the Irish Motor Neurone Disease Association life at home was made as comfortable as could be. Eventually Bernard had to go into the hospice where he got great care and continue to use the equipment on loan from Irish Motor Neurone Disease Association. Bernard past 23rd of August 2014 aged 66 years.

The thing about a diagnosis of Motor Neurone Disease is you don't know what to ask for, you don't know what you will need, but the Irish Motor Neurone Disease Association know exactly what will help you and they have it for you all you need to do is call them and they will be there for you. They put on great fundraising events. Whenever possible I like to take part. Apart from it being for a great because it's always great fun."

Upcoming Events

Croke Park Abseil 2015

All-Ireland winners Richie Power and Ciaran Kilkenny, along with the Gaelic Players Association (GPA), kindly supported our Abseil this year. The county Champs fresh off the training pitch kindly took to the dizzying heights of the Hogan Stand to take a stand against MND.

It takes a lot of courage to live with MND and the players wanted people to have a little courage and take the 100ft leap of faith to raise funds and awareness for this progressive, terminal and incurable disease.

Around 50 dare devils responded to the call and will be taking on the challenge on Saturday 10th of October. We just want to extend a massive thank you to Richie Power, Ciaran Kilkenny, the GPA, Anto Finnegan and Croke Park for making it all happen.

Sponsored Silence 2016

Sometimes Silence Speaks Volumes

Imagine not being able to say 'I Love You'. February is the month of love where couples from across the world openly celebrate their affection for each other. But imagine not being able to say 'I Love You' this Valentine's Day. Most people with Motor Neurone Disease (MND) can't. Between 80-95% of people living with MND will experience some loss of speech before they die.

Last February for the first time we ran our sponsored silence campaign #Voice4MND. In 2016 we are hoping to do the same. Last year's campaign was championed by Sharon Friel and Emma Fitzpatrick. After losing their voices to MND, they wanted you to give up yours for only 30 minutes so you could experience what it would be like to lose your voice.

All you have to do is to pick a day, time and location where you will take on your 30 minute sponsored silence. Sponsor cards are available from our office, just email fundraising@imnda.ie or you can text MND to 50300 to donate €2 (100% of text goes to IMNDA across most network providers. Some providers apply VAT which means a minimum of €1.63 will go to IMNDA. Service Provider: LIKECHARITY. Helpline 076 6805278), then tell us what would be the last thing you would say if you knew you would lose your voice by using #Voice4MND on social media.

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

Support the Irish Motor Neurone Disease Association This Easter Sunday 27th March 2016

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

Raffle sheets will be provided for each hamper, lines are to be sold at €2 each. You could raise up to €400 per hamper and help us to reach our annual target of €40,000!

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

Thank you for your support.

Closing date for orders is 17th March. Please remember the IMNDA incurs a cost for each hamper delivered so please only commit to the raffle if you are confident of selling the lines.

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

White Collar Boxing

BOXING IS BACK WITH A BANG!!!

We are looking for boxers to sign up for our eagerly anticipated "Dandelion Dust Up III!" Think you have what it takes to join the Fight against MND!?

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

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

Places are limited - Email fundraising@imnda.ie or call 01 873 0422 to secure yours

www.imnda.ie

Fundraising & ticket sales is required by all participants

This event is ran in association with **Whitecollarboxing.ie**

iMNDA
CARE AND RESEARCH

Would you like to undertake a

Church Gate Collection

In aid of the Irish Motor Neurone Disease Association?

We are always looking for trustworthy supporters to shake a bucket outside their local church throughout the year.

If you'd like to get involved:

Choose a weekend that suits you, confirm with your Parish Priest then contact the IMNDA who will register your collection, apply for a permit from the Chief Superintendents Office and send out the necessary posters & buckets for your collection. Easy!

Thank you for your support

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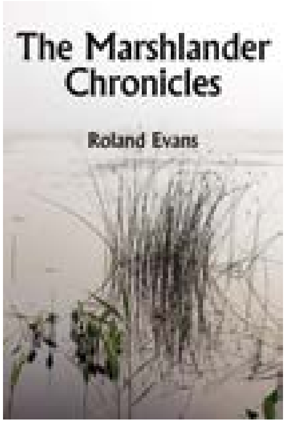
Roland Evans Living with MND

MND: My Part in its Downfall

Huge congratulations to Roland Evans on the publication of his first novel 'The Marshlander Chronicles'. Dubray Books, Blackrock Shopping Centre kindly hosted a fabulous book launch on Thursday 4th June 2015 where there the queue for a signing was out the door! Roland has kindly donated all proceeds from the book sale to the IMNDA to help support people living with MND. We are so grateful Roland, a massive thank you!

For those of you that still want to get a copy of Roland's Book – we only have a few left. All you have to do is purchase one from our online shop at www.imnda.ie or call 1800403403 today. So far nearly €4,000 has been raised from book sales.

To whet the appetite here is a little extract from 'The Marshlander Chronicles'.



'Water is our life. Without water we are slaves.' The words of Solomon Drake rang in the ears of 14 year old Prins, citizen of Marshland, a wetland rich in animal and plant life. Prins is despised by his peers because of his physical weakness. The story opens with the arrival of CORE (the council for renewal and enlightenment) who want to persuade Marshlanders to sell their wooden houses on stilts so the marsh can be drained in return for gold. One of his tormentors, a representative of CORE, drops paper from his pocket. Prins has a secret. He can read, one of the few in his world who can.

Roland and his wife Annette took part in a student documentary shortly after his book was published called, "MND: My Part in its Downfall". Roland also wanted to raise awareness about his life with MND, his daily challenges and how his perspective has changed his diagnosis. This powerful video is available in the Real Life Stories section on our website: http://imnda.ie/news/real-life-stories/.

The Difference We Make Together

To all our supporters and donors we cannot Thank You enough. Your support is so important to us. It allows us to continue doing the vital work needed to help support the MND community. We are so lucky to have so many people who help to fundraise for us each year. Unfortunately it is not possible to thank everybody personally, to those who aren't mentioned here, please accept our sincere thanks.

Thank you to…

BLOOMING FABULOUS

A special thanks to the Association for Irish Floral Artists who have chosen the IMNDA as their Charity for 2014-2016. On the 19th-21st June The National Flower Festival was held in Ennis where The Cathedral of Saints Peter & Paul and Saint Columba's Church were beautiful enhanced with over one hundred floral exhibits, created by AOIFA members who travelled from all over Ireland. Marty Morrissey officially opened the Festival. On Saturday evening a concert "Ceiliuradh na hInse" was held in the Cathedral, in conjunction with the Festival. Members made and donated beautiful crafts, plants, home produce and bric-a-brac for the trade stands This event was organised on a purely voluntary basis and our sincere thanks and appreciation to all our AOIFA members around the country, families, friends, supporters, the general public, local businesses and organisations who helped to make it the resounding success that it was.

MUSIC MADNESS

Many thanks to Margaret Murphy and Sharon Friel, their Summer Choral Service with the Portmarnock Singers and the Aber Valley Welsh Male Voice Choir in St. Anne's Church Portmarnock raised an outstanding €3,000 at their charity concert.

The Churchill players group performed their Springtime Variety show to a full house in Siamsa Tire, Tralee in honour of the late great Timmy Brosnan and raised a fantastic €5,000.

Una Feehan organised an evening of singing in St. James's Church, Limerick in memory of her wonderful Dad, Padriag, the event raised over €6,000 for IMNDA. Collette Nugent, Market bar variety night and karaoke raised a fantastic €1,000. Thanks to all those involved in making all these wonderful events such a success.

THE PRIMROSE BALL

On the 17th of April over 350 people attended the Primrose Gala Ball in the Ballygarry House Hotel in Tralee for a night of glamour, entertainment and fundraising. The Primrose Black Tie Gala Ball was organised by the Brosnan family in memory of their Dad Tommy Brosnan. The event was an incredible success and the Trojan work that the Brosnan's put in really paid off raising an outstanding €42,114. Unbelievable!! Well done ladies!!!

THE JUNE BALL

The June Ball, held in the DoubleTree by Hilton Hotel on June 27th 2015 was another phenomenal success. For the second year running, guests were welcomed with a drinks reception, three-course meal and a jam packed evening of entertainment including games, bands, DJs and silent auction with phenomenal prizes. A special thanks must go to Paul Lannon who made a truly inspirational speech. The event was a massive success and raised over €68,000 for the Irish Motor Neurone Disease Association. We would like to extend our sincerest thanks to all of the June Ball committee for doing an absolutely amazing job!

THE ICE BUCKET CHALLENGE #EVEYAUGUSTUNTILACURE

To all those who dowsed themselves in freezing buckets of ice, thank you!!! #everyaugustuntilacure

Special thanks to Paula McGonnell and Pat O'Hara and their wedding party who took the ice bucket challenge in lieu of wedding favours and donations from their guests and raised an amazing €1,050. A huge thanks to Aoife Campbell and all her family and friends who braved the cold to throw ice over themselves and raised a fantastic €700 #totitch

The Barry family in Waterford took on the #MNDICeBucket Challenge in memory of their hero Michelle, who sadly passed away from MND this year. They bravely too on the challenge to spread awareness of the devastation of IMDNA. CAE Parc Aviation took the challenge in support of a friend and colleague and raised a fantastic €1,038. A big thanks to the cast and crew of Once the Musical and Taylors Three Rock who all covered themselves with ice cubes

BIRTHDAY BASHES

Gertie Heery who was 90 years young this year did the immensely kind gesture of donating her birthday money of €500 to IMNDA, Amy Gilsenen donated her birthday gift of €600 and Joe Kelly generously requested donations instead of gifts to his 70th birthday bash and donated a brilliant €250. Happy birthday and a huge thank you to all!

EASTER EGG RAFFLE

A huge thank you to everyone who helped make our Easter Egg Raffle another eggtraordinary success with over €20,000 raised.

A special mention must go to our young entrepreneurs, Glenn and Conor Cullen whose have set up an egg sale business with a little help from their Mum Padmini and will be donating 20c from every box of eggs sold over 9 months to IMNDA! Thank you guys!!

TEA, COFFEE OR CAKE!

A massive thank you to all those who held who gathered friends and family, baked cakes and poured numerous cups of tea for our Drink Tea of MND campaign. Your generosity and dedication helped us to raise over €60,000!!

A HUGE thank you to Liadán and Cianna Ruddy who dropped in to present us with a cheque for €220 from their fabulous cake sale over the August Bank Holiday weekend and Catherine's National School who organised a fabulous bake sale and raised over €500,

A special thanks to Lorraine Butler and Holy Family secondary school who baked some amazing cakes and raised over €700 in their Bake Sale.

CARD TRICKS

The IMNDA would like to say a massive thank you to John O'Donoghue and all from Cahir GAA, they raised a fantastic €1,500 from their Draw a Joker Raffle. Well done everyone!

Rathan Charity Group and Tom Finnerty deserve a big thanks for raising €3,770 in their Progressive 25 Card Game and raffle on Good Friday, Ellen Simmons raised a fantastic €2,235 in their card drive, Margaret Murphy and all those in the Boot Inn raised an amazing €5,210 in their fundraising event

TABLE QUIZZES

A special thanks to all at Pettits Supervalue in Enniscorthy for raising a fantastic €1,080 in their table quiz in July. Paula O'Reilly raised a brilliant €1,842, Eleanor Taaffe & Linda Weldon raised €2,250 in the table quizzes – thank you ladies!

SCHOOL FUNDRAISERS

A very special thanks to all the Children at Tigín Montessori School Afterschool Club who hosted a 'How Do You Eat Yours' photographic competition where parents and friends were invited to have a humorous photograph taken while eating a cream egg. 160 photographs were displayed with the children on hand with orange collection buckets. The result was an amazing amount raised of €1,480 for IMNDA!

A big thank you to the girls in Loreto St. Stephens Green who donated an amazing €1,160, the Fenit School who raised a brilliant €1,000 in their charity cycle and 6th Class in St Patricks National School who organised a football match and raised a fabulous €115.

The brilliant boys in 5th Class at St Cronin's Boys National School in Bray raised an amazing €460 through their hard work and dedication to fundraising throughout the year.

As did Mount Sackville Secondary School who donated a fabulous €84 from their end of year fundraising events and St. Mary's Knockbeg College raised over €1,100 in their Last Person Standing competition.

To those who donated their confirmation and communion money, a huge thank you for such a wonderful gesture, St. Pius X Girls National School, Garrydoolis National School, Mary Help of Christians G.N.S, Kilmihil N.S and Templederry N.S

LOVE IS IN THE AIR

We would like to thank all the thoughtful and generous couples who made donations in lieu of wedding favours. We hope you had an amazing wedding day and we wish you every happiness in the future - Thanks again!!

CORPORATE DONATIONS

We are extremely lucky to have a number of companies who generous give up their time to raise funds for us, we can't thank you all enough for your support.

We would like to say a massive thank you to the BSM Group for selecting us as their charity of the year and donating the incredible sum of €7,500. Ace European Group donated an outstanding €11,085, Geodis for their donation of €500 and Robert Roberts Ltd for their generous donation of €471

Many thanks to the Hospital Saturday Fund for their very generous donation of €6,000 towards the nursing service. Great amount and deeply appreciated.

A huge thank to Pernod Richard, Irish Distillers Cycle who raised a fantastic €7,072 through their Midleton to Fox & Geese Charity Cycle early this year and their "Responsib'ALL Day" event held in June.

Marks & Spencer Clonmel have been an amazing support and have raised the brilliant amount of €5,248. The Evening Herald and Boylesport joined forces (or rather faced off!!) in their Beat the Bookies fundraising event and brought in €2,885 for IMNDA.

CHURCH GATE COLLECTIONS

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

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

LICENSED TAXI DRIVERS INNOVATE WITH A NATIONAL TAXI APP AND HELP RAISE FUNDS FOR IMNDA

cab:app

connecting the community

Successfully operating as a mobile payment solution for licensed taxis in Ireland and black cab drivers in the UK, cab:app has created the largest taxi network in the UK & Ireland and is now launching it's state of the art hailing platform combined with a loyalty/rewards model.

The business model is built on a unique loyalty and rewards structure. Passengers earn lifetime 'cab:miles' by taking cabs and sharing their personal promo code with friends which they can apply to the cost of future journeys. Drivers share in the profit and ownership of the company earning driver cash back and charity partners share in recurring revenue from every taxi journey. Cab:app's partner in Ireland, Lar Kelly, has a personal association with the IMNDA who supported his mother during her illness and his family following her passing. 'The charity provides invaluable support to those affected by motor neuron disease and I want to do all I can to help. By becoming an affiliate the charity will benefit from passengers choosing to donate their cab:miles directly which will be turned into cash for the IMNDA'.

Combining an exceptional user experience cab:app offers fixed prices to airports and for longer journeys, the convenience of pre-booking, the security of tracking and sharing journey details and the ability to pay by cash or card. Passengers with disabilities can use the wheelchair accessibility or hearing impaired in-app icons to communicate their needs.

Professional drivers offer unparalleled city knowledge with the added assurance that passengers are getting into a fully licensed, vetted and insured taxi that can utilise bus lanes and be legally hailed.

The new platform has launched and can be downloaded on iOS and Android by searching for 'cabapp'. You can donate your cab:miles easily within the app by following the simple instructions.

About cab:app - Invented by a London taxi driver, cab:app is the only mobile booking and payment app which connects passengers in over 90 cities with black cabs across the UK and licensed taxis in Ireland.

cab:app operates a unique loyalty/rewards business model where taxi drivers are co-owners in the company, passengers are rewarded with cab:miles for journeys or sharing with friends, and we support our charity partners with donations to help those less fortunate on their journey – everyone benefits!

Additional features within cab:app include:

Value – Driver 'Knowledge' takes the most direct route, with fixed prices to airports and longer journeys.

Accessibility – Pre-set your accessibility options if you are a wheelchair user or hearing impaired and add special notes for driver assistance.

Safety – Get picked up by a professional licensed driver, share your booking details, track your driver and communicate using the in-app messaging or quick call features.

Convenience – Hail now or pre-book for peace of mind, pay securely by card and receive an email receipt to reclaim your business expenses.

www.cabapp.net Lincoln House, 296 - 302 High Holborn, London, WC1V 7JH, England. 07508 550211 info@cabapp.net

ASSOCIATION OF IRISH FLORAL ARTISTS (AOIFA)

Association of Irish Floral Artists

The Association of Irish Floral Artists was founded in 1973 and is the official organisation of the floral art movement in Ireland. Its aims and objectives are to bring together floral art and gardening clubs for cultural and educational purposes. AOIFA has 83 affiliated clubs throughout the country with circa 4,000 members. Clubs usually meet once per month for floral art demonstrations, workshops, competitions and gardening talks. There is a wonderful social side to the Association and our motto is ***"friendship through flowers".***

The Association selects a charity every two years and holds various fundraising events, including a Festival of Flowers during this period. The Charity for 2014-2016 is the **Irish Motor Neurone Disease Association.** On the 19th-21st June this year The National Flower Festival was held in Ennis, Co. Clare. The Cathedral of Saints Peter & Paul and Saint Columba's Church were beautiful enhanced with over one hundred creative and artistic floral exhibits, created by our AOIFA members who travelled from all over the country. Marty Morrissey, Irish Sports Commenter and Television Presenter officially opened the Festival. We were delighted that Marie Reavy, Regional Development Officer for the IMNDA was also able to attend. Large crowds travelled from far and near over the weekend to support this event. On Saturday evening a concert "Ceiliuradh na hInse" was held in the Cathedral, in conjunction with the Festival. This was one of the highlights for our many visitors as there were many genres of music, song and dance performed by very accomplished artists. Our members also made and donated beautiful crafts, plants, home produce and bric-a-brac for the trade stands which were also very well supported. This event was organised on a purely voluntary basis and our sincere thanks and appreciation to all our AOIFA members around the country, families, friends, supporters, the general public, local businesses and organisations who helped to make it the resounding success that it was.

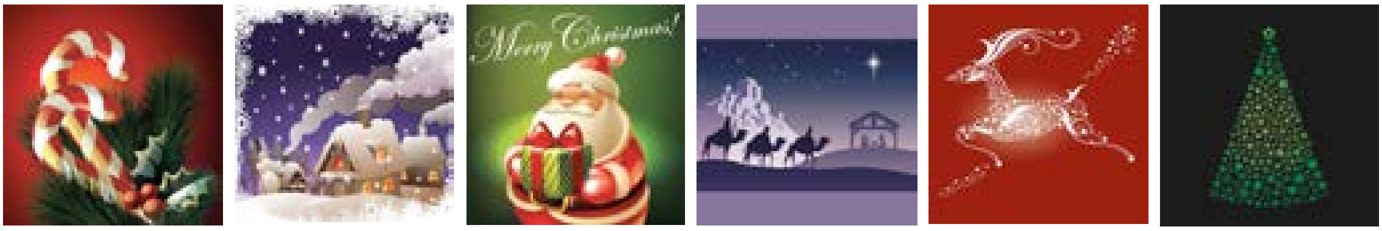
AOIFA is delighted to be able to help such a deserving charity as the IMNDA on this occasion and we commend the Association for the wonderful work they do on a daily basis.

Brid Coonan.

AOIFA Chairman.

EDITORS DESK

Christmas Cards



Spread a little bit of IMNDA festive spirit this Christmas by purchasing a pack of our charming Christmas cards! The cards are €10 per pack of 12 cards (including postage) and each pack has 6 different designs (2 of each design). Buying a pack and sending our cards is a simple and effective way for you to help us raise awareness. Please fill in the order form enclosed with your newsletter and return to the IMNDA or freefone 1800 403 403.

HANG A STAR

To mark our 30th Anniversary we have designed beautiful Irish made wooden stars with our green IMNDA ribbon to have on your Christmas tree. Our special little wooden stars are a small token to hang up during the festive period in memory of someone special or to hang in support of a relative or friend. We chose the star as the light of a star continues to shine long after the star itself is gone. Our stars can be purchased from the IMNDA online shop or by completing the order form included in the Newsletter. Each star is €8 and this includes postage.

Have a Cuppa & a Mince Pie with the IMNDA!

Everyone is welcome to our Christmas Coffee Morning where our Grand Raffle Draw will take place on Wednesday 9th of December at 11.30am in the Richmond Room, Carmichael House, North Brunswick Street, Dublin 7. We'd love to see you there and you might even win a prize! Please RSVP by emailing fundraising@imnda.ie or call 01 8730422.

IMNDA Staff Updates

Congratulations to our PR & Communications Executive, Derbhla Wynne on the birth of her third daughter Sadie. Both Mammy and Baby are doing great.

30th Anniversary Memorial Service

On Saturday 28th November we would like to invite everybody whose lives have been touched by Motor Neurone Disease over the last 30 years to come together with family and friends and join us in remembering those we have sadly lost to MND. Our special 30th Anniversary Memorial Service will be taking place at 3pm in The Law Society of Ireland, Blackhall Place, Dublin 7. Fr Liam Lawton will be performing along with the Celtic Grace Gospel Choir. Guests will also have the opportunity to light candles to remember their loved one on the day. After the service, everyone will then be invited for some refreshments. To attend this commemorative event please email info@imnda.ie or call 01-8730422.

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.

Sharon Malone

Kathleen O'Neill

Thomas Fahy

Anthony McDonagh

Catherine O'Flaherty

Susan Gibbons

Patrick O'Sullivan

Philip Greene

Robert Hindmarsh

Theresa Scully

Brendan Greene

Dinah Bridget Conroy

Bridget O'Sullivan

Tom Byrne

John Given

Ellen Heffernan

James Campbell

Brian Carty

Pat Murphy

Caroline Stapleton

Pat Carmody

Liam Kerwick

Evelyn McGrath

Larry O'Farrelly

Mary Coveney

Vincent Wilson

Nuala Kelly

Patrick Noonan

John McManus

Michael Berns

Peter Conneely

Kathleen O'Connor

Patricia West

Kathleen McGovern

Christine O'Shaughnessy

John Fagan

Margaret Scarlett

Patrick Keating

Christopher Kelly

Mary Barrett

John Patrick Leddy

Eileen Molloy

Michael Ward

Francie Ruane

Michelle Barry

James Keely

Mary Byrnes

Ann Tallon

John Allen

Mat Murphy

Catherine Mullen

Michael O'Donoghue

Vincent Dunne

Richard Mahon

Margaret Byrne

Margaret McGuire

Marie Ormond

Maura Donnelly

Martin Burke

Jay Naidoo

Edward Greene

Gerry Keenan

Jim McCarville

Kathleen Walsh

Edith Nuzum

Una Donnelly

Margaret Joyce

Joan Egan

Peter Kelly

Philomena McClean

Birgitta Keegan

Patrick Quinn

Alison Dowling

Richard Daly

Margaret Griffin

Deirdre Sheils

Tony Kelly

Krystyna Walicka

Margaret Perkins

Martin Coleman

Leslie Taylor

Mary Delaney

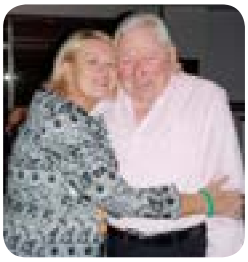
Celine Costigan

Seamus Mooney

Doreen McHugh

David Kennedy

Hear My Song
by Andy McGovern



Introduction

Christmas, a special time to celebrate with family and friends all that we have. I celebrate being on this earth for more than 82 years. I have witnessed many changes. Each period of my life enriched me. Each trial gave me strength, and now I reap the rewards as I harvest all life taught me along the way. Disabled now through years of living with Motor Neurone Disease, I have been given the precious gift of time. It allows me to see and appreciate the many blessings which this world has bestowed upon me.

Listen to my heart, listen to my
song, It has words of happiness,
won't you sing along? My song is of
joy, beyond compare, My great love
for this life is everywhere.

Like the little swallow with gleaming
wings, My Spirit is lifted by the 'little
things'. Morning bird song is the
music in my ears, A glorious moonlit
evening can stir my tears.

On the outside, my body may differ
from you, Judge not by appearance
is what you should do. God has
made all hearts the very same,
To be filled with love and
understanding in his name.

In this world I now play an
important role, Sometimes my friend,
you need to be told. In the eyes of
God, we are all valued the same,
Each a vital player in the Lord's
great game. As you run your life, in
this mad human race, I can slow you
down, and put a smile on your face.
As you rush blindly, through your
lows and highs, I'm the one who
often, has to open your eyes.

So listen to my heart, listen to my
song, Follow my example, you won't
go wrong. In the dept of darkness, I
always find a light, With my faith in
God, I never loose sight.

See the joys of life, in all that you
do, You will find much happiness
waiting for you. With open eyes,
see the world made by God above,
Slow down and take time to witness
his love.

The weight on my shoulders makes
me a stronger man, I treat my
troubles lightly, doing what I can.
I sing a song of happiness in my
heart, In this wonderful world, I too
play my part.

~ Andy McGovern ~

Atlantic way

Accessible Accommodation in the Kingdom

If you are thinking of getting away for the Christmas period then this might be somewhere to consider.

Atlantic Way Lodge

The concept behind Atlantic Way Lodge is to make tourism to The Kingdom accessible to all. Atlantic Way Lodge is a unique Bed and Breakfast in Kerry in that it focuses on providing comfortable and friendly accommodation for people with limited mobility, wheelchair users and their families. The Lodge provides all of its' facilities on ground floor level. Our spacious accommodation comprises of wheelchair accessible bedrooms with en-suites and showering facilities. All of our beds are low-low profiling single beds with pressure mattresses. We also provide specialist air mattresses, hoists, shower commodes, monkey poles, bed rails etc. Having such specialist equipment on-site allows us to cater for stays of varying durations.

Other facilities include a Conservatory and Breakfast room which overlook Tralee Bay. We have a spacious outdoor seating area which is overlooked by the stunning Slieve Mish Mountains. There is ample parking for both cars and small busses. Packed lunches for day trips can be provided as can evening meals at the Lodge should you wish to stay in after a day's touring. Alternatively, since the Atlantic Way Lodge is situated so close to the town of Tralee there are a number of wheelchair accessible restaurants which we can recommend for evening meals.

For groups who wish to hire the premises on a weekly basis, there is a secure, separate Nurse's station. We would certainly like you to consider staying with us here and we can promise you an enjoyable, hassle free holiday exploring the spoils of our beautiful county. **For more info please contact call 066-7130134/ 086-4673131 or e-mail atlanticwaylodge@gmail.com**

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

FOOD FOR HOPE A Cookbook

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

All proceeds go to the Irish Motor Neurone Disease Association

01-873 0422

www.imnda.ie
info@imnda.ie

https://www.facebook.com/IrishMND2011

https://twitter.com/IMNDA

iMNDA
CARE AND RESEARCH