IMNDA
CARE AND RESEARCH

CONNECT

ISSUE 18

Spring 2017

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- NATIONAL AWARENESS CAMPAIGN 2017
- DRINK TEA FOR MND
- RESEARCH UPDATES

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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.

2017 CALENDAR OF EVENTS/ DIARY DATES

A WELCOME NOTE FROM OUR CEO

Disclaimer

A NOTE FROM OUR CEO

On behalf of the IMNDA, I would like to welcome you to the first Edition of the Connect Magazine for 2017.

We have had a busy few months. We recently hosted the 27th International Symposium on ALS/MND which took place in the Convention Centre from the 4th – 9th of December and saw over 1,200 arrive in Dublin. I would personally like to thank all the IMNDA staff and Trinity volunteers who assisted in making the event such a huge success.

We were also thrilled to hear all about the huge breakthrough that came from Prof. Hardiman and her team. They have found a previously unrecognized biological link between two seemingly diverse disease's MND and schizophrenia. Neurological and psychiatric conditions are both disorders of brain function, but there is still much to learn. Schizophrenia is now thought to be a disorder of brain networking. The genetic overlap with schizophrenia, (along with imaging and EEG studies,) indicate that Motor Neurone Disease is also likely to be a disorder of brain networks. Instead of thinking of ALS as a degeneration of one motor cell at a time and looking for a "magic bullet" treatment that works, these findings indicates that clinician's should look for drugs that help to stabilize brain networks and prevent network disintegration.

These new findings by the researchers at Trinity College, biologically linking MND/ALS and schizophrenia, is a huge breakthrough in the research of MND and neurology as a whole. These findings shine a new light and way of thinking about MND/ALS, which is it's not just a disorder of individual nerve cells, but a disorder of the way these nerves connect as part of a larger brain network. We welcome these new findings and hope this will be one step towards developing new drugs that will help to stabilize these brain networks and ultimately prevent the progression of MND in our families

We are really looking forward to all that 2017 has to offer and we hope you are too. Let's hope 2017 is the year where we see a world free of MND!

Aisling Farrell

CEO

DIARY DATES DO SOMETHING SPECIAL IN 2017

SPRING INTO MAY

- Getting married this summer? Donate in lieu of wedding favours. Wedding Cards available from our online shop.
- Buy your IMNDA Performance top from the office or online for just €10 in preparation for your summer run, cycle or walk.

AWARENESS JUNE

- MND National Awareness Day is 21st June - *Drink Tea for MND* during June – tea packs available from the IMNDA.
- Monday 5th June@ 2pm: VHI Women's Mini Marathon – run the race to make a difference.
- Friday 23rd June: Midsummer Ball at the Headfort Arms, Kells, Co Meath.
- Saturday 24th June: D2K Cycle
- Date TBC: Charity Gig featuring Hermitage Green in Dolans, Limerick.

D-FEET JULY

- Saturday 15th July @ 12pm : Walk to D-Feet MND in the beautiful grounds of Castletown House, Celbridge, Co Kildare OR organise a walk in your local area.

ACTIVE AUGUST

- **20K, your way! Active 20** – cycle / run / walk / swim 20km in one go or do 5k a week. Contact us to find out some of our suggested routes.

SEMINAR SEPTEMBER

- IMNDA's AGM, Annual Conference and Patient & Carer Respite Weekend – Details TBC.
- Cooking Demonstration with TV chef Neven Maguire – Details TBC.
- Help your Employer to choose their 2017 Charity Partner and nominate the IMNDA!

ADVENTURE OCTOBER

- Saturday 7th October: Abseil off the roof of Croke Park's famous Hogan Stand, 100ft from top to bottom!
- Sunday 29th October: Run the Dublin City Marathon

Registering your Fundraising Event

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

To register and receive promo items / lodgement slip etc:

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

Thank you for your support and co-operation.

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

IMNDA
CARE AND RESEARCH

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NEWS & RESEARCH

The 2016 ALS/MND International Symposium *by Tracy Hutchin, Client Services Manager*

The 2016 ALS/MND International Symposium was held in the Dublin Convention Centre and was attended by over 1,100 delegates. The IMNDA was proud to welcome so many people to Ireland for such an important event. The Symposium is an opportunity for all of those working with MND throughout the world to come together and share their research on a cause/cure/treatment for MND. Healthcare professionals also shared what they have learned in practice from working with people with MND.

The event opened on 5th December with the Prize4Life Assistive Technology Challenge exhibition. The competition had been launched at the 2015 Symposium in Florida and had a prize fund of $400,000 sponsored by the ALS Association. The organisers were looking for innovative new ideas for products/devices to help with communication and easy access to technology. The 5 finalists were present on Monday morning and all demonstrated their products to the judging panel. The products were all still in the prototype stage and the winning team would use the prize fund to further develop their product to get it to the stage where it would be ready for market.

The final 5 products were:

- a computer which could tell which part of the screen you are looking at by tracing your brain activity via a headband with built in electrodes (received $300,000 first prize)
- a mount for use with an eye gaze computer which followed head movement to keep the eye tracking camera in the correct alignment
- a scanning switch (like a wireless buddy button) attached to a muscle (on the arm or leg) which was 'clicked' by the person thinking about moving the muscle – even when the muscle 'no longer worked' the electrical impulse of the controlling thought was enough to work the switch allowing someone to type by thought (received $100,000 second prize)
- New software for managing message banking which sorts the messages into categories much more quickly
- Wearable switches for communication aids

It was so encouraging to see such varied technology and to see how many companies and individuals are working behind the scenes to develop technology that will assist people with MND. The potential for each product is huge and with the right funding I'm sure each will be developed successfully.

Monday afternoon saw the 'Ask The Experts' session which was an opportunity for people with MND, their families, healthcare professionals and anyone with an interest in MND to listen to the three guest speakers:

Clinical Trials in ALS/MND: Where Are We Now?

Dr. Jeremy Shefner, MD, PhD Kemper and Ethel Marley Professor and Chair of Neurology and Senior Vice President of Barrow Neurological Institute

Stem Cells: The Hope and the Hype

Jonathan Glass, MD Professor of Neurology and Pathology at Emory University School of Medicine; Director of the Emory ALS Clinic

Project MinE: The New Genetics of ALS/MND

Dr. Jan H. Veldink, MD, PhD Professor of Neurology and Neurogenetics and Head of the Human Neurogenetics Unit at University Medical Center-Utrecht

The session was also streamed live on the internet and people around the world were able to ask questions via Twitter.

Each of the three speakers was very warmly received and they spoke openly about where they see current research in their own field. They also talked about how they work with each other and how their work is linked.

In his talk on drug trials, Dr Jeremy Shefner was very positive about where things are now and he feels that science is "well on the way to effective therapies". He initially gave an overview of pharmaceutical trials. In the USA there are 25-30 new drugs developed each year for all diseases. Each drug costs approximately $1 Billion to develop. Dr Shefner then talked about a number of drugs which are currently on trial or are about to go on trial including Edaravone and Tirasemtive. He seemed most positive about Tirasemtive and results of this trial are due in late 2017. As the cause of MND is still unknown, it makes it more difficult to develop a drug to cure the disease. However, a number of drugs are being trialled/developed which aim to stop/reduce the changes MND causes in the body & brain.

Dr Jonathan Glass then spoke about stem cell treatments. He feels that the answer is in the science and that we need to have hope but we have to be careful of hype.

The Hope:

"Stem cells are magic but we don't know how they work". Therefore, stem cells need to be tested. For the last 15-20 years scientists have been investigating stem cells for neurodegenerative diseases and they are now being studied in human trials. Stem cells could promote the survival of affected neurons but the difficulty is in getting them to the affected areas. Investigators in other diseases are also studying stem cells so the there is a lot of knowledge to be shared. There have been positive results in animal studies. Dr Glass is involved in a study where 30 humans have had stem cells injected into the spinal cord. In each case the operation took 4-5 hours. We still need to learn what happens to these cells after injection. Do they develop into neurones and then connect with motor neurones?

The Hype:

There are a number of websites which sell stem cells. They often have spectacular claims of success which haven't been substantiated. The website ALS Untangled (www.alsuntangled.com) investigates claims of all possible ALS/MND treatments/cures in a scientific manner. Dr Glass advised to be wary of companies/organisations looking to make money from stem cells. Press releases can create hype as they interpret data in a less scientific way than medical journals.

His conclusion was that stem cells can be safely injected into the human spine but there needs to be a lot more data from a lot more patients over a longer period of time.

Next it was on to Dr Jan Veldink and Project MinE. He began with a basic biology lesson of how DNA is created within each cell in the body. He explained that while not all answers will come from genetics, most scientific breakthroughs are genetics based. He stressed that 'Healthy controls have bad ALS mutations'. The first MND/ALD gene was identified in 1993 and is called SOD1. Advances in technology have made it easier to study the genome sequence so more genes have been identified in recent years. Project MinE was set up with a target of colleting 22,500 DNA profiles (15,000 with MND and 7,500 controls). They now have sequenced almost 10,000 profiles. The data is shared with genetic researchers and so far 4 new genes have been identified (TUBA4A, TBK1, C21orf2 and NEK1). So why was it important to set up Project MinE

- Academic interest
- Making models for efficient drug screenings
- Precision medicine (gene based therapy)

The panel then answered a number of questions from the audience.

Tuesday was the Allied Professionals Forum for healthcare professionals which began with presentation of the prizes form the Assistive Technology Challenge. This was followed by talks from 15 speakers on topics which included Voice & message banking, Caring for families living with MND, Identifying Carer Support Needs, Anticipatory Approach to Palliative Care, Withdrawal of Mechanical Ventilation at Patient Request, New Technology & 3D Printing. The speakers were from Australia, USA, Ireland, UK and Denmark.

The topics were very varied but were grouped together as much as possible. Some looked at the outcome of a situation for an individual client, some were reviews of patient trials and some were reviews of training with healthcare professionals. It was inspiring to see so many speakers talk so passionately about such different aspects of caring for people with MND.

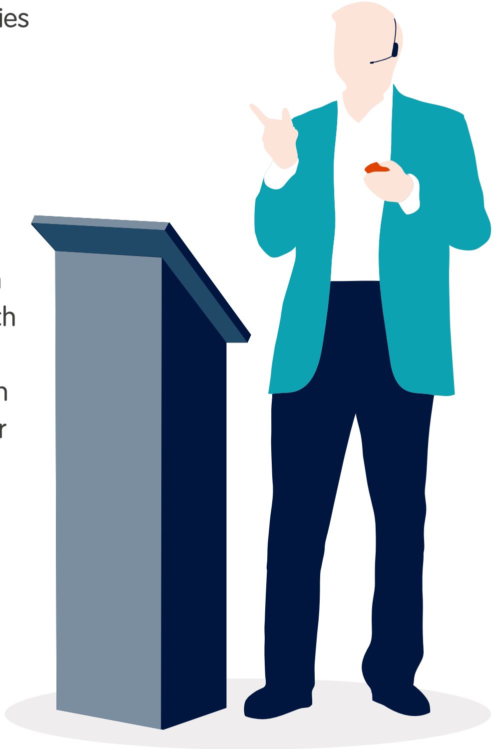
Colin Pearson, a Regional Care Development Advisor with the Motor Neurone Disease Association in Yorkshire set up a project with his local hospice. Colin found that people with MND were accessing palliative care at quite a late stage of progression of the disease. He felt there was a stigma around the hospice – that it was a place to die. There is so much more to the hospice service that he wanted to share with people. Colin put together a 'drop in day' so that each Friday those with MND (who were still working/living independently) could attend the hospice for complementary therapies as an introduction to the local palliative care team. The pilot project was a great success with increased take up of MND Association support, hospice palliative care services and support for carers. The project has now been replicated at a second hospice in the area and others are considering the model.

Videos of all of the presentations are on the YouTube channel of the The International Alliance of ALS/MND Associations.

Wednesday saw the beginning of the clinical & scientific presentations from the worldwide MND researchers. As with the Allied Professionals Forum the range of topics was very broad but these three days were much more technical and in depth. The range of subjects covered included RNA Processing & Dysregulation, RNA and Neurodegeneration, Protein Misfolding and Aggression, Management of Cognitive & Psychological Change, Neuroimaging, Cell Biology & Pathology, Nutritional Management & Metabolism, Epigenetics and Genomics, Symtomatic treatments and Clinical Genetics.

As well as the 100 talks over 450 research posters were displayed at the symposium. The Biomedical and Clinical poster prizes are an opportunity to recognise and celebrate the excellent research and clinical practice being conducted by those early in their career. This year the Panel selected an international group of winners: Dr Albert Lee from Australia and Elsa Tremblay from Canada were jointly awarded the Biomedical poster prize and Ruben van Eijk from The Netherlands won the Clinical poster prize. The prize winning research ranged from understanding the consequences of a newly discovered gene mutation linked to MND, to why the junction between nerves and muscles is one of the earliest signs of motor neurone damage, to a new statistical analysis to make clinical trials quicker and more efficient.

The opportunities for networking and sharing information will continue at the 28th International Symposium on ALS/MND which will be held in Boston, USA on 8-10 December 2017.



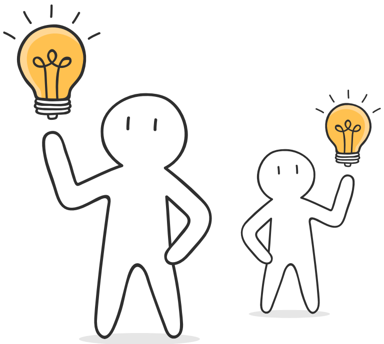
Research Update

Dr Tom Burke
Cognitive Researsch Update

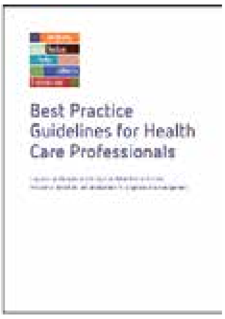
Within the Irish MND Research group at Trinity College Dublin, led by Prof. Orla Hardiman, there is a dedicated neuropsychology team who investigate the psychological (quality of life and well-being), and neuropsychological (thinking and behaviour) changes which may occur as a result of MND. This team is led by Prof. Niall Pender, Principal Clinical Neuropsychologist and Head of Department of Psychology at Beaumont Hospital, and in recent months has gained national and international attention, awards, and funding for their novel findings and publications.

Changes in Thinking and Behaviour

It is now established that some people with MND can develop difficulties with thinking and changes in their behaviour during the course of their illness. These difficulties can occur alongside, or even before the onset of the motor symptoms which are characteristic of MND. Changes in thinking and behaviour can present challenges for both patient and caregivers alike, and also pose challenges for some healthcare professionals.



In recent months, the Irish MND Research group have published a number of leading papers relating to social cognition, behaviour change, how to support caregivers, which was made possible by patients, caregivers, and families of those with MND who take part in these studies. We have also designed, developed, validated, and published new MND specific measures for identifying behaviour change, and changes in thinking, thanks to the participation of those attending the MND clinic at Beaumont Hospital.



Best Practice Guidelines for Health Care Professionals

National and International Impact

As a result of these publications we can raise awareness of some of the challenges associated with MND that may be less known. For example, recently on the 25th of November the Irish MND Research team invited Allied Health Professionals (AHPs) from across Ireland to attend a day of seminars and workshops in Beaumont Hospital, specifically relating to MND and what healthcare professionals need to know. This meeting, which was attended by over 250 AHPs, also saw the launch of the 'Best Practice Guidelines for Health Care Professionals' which were developed by our team through support from the Health Research Board and IMNDA, based on the research we conduct in the clinic, and with patients in their homes.

Internationally our research is reaching a global platform as recently demonstrated at the 27th International ALS/MND Symposium, where Prof. Niall Pender gave the keynote address on changes in thinking and behaviour in ALS, how we measure it, and what impact it has for patients. This talk was then followed by Dr Tom Burke who spoke about the impact such changes may have on caregivers' well-being and quality of life.

Members of this team have recently been awarded competitive international funding to investigate very specific aspects of cognitive/behavioural change (Prof. Orla Hardiman, Prof. Niall Pender, & Ms Marta Pinto Grau) by the Motor Neuron Disease Association (MNDA), and also our team has been awarded further funding from the ALS Association (ALSA), to define and address the complex needs of caregivers (Prof. Orla Hardiman, Prof. Niall Pender, Dr Miriam Galvin, & Dr Tom Burke).

These new projects are due to begin recruitment soon in 2017!

If you are interested in taking part in research, or in finding out more see the website Research Motor Neurone (www.mnd.ie/current-research/). We wish to take this opportunity to thank the kind efforts of all those involved in the research, past, present, and future, *helping you today to help others tomorrow.*

Research Update

Mark Heverin
IMNDA Register & Research Overview

A full programme of Motor Neurone Disease research continues between Trinity College, and Beaumont and St. James' Hospitals under the leadership of Prof. Orla Hardiman. Her team is comprised of a group of researchers from a variety of disciplines working on projects in the fields of genetics, MRI scanning, neuropsychology, EEG, epidemiology, health services research and family history studies. This research is coordinated from the Academic Unit of Neurology at Trinity Biomedical Sciences Institute (TBSI) in Trinity College, Dublin.

A key part of coordinating these research efforts involves maintaining a detailed source of information about the population of people with MND in Ireland. This is achieved through the valuable resource known as the Irish ALS/MND Register. This is a database that allows us to track the number of people diagnosed with MND in Ireland annually as well as the number living with the condition in the country at any one time. It also provides us with a platform to recruit people to the various research projects that are ongoing at any given time. Mark Heverin, the current research manager, who has been with Prof. Hardiman's group since 2011, has had primary responsibility for the register over the last number of years.

Founded in 1995, the register now has information on over 2,300 patients with MND. It is the longest running register of its kind in the world, and we are frequently asked for advice by groups from Ireland and other countries who are interested in developing a similar research resource. Our register is closely linked with other registers in Scotland, Netherlands, Germany and Italy, through our European Research Consortium (European Network for the Cure of ALS – ENCALS). Together we can map the disease across Europe and search for genetic and environmental causes.

New cases are identified through a combination of means including the Multidisciplinary MND clinic run by Prof. Hardiman in Beaumont Hospital, close ties with the IMNDA, and the valuable help of neurologists around the country. A short interview is conducted with new cases if they are happy to participate to ask about a number of areas in which we are particularly interested. This information ranges from basic demographics, ancestry, clinical information, (e.g. date of onset, date of diagnosis, first symptom, etc), to some basic family history information. All of the other research projects we are conducting are informed by this data making the register a cornerstone of the Irish ALS/MND research group.

At work on the MND Register in Trinity College
(L-R: Mark Heverin, Prof. Orla Hardiman & Dr. Alice Vajda)

A DNA bank, run in close parallel with the register, has been maintained since the year 2000 and currently contains samples from around 1300 patients. DNA is extracted from blood samples mainly taken in the MND Clinic in Beaumont Hospital. This added resource allows us to work in collaboration with Prof. Dan Bradley and Dr. Russell McLaughlin at the Smurfit Institute of Genetics, to conduct research into the complex genetics of MND and to take part in international efforts like Project MinE which strives to discover more genes involved in the disease, (More information on Project MinE can be found at: www.projectmine.com/country/ireland/).

Two particularly busy areas of research at the moment are the family history studies and health services research. Previous work from our group has shown higher rates of suicide and schizophrenia in the families of people with MND compared to the families of controls, (i.e. people of the same age and sex who don't have MND). While this has helped steer our genetics research it is also important that we confirm the finding with a new group of people to make sure it is reliable. As well as trying to replicate the previous work we are also exploring families in more detail by meeting with individual family members of patients and controls to obtained more detailed information, and where possible, to draw a blood sample for our DNA bank. The purpose of this is to examine in greater detail the potential differences between the kinds of traits and, indeed illnesses, present in families of people with MND and those in the families of the general population. This type of work can tell us more about potential genetic links between MND and certain other conditions which helps to develop our understanding of this complex disease that will in turn help in the development of new treatments. This work is currently being led by PhD candidate Dr. Marie Ryan who joined the group in October 2016.

Through our programme of Health Services Research we aim to develop best practice frameworks for the management of MND/ALS, as well as other neurodegenerative disorders.

Building on work already done on the patient journey and funded by a HRB Interdisciplinary Capacity Enhancement Award, current work includes *ALS-CarE A Programme for ALS Care in Europe* which brings together prospective longitudinal data from 8 centres across 6 European countries and addresses issues around disease staging, end of life decisions, quality of life, caregiver burden, as well as examining the cost effectiveness of various models of service delivery.

Upcoming research in this area includes *Defining and Addressing the Complex needs of ALS caregivers (ALSA)* which focuses on the informal caregivers, by identifying and characterizing caregiver burden in detail, including assessment of support, and coping styles, and aligning these factors with physical, cognitive and behavioral status of people with ALS. The main researcher on this project is PhD candidate Sile Carney under the supervision of Research Fellow Dr. Miriam Galvin.

Irish Motor Neurone Disease Association

Summer Gala Ball

in The Headfort Arms Hotel, Kells
on Friday 23rd June 2017 at 7.30 p.m.
Prosecco Reception followed by Dinner

M.C. Miriam O'Callaghan
Music by: Ronan Collins and his Band

Formal Dress • Ticket: €75.00 • Auction & raffle on the night

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

Summer Gala Ball

An evening not to be missed in the Headfort Arms, Kells, Co Meath on Friday 23rd June in aid of the IMNDA. Summer Ball MC'd by Miriam O'Callaghan with music from Ronan Collins and his band. Prosecco reception, delicious meal and auction and raffle on the night.

Tickets are now on sale for just €75.00 from the IMNDA Online Shop or by contacting Micky on 086 3601338 or John 087 2248503.

LIVING WITH MND

Karl by Norman Hughes

“On his way to work one very cold morning in January 2010, Karl was crossing the road in the IFSC when he slipped and fell on the ice, smashing his hip bone. During the operation and while under general anaesthetic, Karl went into respiratory arrest and had to be resuscitated. Further investigations showed that the valve in Karl’s throat wasn’t functioning as it should and had let fluids into his lungs. After a number of weeks and a whole series of further tests, Karl was diagnosed with Motor Neurone Disease.

Needless to say, the diagnosis came as a terrible shock to Karl and after keeping it to himself for a couple of days, he then felt ready to disclose it to family and friends. As family members, we naturally wanted to find out all we could about MND and our first port of call was the IMNDA. From that initial contact to today, the IMNDA have been there for us, initially for information and advice, then latterly for equipment etc for Karl’s use at home. The IMNDA staff are a terrific team of kind, considerate and yet truly professional individuals.

Karl worked in the Finance Industry and his company were very good to him, offering him all types of work options. Karl gave serious thought to going back to work but decided against it, wishing to spend as much time as he could with family and friends and developing the special bond he had with his nieces and nephews.

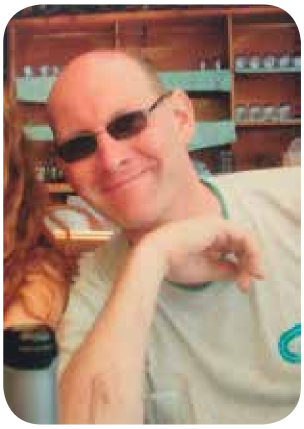
Karl made the most of his time and increasingly made great use of social media to keep in regular contact with many friends and colleagues. It was during this time that he made great friends with many fellow-MND sufferers through his association with the IMNDA – many of whom were a source of great inspiration to Karl. Karl liked to attend the IMNDA annual conference, affording him the opportunity to chat to fellow sufferers, sharing experiences and coping mechanisms.

In June 2015, Karl and I chatted about what his greatest worry was. He said “I worry most about the people who worry about me. I have accepted the cards I have been dealt”. This one sentence said everything about Karl; he was worried about everyone else, not himself. I asked Karl about his wishes and after acting the maggot for a couple of minutes, pretending not to understand what I was talking about, I was amazed at just how much consideration he had given to his future. Karl was delighted with the opportunity to share his thoughts at that point.

Independence was very important to Karl and he chose to continue living on his own. As his mobility deteriorated, Karl had adaptions made to his car and he continued to drive up until July 2016 when he had a fall at home and was hospitalised. Although the staff in St Vincent’s Hospital provided him with great care and attention for a number of months, Karl wanted to return to the peace and comfort of his own home, where he was the boss. Karl returned home on 1st Nov 2016 and received around the clock private home-care until the early hours of Friday 18th Nov 2016, when he passed away – very peacefully in the presence of his loving family.

When it came to organising the Karl’s funeral, we were delighted that Karl had shared his wishes with us when he was well enough to do so, content in the knowledge that we were fulfilling those wishes.

The IMNDA is an association of members and on behalf of Karl’s family; I would like to thank each and every one of you who came into contact with Karl while living with MND. He had a wonderful connection with you.”



Karl Hughes RIP

27th June 1966
to
18th Nov 2016

Living with MND by Colette Gill Senior OT

Throughout my 8 year career to date as a Speech and Language Therapist I have encountered Motor Neuron Disease. I started my career in acute care, working in St. Vincent's University Hospital for over 5 years, initially on the wards and then moving into outpatients and community liaison. I transitioned into Primary Care where I have been working for the last few years. As a result of this I have met people with MND at every stage of their journey from diagnosis right through to the end-of-life. As therapists we strive to maintain professionalism and be objective, but I would be lying if I said I wasn't emotionally attached to any of my clients. There have been days where I have found myself sitting in the car after a home visit, with a tear in my eye, thinking about 'what if this was my loved one?'.

There are many positive experiences when working with people with MND and their families. Building close relationships and rapport with families and clients is a natural and mutual path. Instead of the formal knock on the door and waiting for it to be answered as it would be with my less familiar clients, it is a quick tap on the door and enter in the one sweeping movement as you say 'hello'. Helping people with communication and swallowing difficulties is very rewarding and you can walk away saying I have improved that person's quality of life. Each and every time I leave a home visit, I think how amazing the carers and families are.

From a swallow perspective, it can be very varied. Some people with MND will experience virtually no issues with swallowing, even in the latter stages of the disease, while others will show signs of difficulty from an early stage. There is often the discussion around alternative tube feeding versus continued oral intake. This can be difficult and I have learnt to respect the decisions of families and clients as often my preferred recommendations are not the wishes and options they choose. As I have gained experience I have became more comfortable facilitating families with decisions about care and treatment; realising that by providing them with support, information and advice I have empowered families to make an informed decision. I am hopeful that with the introduction of the new Assisted Decision-Making (Capacity) Act 2015, there will be a clearer pathway regarding these complex decisions. It is so important that these tough and often emotional conversations are started earlier so we can ensure the person's wishes are being respected at a later stage.

In the Irish culture, a cup of tea tends to be a significant social event. This event can become stressful and less enjoyable for people who have swallowing difficulties. My goal is always to ensure the person can eat and drink safely however I endeavour to maintain the enjoyment of these everyday social events as much as possible.

A few years ago, I had a lovely gentleman who had lived for his cup of tea as it always signalled having the craic with family and friends. They lived out in the country and like many Irish families "the door was always open" and the kettle was always on. I became involved in his care at a very late stage as I was taking over from another therapist so one of my key goals involved re-establishing this social aspect of his life that had been compromised. We worked on a number of things including providing assistance to feed, positioning, the correct consistency of the tea, correct cup and family members not being afraid to continue as normal. Within a short space of time, he was enjoying his cup of tea, listening to stories and local gossip again.

From a communication point of view, again speech difficulties range from mild to severe at various stages of the journey. It is an ever changing field with new developments in technology and equipment happening all the time. It can be had to keep up-to-date with it all, but fortunately, the team in the Central Remedial Clinic (CRC) are on hand to help with this.

In many cases, the introduction of technology can be daunting if it is something that was not part of your life and you were not accustomed to. As the years fly by for us all, I am definitely seeing a change towards people being more open to technology to support communication. There are still some people who do not wish to even try it and again it is a case of respecting that. I have one lady who uses pen and paper just as well as another man on my caseload with the latest eye-gaze equipment. The bottom line is that if you can get your message across, by whatever means, then we are achieving our goal. Technology is not without its draw backs; it can be difficult to set up, funding can be hard to secure and sometimes by time it's in place, the original goals have changed. But when it does work, it works brilliantly.

Working with people with MND is very different to working with other conditions in that its presentation can change quickly. I thoroughly enjoy working in primary care and getting to know the person with MND and their families; supporting them every step of the way and trying to help them in any way I can. The management of MND is very much team based and regular communication with all team members is crucial. I think our poor OT Bridget must wonder what random question I will have for her every time I ring her. The nurses with IMNDA are so unbelievably supportive and although people often say 'I'm only a phonecall away', they really are. As an SLT I always strive to provide the best quality of service possible, working as part of the wider team. Supporting, educating and empowering people is fundamental to our work. 'When it rains, look for rainbows. When it's dark, look for stars'.

Colette Gill - Senior SLT
Roscommon Primary Care

Losing My Voice to MND by Sharon Friel

In the early days of my diagnosis I hated going to the Motor Neurone Disease clinic and witnessing all the other patients with varying degrees of war wounds from their battle with this cruel disease. See, I was still in denial and somehow closing my eyes was my pathetic attempt to protect myself from my hopeless future. Unable to block my ears, I was forced to hear the frightening tones of a patient who was losing their voice to MND. Something about the pitch of their groaning muffled voice used to make me feel nauseous with fear. It was a voice you would never forget, an unpleasant sound, it felt uncomfortable in my ear. Without knowing, you could sense behind this ugly sound there was a serious problem.

My voice has been the hardest thing I've lost to MND. So much of your identity and personality is contained in your voice. It's your means of engaging and immediately interacting with the world around you. I didn't lose my voice overnight; it eroded over a year and a half. At the beginning I was slurring certain words, eventually all my words sounded drunk. Then the tone and pitch altered, the horrible groaning muffled tone made it more prominent. The sound attracted curious ears, it was impossible to ignore. No matter how hard I tried to enunciate words, my mouth muscles just wouldn't play along. Everybody tried really hard to understand my attempt at every word. Countless frustrating moments were experienced by us all – my tears were never far away as I struggled to come to terms with my latest MND crisis.

When I first got my Eye Gaze Computer I was excited and couldn't wait to use it. By the second day, I hated it. It was just so hard to use. I ignored it for a few months until I eventually lost the power in my hand and could no longer use the communication app on my iPad. Until I had no means of communication except nodding my head I was forced to work with my nemesis.

The early days were tough, with lots of teething problems. You have to train your eyes to focus on the letters and turn off your peripheral vision. Sounds simple but it takes weeks of practice. Position and distance from screen, glare from sun and lights, medication, other people's eyes and even wearing glasses all affect the Eye Gaze performance. [I eventually had to ditch my glasses, I'm short-sighted so can see the screen but everything beyond is a blur.] These obstacles are all equally annoying in their own right.

I like to prepare people in advance of what to expect with the Eye Gaze. It's an unnatural and unsociable means of having a conversation:

* It's slow, it takes me time to type out a response, I'm always a conversation behind.

* The eye trackers at the bottom of the screen that read my eye movements are extremely sensitive; if I look away they lose my eyes and can take up to 30 seconds to reconnect. In the meantime, I get frustrated, throw my head back and close my eyes, trying to re-establish connection. This happens numerous times a day.

* I have to concentrate on typing so I keep focused on the screen; consequently I don't make as much eye contact and people presume I'm not listening. To make matters worse my neck muscles are weakening so I can't even nod to acknowledge anymore.

* People stand beside me and read while I type, it's a natural reaction but the eye trackers are so sensitive they pick up the other eyes and throw me off course, forcing me to reconnect again.

Those issues aside; once I sorted out the teething problems and everyone around me got used to the Eye Gaze, I began to love it. Now, I couldn't imagine life without it. It's an extraordinary piece of technology which gets many wows and looks of amazement. It has allowed my brain run free from my paralysed self. Without it I would be trapped inside my own body, unable to express myself, unable to talk to my little boy, my husband or my family and friends. I firmly believe I would be gone by now if it wasn't for my Eye Gaze; it's my portal to having a life.

Sharon x

My 2016; the Year that was by Michael Clancy

For most Irish men and Irish women the year 2016 was a year of remembrance, commemoration and celebration. For me it was just that, but it was also a year of profound sorrow. Oh it started off okay-ish. I had gotten indications from a doctor in the latter part of the previous year that following a battery of tests that I may have a rare form of MND but nothing definite. "We're still doing tests. It's a process of elimination." The only things we had eliminated were Parkinson's and MS. But who knows, it may be something else. I am an optimist, I think, or maybe I'm just in Egypt (in De Nile).

I just knew I was not right. My speech was beginning to change (slur) so I had to slow down to make myself understood. People told me it was fine but I felt it was a lot worse. I also found my balance, coordination and strength (power) was diminishing. But I had to keep up the facade; I didn't look ill so it was that bit easier to pull it off. You get terribly inventive when you want to hide that which is not obvious to others.

My mother turned 86 years in December 2015. She was in a nursing home, a diabetic with advanced dementia. Thankfully she still recognised me as one of hers, albeit at times her son, her brother or even her husband. She knew I was hers. I did not want her to know that there was anything the matter with me. She could do nothing for me other than worry. I felt she didn't need the worry so why tell her. Please forgive me Mam, I hope you understand.

2016 turned real sour for me and my family on Sunday 1st May when Mam passed away suddenly but peacefully on the 45th anniversary of my father's death. He was 50 years old when he died. Two months later, on the 27th June the man above came calling again and this time he took my beautiful wife. It is said that the good Lord will not burden you with more than you can carry. He must have a strange sense of my strength, because he is surely testing my resolve. From May to July we had 5 funerals of close family members.

I made contact with IMNDA in mid May through my SALT. Within one week I was interrogated (joke) interviewed by Fidelma in my own home. I couldn't believe the speed of action. Fidelma had assured me not to worry when I told her that I did not have a definitive diagnosis yet. She said that will be all sorted when you meet the Professor.

Life then took over as happens. They say "Man makes plans and God smiles". Monique (my wife) and I had planned to go to Brighton for Dawn's (our daughter) graduation. She

had completed her Physiotherapy Masters in February and the graduation was on in July. We had said we would go so I could not disappoint her. She was home 2 weeks later for Monique's months mind Mass. All the family were gathered in the kitchen that Friday night when Sophie (our married daughter) and Patrick (her husband) said they had a bit of good news. Sophie said that Patrick had entered one of his hanging flower baskets in a competition and had only just won 1st prize. She then asked if we wanted to see photos and handed 2 or 3 to her sisters and brother. Within about 5 seconds there were screams, tears and hugs. The photos were scans of the baby that is due in mid February. And that I believe is the circle of life.

I did meet with the Professor and her team. You know when you get "bad news" health wise. One of the first questions asked is "HOW LONG?" You may get the "well it's hard to say, things are complicated, it depends on blah de blah de blah". Basically – how long is a piece of STRING? The Professor explained to me what my variant of MND was and what to expect. Then she said to me that I would not die from MND. I felt like she handed me a ball of twine and not a piece of STRING. Susan, my sister, expressed my situation very well when she said "If Carlsberg did MND, then my version (PLS) would be their version".

I am living with MND. I've had, what some would say, a hard year. But I get up out of bed every day, I leave the house, I meet people. If I went into myself and stayed indoors, I may as well be in the grave beside Monique. I will be there someday but not before time. I meet people and they tell me I'm doing great and I'm looking great. I tell them I think my glass is half full. I say this but there are times when I find it hard to believe. I suspect at times that some bugger keeps changing the glass for a smaller one though.

I'm nothing special. I'm extremely fortunate to have a very loving family. I suppose I could claim a tiny bit of credit for that. I find in life you get out what you put in, or at least some. I believe in the spirit of volunteering and giving of one's time, knowledge, experience or whatever freely. Because believe me that – Well done, Good job, You're great, You're the best or even a simple Thank you is well worth all the effort. The best volunteers are not paid money. Not because they are worthless but because they are priceless.

I am a volunteer in many different areas of life. 41 years Army reserve, 39 years Rugby clubs, 20 + years Rugby Referees etc... I never wanted to be a passenger in any group I was involved with. I always wanted to be a driver. This enabled me to push myself to the limit, get the best out of myself in every situation and most of all enjoy life to the fullest in everything I did in my life. I am now not just a member of IMNDA, but also a volunteer for the association and will do whatever I can for as long as I can. I intend banking some brownie points before I will need help. That's just the way I'm built. Like I said, I'm nothing special. Just doing what I can while I can.

Tina's Story by Denis Johnston

“My name is Denis Johnston, husband of the late Tina Johnston, and I will try to give a voice to her story.

Tina was a very diligent, conscientious student all the way through school. She completed her Leaving Certificate in Presentation Convent Ballypheane in 1970, in a groundbreaking class of four students! She went on to become a dedicated and caring nurse, working in St. Finabarr's Hospital and Cork University Hospital.

Along the way, we started to go out and got engaged, and later married in 1979. Tina then retired from nursing and the babies came along in 1980 and 1981. For the next number of years, she lovingly cared for Sarah and David and looked after all our needs.

Tina was a person who loved her own family and extended family. Her childhood friends and work colleagues were always treasured. She looked after herself, didn't smoke or drink and tried to stick to a healthy diet. She later returned to her nursing career, this time looking after Alzheimer's patients with great devotion. She also made many friends along the way, who stayed loyal and true to the end. In 1987, our youngest daughter Frances was born and Tina took great pride in seeing Frances go back to college to study for her degree as a mature student.

In 2013, we started to notice slurring of speech and tiredness. After a few medical consultations, and tests, all our lives changed forever when the dreaded diagnosis was given in 2014. We had to face an uncertain future.

Changes came quickly for everyone involved, especially Tina. We had to begin to adapt to these changes, particularly with regard to communication. Tina stuck with her pen and paper and her 'Faulty Towers' bell. Modifications were made to the house, a stairlift fitted, thanks to the IMNDA, the garage converted to a beautiful bedroom and wetroom. We all had to get used to having lots of appointments and clinics, and as someone said, "having people in your house".

Tina accepted and coped as best she could with all that was going on. She never complained, showed anger or questioned "why me?". She never forgot her friends and family and frequently went for coffee and get togethers with them. The support she received from them helped to lift her spirits and maintained some sense of normality for Tina.

She loved hearing from Sarah in Edinburgh and they had lots of laughs and plenty trips away. David and Sarah in Sligo gave us the gift of our first grandchild, Amy in July 2015, and this was an occasion of great joy for Tina. We tried to continue to visit and went on many trips to Sligo and Edinburgh. Tina always looked forward to and enjoyed these visits.

Tina's spirituality and faith was very important to her. She attended Mass every Sunday and prayed each night. She had a strong belief in the resurrection and this was a great consolation to both of us.

I very much want to acknowledge the IMNDA's tremendous help and the support given by the Marymount Hospice team. They made a difficult situation easier to accept. Thank you all. A quick word of thanks also to the care team that looked after Tina: the speech therapist, the physiotherapists, dieticians, the occupational therapist and the CUH team under Dr. Aisling Ryan. Thanks as well to two ladies, Tina's carer Gemma (who always managed to get her hair looking beautiful!) and our housekeeper Eleanor, who tried her best to keep the house looking as Tina would want herself. Another word of thanks also, to Shirley and Clara, Tina's night carer's for a short while.

On Tuesday, September 20th 2016, Tina passed away very peacefully in Marymount Hospice, surrounded by love: the love of her family and lifelong friends.

She fought the good fight, she kept the faith.

Rest in peace, until we meet again.”

FUNDRAISING

The Difference We Make Together

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

Thank you to...

AFTERNOON TEA

The ever popular tea and coffee mornings proved once again a timeless treat. Thanks to Alan Twomey and all in the Donoughmore Macra na Feirme as their Coffee morning raised over €1,760.

Jennifer Wallace was brewing up at storm and her Coffee Morning tea-totalled €765!

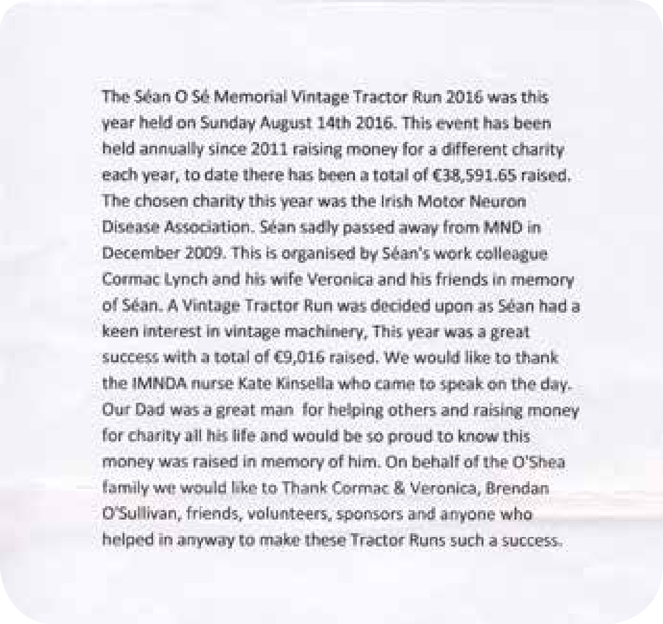
Jenny Roberts and her coffee crew made a strong €229 and the Harbour Bar were full of coffee beans as their fundraiser brought in over €1,300. Well done guys!!

All at the IMNDA would just also like to say a massive thank you to Alan Oliver, Monex and all the staff and customers of the Lir Cafe in Killarney. Their coffee morning raised over €5,600!! Phenomenal amount - congrats!

FUN-RAISING!

Francis Malone and his fundraising friends organise the Balbriggan Annual Charity Event every year for various charities. We were delighted to be chosen this year and Francis, through various events, raised a fantastic €5,023 for the IMNDA. Thank you Francis! And thanks to all who helped him raise a terrific amount.

The IMNDA would just like to say a huge thank you to James and all his family. James recently held his 40th birthday in aid of the IMNDA and raised over €1,000. Fair play to you James and thanks so much to everyone who gave so generously! Special thanks also to Ann O'Farrell and all who took part in the Wren Day Collection, great day was had by all.



The Séan O Sé Memorial Vintage Tractor Run 2016 was this year held on Sunday August 14th 2016. This event has been held annually since 2011 raising money for a different charity each year, to date there has been a total of €38,591.65 raised. The chosen charity this year was the Irish Motor Neuron Disease Association. Séan sadly passed away from MND in December 2009. This is organised by Séan's work colleague Cormac Lynch and his wife Veronica and his friends in memory of Séan. A Vintage Tractor Run was decided upon as Séan had a keen interest in vintage machinery, This year was a great success with a total of €9,016 raised. We would like to thank the IMNDA nurse Kate Kinsella who came to speak on the day. Our Dad was a great man for helping others and raising money for charity all his life and would be so proud to know this money was raised in memory of him. On behalf of the O'Shea family we would like to Thank Cormac & Veronica, Brendan O'Sullivan, friends, volunteers, sponsors and anyone who helped in anyway to make these Tractor Runs such a success.

Huge congratulations to Eileen O'Sé and everyone who helped make the Sean O'Se Memorial Vintage Tractor Run such a success. This incredible event raised €9,016 for the IMNDA!! Massive thanks to Skelligs Chocolates for their generous sponsorship and absolutely everyone who donated - well done!!! Here is a lovely account that they sent us in.

The fantastic team at Scoil Oilibhéar Naofa held a very festive Christmas Fair in November. They had a beautiful memorial Christmas Tree with donations coming to the IMNDA. Thanks to all the staff, students and parents who supported this lovely event. Special mention must also go to Nicola White and all who got festive and wore their Christmas Jumpers to work for the IMNDA.

A huge thank you and well done to Paul, Claire, Barbara Elliott and Conor Cummins who organised a Casino Night last October which raised an amazing €10,100!!!!!! The IMNDA is so grateful to everybody who supported this fantastic event, thank you!

Helen McDonnell held a very successful Bridge Night for the IMNDA and raised a brilliant €1,894. Thank you to all who gave so kindly.

Caroline Austin and all in Matheson treated us to a special Baking Competition. It raised €1,200 which really was the icing on the cake. Power to Mary Whittle who got blooming creative and organised a fabulous Flower Evening. Thanks Mary!

The North East Vintage Car Club Charity Rally once again raised a tremendous amount of over €3000. All that motoring has really mounted up – thank you for the amazing support.

MUSIC MOMENTS

Geraldine Collins and her amazing group of singers from St. Fergal's Gospel Choir hit all the right notes and collected some too. Their Christmas Carol Singing in Dundrum saw them raise over €500. We cannot thank them enough for their continued support.

Tony McKenna, Nicola White and everyone from Oblate Gospel Choir held two fantastic events for us which collectively raised €3525.07. Their Christmas Carol Singing at Tallaght Shopping Centre raised a fantastic €795.07. They also performed a beautiful concert at Our Lady of the Wayside Church in Bluebell which raised an outstanding €2,730! Well done to all involved.

Kathleen Burkhill and the Longford Circle of Friends came together in the Longford Town Centre and also took on some Christmas Carolling. Well done to all – Longford never heard such sweet singing!

Mark Murray and everyone from the Department of Agriculture, the Environment and the Marine Choir chose the IMNDA to benefit from their Christmas Carol singing. We are very grateful – well done to you all.

Department of
Agriculture,
Food and the Marine
An Roinn
Talmhaíochta,
Bia agus Mara

Marion Wyatt directed a GALA performance of 'Man of La Mancha' at the Cork Arts Theatre in memory of their friend and fellow performer, Hugh Moynihan. Their show wowed audiences and brought in an amazing €3,410! A massive thank you to everyone involved.

Gabriel Egan paid a beautiful tribute to his late wife, Joan Egan by organising 'Achill Aid', a benefit concert which consisted of performances from Ireland's iconic Riverdance and legendary singer-songwriter Declan O'Rourke. The night was a huge success and raised a fantastic €4,690 for the IMNDA. A big thank you to everyone who helped make this event such a success.

Des Hopkins got jazzy with it and his music night in Clane collected over €300. Other fantastic music nights included PJ Hoare's rocking evening and Remy Naidoo really deserves a standing ovation for her event in the Workman's Club in Dublin.

Pamela O'Keeffe was queen of the mike and her Cabaret Night sung in over €5,000. Pat Langton also must be commended for his fantastic affair and for raising over €3,000. Thanks guys!!

WITCHES AND GHOSTS

Karen Kavanagh was bewitching and tricked all her work crew to Dress up last Halloween for the IMNDA. What a treat!!! The entire workforce in Welch Allyn was similarly inspired and their ghoulish costumes scared people into sponsoring them. Brilliant effort by all! Thanks to everyone who took part and did their bit for people living with MND.

EGG-STRA EGG-STRA!

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

iMNDA
CARE AND RESEARCH

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

Walk to D-FEET MND

SATURDAY 15TH JULY

12 NOON

CASTLETOWN HOUSE , CELBRIDGE, CO KILDARE

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

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

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

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

www.imnda.ie

Charity No. 8510

Getting Active for your Association in 2017!

Walk to D-Feet MND

On **Saturday 15th July at 12.00pm**, the IMNDA is hosting our 'Walk to D-Feet MND' once again. Last year over 100 people came together with friends and family on for a beautiful 5k walk (or run!) in the stunning grounds of **Castletown House, Celbridge, Co Kildare** in aid of Motor Neurone Disease.

Register online - just **€20 per person** at www.imnda.ie or alternatively complete the below form and return it to us with payment. Walkers will also be able to pay on the day. The IMNDA will be based in front of the house and registration opens at 11.30am on the 15th. All children under the age of 12 go free. All walkers receive an IMNDA t-shirt and light refreshments. The route is fully wheelchair & buggy accessible.

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

Can't make Castletown on the 15th July? Why not organise your own Walk to D-Feet MND in your local area this summer! We'd love to have as many walks taking place across Ireland as possible in conjunction with our own so we can spread the message further afield. Get in touch to discuss your walk and we will provide you with some tips and practical information. Freefone 1800 403 403 or email fundraising@imnda.ie

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

Your details: (Please use BLOCK CAPITALS)

First name: ______________________ Surname: ______________________

Address: ____

____

Phone: ____________________ Email: ______________________

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

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

Total payment amount due: ____________

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

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

☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐

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

Cardholders Name: ______________________ Cardholders Signature: ____________

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

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

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DRINK TEA FOR MND

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

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

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

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

As we have already mentioned, Michael Clancy is fronting our National Awareness Campaign and he is encouraging everyone to lend a hand and Drink Tea for MND in 2017!

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

We want as many people as possible drinking tea for MND throughout June. Tea packs, which have been sponsored by SuperValu, are available from the IMNDA office so call 1800403403 or email fundraising@imnda.ie to get yours today.

Let's Drink Tea for MND!!

Sponsored Silence

Sometimes Silence Speaks Volumes

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

To create awareness around this fact Amanda McCormack, Sharon Friel and Paul Lannon bravely fronted our Sponsored Silence 2017. We asked people to take on a sponsored silence during the month of February to experience what it would be like to not be able to communicate.

Amanda McCormack was diagnosed with MND when she was 26 years old. At the time she was living the dream in Australia but two years after diagnosis she was back in Cavan and confined to a wheelchair.

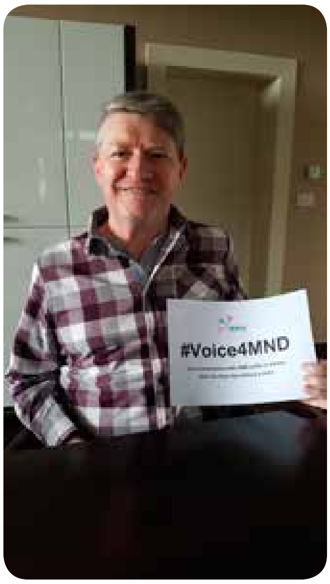
"I hadn't a clue what Motor Neurone Disease was, let alone what was in store for me", said Amanda.

She is now 44 years old and has been living with this disease for nearly 18 years. She was initially given a diagnosis of between 3 and 5 years.

"I never imagined my speech would go. If I knew then, what I know now, I wouldn't be here writing this. MND has ruined my life, it's a catastrophe. I am just a shadow of my former self. But there is no point crying over spilt milk, I'm making the most of a bad situation." said Amanda.

Sharon Friel is a 42 year old Mum living in Donabate in Co. Dublin. She was diagnosed with MND in 2012. Sadly Sharon can no longer walk or speak. She communicates to her 8 year old son Senan mainly with the use of a communication aid.

"Losing my voice has been the cruellest symptom of MND. Losing my voice has been the hardest loss from MND," said Sharon.



Paul Lannon was diagnosed with MND in 2011. He originally hails from Kilkenny but is now living with his wife Sandra in Dunleer, Co Louth. Paul's speech is now slowly starting to deteriorate.

"Having an itch...annoying! Having no movement and not able to scratch it...frustrating!! Having no speech as well and not able to ask for it to be scratched...TORTURE!!!" said Paul.

People took on the challenge at home, in work and in their communities. We had a great response from families, work colleagues and schools coming together to take on our silent challenge. They took sponsor cards and donated by texting MND to 50300 to donate €2. The length people stayed quiet for ranged from 30 minutes right up to a few hours to a few days!

Thanks to Amanda, Sharon and Paul championing the campaign it was a tremendous success. More people took on the challenge than last year. More people quit speaking and stayed quiet for MND. Thank you to absolutely everyone for taking part - the word is now out, now our silence shouts!

#VOICE4MND REFLECTION BY DIANE UÍ NÉILL

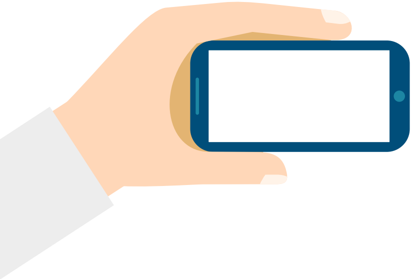
As you all know on Sunday 19th and Monday 20th February I decided to do a 48hr sponsored silence for Motor Neurone Disease Association Ireland to help raise so much needed funds for possible research or help and support for those diagnosed and their families.

The reason I picked Sunday and Monday is that:-

1. Sundays are my days for doing one of my most favourite things in the whole world - Sing - and then go for a very sociable cup of tea with my fellow choir members but I opted to go for silence instead and give this a miss as for me to not be able to sing would be heart-breaking but it was a challenge for me to give it up for the day - but worth it.

Also it is a day where my kids and husband are at home all day so a challenge in itself too. I decided to use pen and paper this day but found this quite frustrating as it was slow for me to respond to conversations and many questions that were being asked of me. It was quite frustrating for them too as they had to filter their requests to hopefully give me a question then that yielded a "yes or no" answer. Even to laugh at something funny they did or what I might see on the TV was difficult to block as I would love a good laugh anytime of the day.

2. Monday because my kids were going to be off school on their Mid-term and this day I knew would challenge me more too as most days I would be home alone with my Dog.



I downloaded an app this day to help me speak but this yielded pretty much the same frustrations as the previous day as conversations were well ahead of responses I was giving. Then some names or words I would type in when pronounced were not like the word I wanted to be heard at all - this brought different frustrations to me for this day. I wasn't able to speak to my dog in my usual way which was confusing for her at times too.

Coming towards the late afternoon of day 2, I had a massive tension headache from trying not to speak but also frustrated in trying to communicate in some manner that I could get my point across in a very limited manner.

I have to be honest and say that this did put me in bad form and I started to feel quite isolated and excluded from my family as it was easier not to contribute anything at all.

Overall as I reflect on this experience of being silent for 48 hrs, it has brought into my awareness the depths of Impact this disease can have on the person diagnosed but also their families and friends too - even pets - it is life changing!!

To not be able to share a laugh, sing a song, add an opinion or even just want to be a vocal part of the family is very difficult and frustrating and heart-breaking too as I thought of my children growing up and me not being able to tell them how proud I am or tell my husband that I love him. Thank God my children are the age they are though too as it got me thinking of those who may have smaller kids and the difficulty this may bring into trying to help them understand the changes that are happening to a loved one. This is a reality for the families of MND sufferers and such a tough reality too.

I really would like to thank everyone for all their support, sponsorship and texts to donate to this very important cause that has crossed my path twice in my lifetime so far!!

VHI Women's Mini Marathon 2017

Anna, Ciara, Aisling and Jenny Conway have taken part in the VHI Women's Mini Marathon for 10 years now. They run the race to make a difference as they sadly lost Paddy, a Father and Grandfather, to Motor Neurone Disease (MND) in 2007.

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

"The IMNDA provided Paddy with a custom made wheelchair which was essential as his illness progressed. This greatly improved his quality of life at this time and also meant Paddy was still able to go outside and enjoy walks with his family. The IMNDA also provided a nurse who supported the family during Paddy's illness," said Ciara.

Please run the VHI Women's Mini Marathon this June and help us to continue caring for as long as we're needed. Please contact the IMNDA for your VHI Women's Mini Marathon sponsor pack.

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

Corporate Update

The IMNDA is honoured and grateful to have the support of so many companies, organisations and individuals. Our primary corporate partners are Arthur Cox and Goodbody Stockbrokers but we have also had the pleasure of working with Equifax in 2016 and in 2017 we will partner with Brown Thomas Limerick and Capita Assets.

GOODBODY

The IMNDA secures a two year Corporate Partnership with Goodbody Stockbrokers

We are delighted to announce that we kicked off 2017 with some great news… Goodbody Stockbrokers chose the IMNDA as their charity partner for 2017-2018!!

For the next two years the enthusiastic and supportive employees of Goodbody will be engaging regularly with our events and campaigns as well as running their own initiatives to raise funds and awareness.

They started as they mean to go on at their staff ball in February where a whopping €5,231 was raised just from the raffle. The tuxedos were then swapped for boxing gloves as those brave enough volunteered to train for seven weeks under the tutelage of former Olympian and Professional heavy weight boxer Cathal O'Grady and his White Collar Boxing coaches. Their hard training and fundraising efforts culminated in an evening of boxing match-ups on Friday 31st March in Leopardstown's Club 92. A fantastic night was had by all!

Once the bloody noses and black eyes had healed our philanthropic stockbrokers dusted themselves off and took to St Anne's Park in Raheny on Good Friday for the annual Good Run of which they were the main sponsor. Some brought the family and walked the 2.5km route whereas others were more competitive and had times to beat in the 5km race. It was a super day and we look forward to next year's Goodbody Good Run!

There are many more events planned for the coming months and the IMNDA is honoured to be associated with such a dedicated corporate partner.

Thanks to everybody in Goodbody and here's to a very successful and fun two years together!

Thank you for getting active for your Association!

ON YOUR MARKS!

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

To all the amazing ladies who took part in the Cork Women's Mini Marathon, the Cork City Marathon and the Limerick Mini Marathon thank you! Over €6,200 was raised from these Munster races.

Thanks to all the fabulous runners who took part in the Dublin City Marathon including Sharon Nugent, Tomás Kavanagh, Tony McEnteggart, Aoibheann McGuigan, Aidan Hand, John Larkin and Simon Greene - collectively €31,510.57 was raised.

A massive thank you to you all!!

Well done to Barry Sherlock and Anthony Doyle who did a Movember Run and ran in over €800.

FUN-RAISING!

Caroline Culbert and her troop of juniors took on the 5k Valentine Muckfest and raised an amazing €900. Well done to all!

Peter Walsh held a week of Charity Yoga Classes for the association. His sessions created over €700 for people living with MND. Namaste Peter!

Michael Broderick and his friend Peadar took on the challenge of a lifetime and cycled from Dublin to Iran! They raised an amazing €3,925. Well done to you both and everyone who supported them along the way!

Niamh Ní Dhrisceoil and friends organised the 9th annual Cape Clear Charity Fun Day which was a great success and raised a brilliant €2,700 for the IMNDA. Well done to all involved.

A huge thank you to all involved with the organising of the 'Stephen Melia 7s competition' back in 2016. We are delighted to announce that this fantastic event has raised

over €8,000 for the IMNDA. The event was organised by Stephen's two Louth club, The John Mitchels and St Joseph's GFC in association with Louth GAA. Well done to everybody who helped to make this event such a success!

ABSEIL

An overwhelming thank you to all our amazing supporters who climbed onto the roof of the Hogan Stand in Croke Park in October and abseiled the 100ft to the pitch! We were absolutely blown away by the incredible fundraising efforts you all made. Nearly €70,000 was raised!!!

We would like to make a special mention of a few of our outstanding supporters who took on the dizzying heights of our Croker abseil this year. Eileen Boland is a formidable woman who tirelessly fundraises for the IMNDA as she lost her husband to the disease some years back. Her infectious enthusiasm and courage saw her barely blink at the 100ft drop! She roped in support from across Tipperary; we especially want to thank Pat Fleming and all from her cherished Moyle Rovers GAA club as well as all her family who cheered her on on the day. Eileen – you really are one in a million!

Two fellow formidable women were sisters Mary Lynch and Esther Naughton. This dynamic duo was a force to be reckoned with and even organised a dance to help them with their sponsorship. The pair raised over €8,000 and would like to thank all who gave so generously from family, friends and their collective communities in Cork and Nenagh. Well done women!!

HOLE IN ONE

To all our golfers out there thank you! You braved the elements on many occasion proving you are not fair weather golfers when it comes to raising cash.

Massive thank you to Frank Newman and all from Stackstown Golf Club, their Golf Classic raised an impressive €3,580. Josephine Fahy's Golf AM was a swinging success raisin €3,240. Thanks also to Kaleen Bray and everyone in Collinstown Pitch & Putt Club, their raffle was once again well received.

THE SKY IS THE LIMITS!

Not content with their feet on solid ground Lynda O'Connor, Brendan McClean and James Cussen took to the skies! They all jumped out of planes for the IMNDA – we applaud and admire your gusto guys!!!

CHRISTMAS DIP!

A few dared to bear all as they left their cosy homes on Christmas Day for a chilly dip for the IMNDA. Well done to Donal O'Flaherty and to everyone who took part in the Annual Nenagh Christmas swim which raised over €7,000!!

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

The Irish Motor Neurone Disease Association
dares you to take part in the

Croke Park ABSEILS!

EXPERIENCE THE *ULTIMATE ADRENALIN RUSH* & ABSEIL 100FT FROM THE ROOF OF CROKER'S FAMOUS HOGAN STAND.

SATURDAY 7TH OCTOBER 2017

The IMNDA is looking for people to abseil from the roof of Croke Park Stadium, Dublin; 100ft from top to bottom! ARE YOU GAME? Contact the IMNDA today – Freefone **1800 403 403** / email **fundraising@Imnda.ie** / **www.imnda.ie**

Over 18's only / no experience necessary / full training provided on the day

Event run in association with **www.adventure.ie**

Places are limited; a non-refundable deposit of €100 and fundraising is required of all participants. All proceeds raised will go directly to supporting people affected by Motor Neurone Disease; a progressive, incurable and terminal condition.

Charity No. 8510

EDITORS DESK

In Remembrance

Those We Love Remain With Us

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

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

Stella Nolan
Anne Grant
Bridget Hennebry
Patrick Hogan
Brenda Maguire
Mary Kelly
Michael Moss
John Clowry
Elizabeth Roche
Elizabeth (Betty) O'Hanlon
Loretto Dempsey
Jimmy Swords
Sandra McGavin Connolly
Zbigniew Pruciak
Ann Henehan
Liam Kearney
R.N. Wije Nemal Perara
Anastasia Kehoe
Brian Murphy
Brendan Nolan
Robert Nicholson
Patrick McLaughlin
Margaret Slevin
Mary Walsh
Noreen Healy
Walter Hegarty
Michael Fallon
Norbert Walecki
Hazel Stephens
Noel Collins
Michael Coogan
Vincent Walsh
Michael Carr
Sally Cody
Peadar Ó'Flatharta
Patrick Finneran
Maura Sweeney
John Gorman
Robert Haynes
William Roche
Edith Okoro Nwarie
Michael Carey
Patrick J O'Brien
Martha Barry
Catherine Brady
Bernadette Oliver
Joseph Chambers
James Connors
Sandra Stapleton Kirwan
Noel Brooks
Karl Hughes
Arthur Lackey
Michael Morrissey
Michael Moyles
Michael Dwyer
John Murtagh
Martin Gerard Wallace
Philomena Sheehy
Fergus Callan
John Carpenter
Denis O'Mahony
Molly Finlay
Martin Wallace
Kathleen Jones
Ann Whitty

IMNDA Staff Update

We are delighted to announce Jackie Martin has become our fulltime Fundraising Executive. Jackie initially started with the IMNDA when Arthur Cox sponsored a member of staff. We are thrilled that Jackie has chosen to stay on and carry on working as part of our team. Arthur Cox initially sponsored this post as they had seen first-hand how debilitating MND can be as one of their colleagues Loretto was diagnosed with the disease. Arthur Cox wanted to provide a legacy of support for others suffering with MND by assisting with the services that IMNDA provides day to day. The placement was named the Loretto Dempsey Placement in recognition of their colleague who sadly passed away from MND. May Loretto rest in peace.

"The Loretto Dempsey placement was a great experience and I am honoured to continue working for an organisation that I have come to love and respect. I have learnt so much here and I am really looking forward to the coming year and progressing in my new role", said Jackie.

In other staffing additions Maeve Leahy has now become our new PR & Communications Executive. Maeve has been with the IMNDA since August 2010 and will now look after the management and implementation of the IMNDA's PR and Communications Strategy. She took on the post in February and is looking forward to the task of keeping MND topical and making sure our clients voices will continue to be heard.

"Over the past 7 years I have worked for and alongside the most amazing people. I am constantly awed, overwhelmed and proud of what we do and why we do it. We are a small organisation achieving big things in the fight against MND and I will continue to shout this from the rooftops", said Maeve.

Church Gate Collections

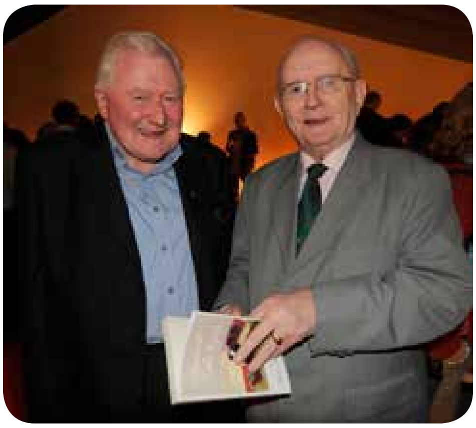
Church Gate Collections still bring in a fantastic amount of income and the IMNDA are always looking for trustworthy people to co-ordinate and carry out Collections in their local area throughout the year. Just pick a weekend that suits you and your church and contact the IMNDA with your preferred date.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

A few tips for collections:

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

Thank you for your support and we look forward to hearing from you.

2017 – Outlook of an MND Patient



We have bid goodbye to Christmas and all its celebrations. With an open heart I welcome the New Year 2017. Little Christmas has come and gone, that very special period many moons ago when three wise men came from the East, bearing gifts of gold, frankincense and myrrh. Today, as I relax in the quiet of my little Leitrim cottage, I gaze around me. There is not much evidence of those precious eastern gifts in this humble house. However, I have what money cannot buy – an abundance of family and friends. Some are very close; others are far way and yet with the click of a keyboard they are brought right into my sitting room. I know that they will be here in a flash if I need them. Today I chose to let the past go, rather than enduring the pain of trying to hold on to it. I want to enjoy this very moment because it can never be repeated. Each moment is new so I dig deep inside my heart to treasure and appreciate all that I have.

I think of the many friends who are the rich fabric of my life. In the quiet of the moment I give thanks for a very special group of people who through the passing of the years have become a big part of what is my life, a life living with Motor Neurone Disease. The IMNDA was born 34 years ago to support those whose lives are touched with MND. From humble beginnings the association has grown to become a vital service which delivers a wonderful commodity. The one thing which every human heart desires, that those living with MND can be supported to live in their own homes. The IMNDA with its highly qualified staff provide all of that and much more. Their three nurses who travel all over Ireland are the backbone of the association. They provide care and support to so many families.

The equipment bank which is at the disposal of all patients brings comfort and ease to the lives of all. The cheerful staff who man the phones are often a lifeline for those in despair. They are actually Samaritans as they listen day in and day out to our tale of woe, in reality; the IMNDA is our only crutch.

In September I had the pleasure of attending the IMNDA Patient and Carer weekend in Galway. Many who attended that weekend came away knowing that this world is a pretty amazing place. They had experienced a weekend with a difference where many small acts of kindness came together. We can never underestimate the ripple effect of small actions in this world. Receiving a MND diagnosis brings waves of devastation and pain to a family. However, during the many years that I have been blessed to attend the IMNDA Week-ends, I have witnessed MND bringing out the best in families. I see them united in their care for their loved one. Beautiful acts of human kindness often go unnoticed. Those blessed to see them know that they are witnessing God working at his very best. As I release 2016 to the windows of my past, I would like to acknowledge and thank the IMNDA for the wonderful work which they do. I thank God that I am here to welcome 2017. I wish everybody in the IMNDA and all my very special MND friends a happy and peaceful New Year. United in thoughts and prayers we go forward together, waiting, hoping, and pleading. We pray to God that this will be the year that the three wise men return from the East to give us our golden gift, our much sought after cure which will release us from the chains of our disease and give back to us: "A World Free of MND". Andy

Adapted Vehicle for Sale

Denis Johnston has a Wheelchair Access Van that he would like to go to the MND Community. He got great use out of this vehicle during his wife's illness. If anyone is thinking of purchasing a similar vehicle please contact Denis on 086 075 4594 for further details and price.

- 6-seater plus wheelchair space
- Hydraulic ramps, safety clamps and belts
- 1.6 Diesel
- Perfect condition

THE JUNE PARTY IN THE PARK

PHOENIX PARK POLO CLUB

SAT 10 JUNE 2017 3PM TILL LATE

TICKETS €95 + BOOKING FEE ON THEJUNEBALL.COM

EARLY BIRD TICKETS (€80) AVAILABLE UNTIL MAY 1ST

EXCLUSIVE AFTER-PARTY HOSTED BY DJ ROMÁN CLEISS

THIS EVENT IS OVER 21s

PROSECCO & STRAWBERRIES
GOURMET TASTER MENU
MUSIC • GARDEN GAMES
6 TEAM POLO COMPETITION

IMNDA
CARE AND RESEARCH

ALL PROCEEDS GO TO THE
IRISH MOTOR NEURONE
DISEASE ASSOCIATION

Everyone needs a helping hand... and sometimes it's as easy as making a cup of tea.

drink tea FOR MND

Michael Clancy, 59

> *Sometimes people think I'm drunk, but I promise you, tea is the only thing I've been drinking! My voice is slurred because I have Motor Neurone Disease.*

Please help the Irish Motor Neurone Disease Association (IMNDA) continue to provide vital services to people like Michael by hosting a tea party.

Text MND to 50300 to Donate €2*

Contact the IMNDA for your free 'Tea Pack'

sponsored by SuperValu Real Food, Real People

* Some network providers charge VAT, meaning a minimum of €1.63 will go to IMNDA. Service Provider LIKECHARITY 0766805278

IMNDA CARE AND RESEARCH

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

www.imnda.ie

CHY 8510