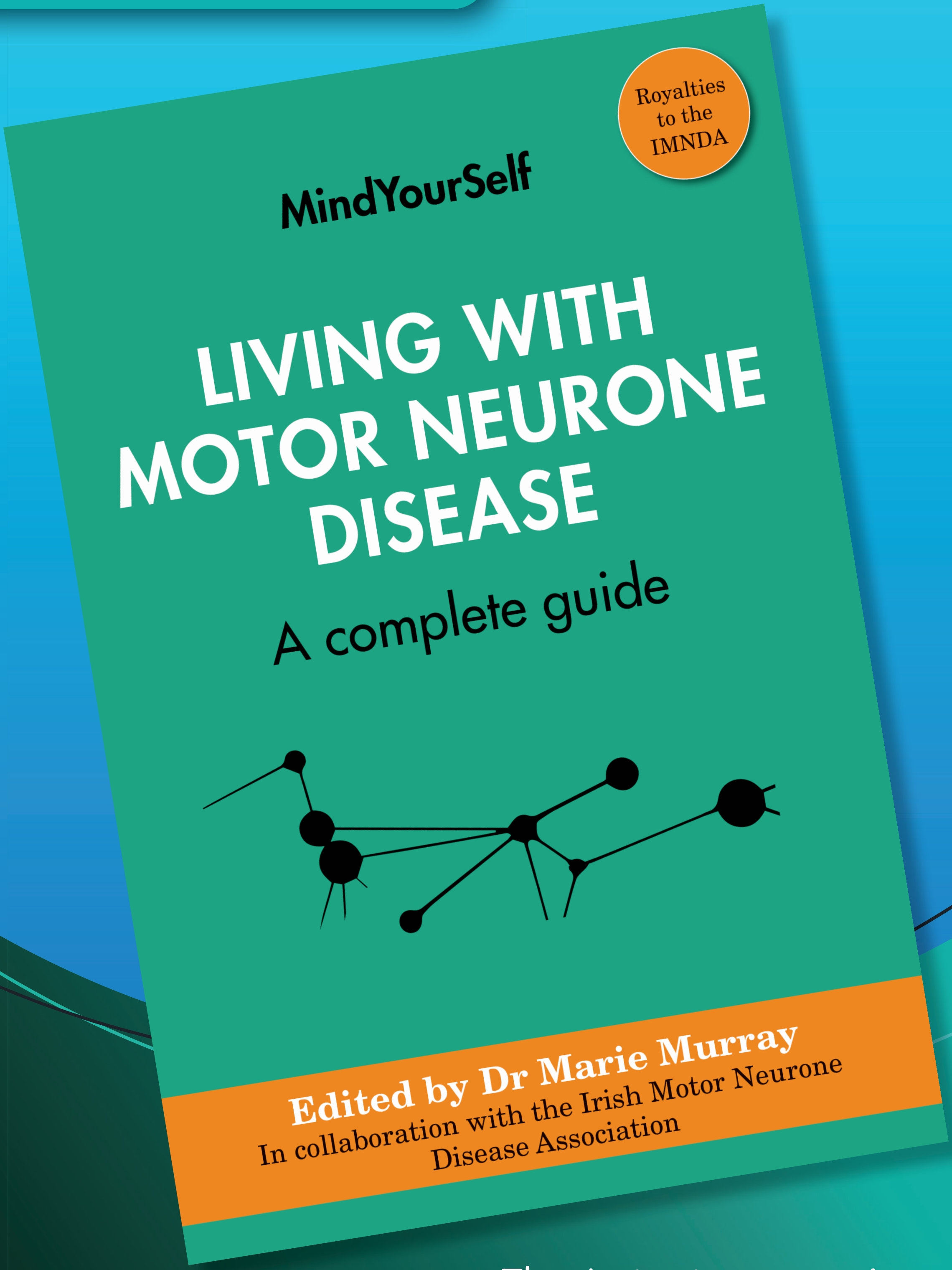
Irish
Motor
Neurone
Disease
Association

CONNECT

ISSUE 24 | AUTUMN 2021



Royalties to the IMNDA

MindYourSelf

LIVING WITH MOTOR NEURONE DISEASE

A complete guide

Edited by Dr Marie Murray
In collaboration with the Irish Motor Neurone Disease Association

The Latest news, views and information from IMNDA

CONTENTS

NEWS & RESEARCH

LIVING WITH MND

FUNDRAISING

Upcoming:

EDITORS DESK

A NOTE FROM OUR CEO

Welcome to the winter edition of our Newsletter.

I have recently been appointed as the new CEO with IMNDA. I have been involved with the Association since 2018 and I have seen first-hand the importance of timely support for those families facing the motor Neurone disease journey. I recognise the importance of this support being provided by trained nurses and support workers who understand the evolving and changing needs of each family at every stage of their illness.

I have great confidence that the entire team at IMNDA provide this very necessary support to the highest standard to everyone who needs our help, regardless of where they live in Ireland.

We plan to build on this service over the coming years. Armed with a clear roadmap for the next few years, our ambition is to create a stronger level of support where gaps exist, to communicate more effectively with you, our MND community as well as taking a stronger role in advocating on your behalf when you need us to.

Our 2021 AGM and Conference was a great success as we conducted it on-line for the second year due to the pandemic. Feedback from you has been very positive and it is clearly evident that you want to hear from experts in the areas of research as well as new technologies and services. We were also very heartened by the huge increase in healthcare professionals who joined us for the event this year. This was made possible for them by the "online" facility and is an indication to us of the interest and commitment of those who work with our MND community in many varied fields.

While we look forward to seeing you in person next year when we re-commence our annual weekend away we will continue to make our conferences and further events available on-line as a new norm. If you have any ideas as to how to improve on our Conference please do let us know so that we can tailor our event to suit your needs.

As we emerge from the global pandemic and begin to move back to a new sense of normality our fundraising efforts have bounced back beyond expectations. Thanks to you, our loyal supporters our annual "Drink Tea for MND" in June last raised an incredible €254,000 – the highest amount ever raised. A great testament to the generosity of our MND community yet again.

I've had the pleasure to meet with some of our supporters around the country over the last few months as part of their fundraising initiatives and I've been amazed at the level of community support for our events. I look forward to meeting with more of our supporters over the coming months now that we can start to re-engage with each other again in person.

We're in the planning stage for our Annual Memorial Service on Saturday, November 27th next (3pm) at the O'Reilly Hall at University College, Dublin remembering those family members who have sadly passed away. 2020 was a year like no other, and our deepest sympathies go to those who lost a loved one during the year. We know how important this event is for our community and for that reason we have arranged to host it this year at the O'Reilly Hall to facilitate all those who wish to attend on the day.

I look forward to meeting with you in person over the coming months.

My best regards

Lillian McGovern
Chief Executive

Until there's a CURE, there is CARE.

VIRTUAL AGM & CONFERENCE 2021

The AMG & Conference took place on the 30th September on Zoom yet again this year. The AGM itself started at 9.30am, followed by the Conference at 10.15. The event was an amazing success as over 170 people logged on this year to join us!

Our resident MC this year was Norman Hughes who serves on the IMNDA board and he did a tremendous job keeping the conference ticking along with impeccable time keeping!

After Norman did all the necessary house-keeping and reminding us all to mute ourselves and turn off cameras etc., the only thing that could be heard was the sound of each speaker! The Audience was very well behaved! Take a bow….

So here are the highlights for those of you who missed it…. First up was the renowned Professor Orla Hardiman, Orla is Professor of Neurology at Trinity College Dublin and Consultant Neurologist at Beaumont Hospital.

Prof Hardiman delivered her talk on MND Research in Ireland and a time for Optimism! She spoke about Ireland being the leading international hub on MND, she started off explaining What They do. From World Class clinical care, genetics and causes, cutting edge neural engineering to longitudinal studies. With 50+ brilliant young researchers World class science, 20+ PhDs in the past 10 years, with innovative cross-disciplinary projects.

Then we had our new CEO Lillian McGovern who delivered a welcome and update to everyone, she introduced herself and talked about her experience of IMNDA having served on the board for a number of years. She spoke about COVID and the impact it had on MND Community. She talked about the link between IMNDA & Beaumont Hospital particularly during pandemic and how people worked together to serve the MND community. She spoke about the new office move and hoped it could be a place for all to come and visit. She spoke about the Strategic plan and how we are going to continue to fulfil the strategies. She concluded by looking to next year where it is hoped that a physical AGM & Conference will be held.

Next up we had Dr Ailin O'Dea who delivered her talk on "People need to know they are not alone". Her presentation was an update from a study that both she and Caroline Wheeler conducted through a course with caregivers in the MND community. She spoke about the caregiver in MND being a rewarding and demanding role. She then went on to talk about getting access to supports, financial burdens, and about resistance and acceptance of MND. She also spoke about connecting with other people in similar situations. She reviewed what the participants learned from the course and what they learned about each other. She spoke about the caregiver and isolation felt and the need to stay well. She concluded by thanking the caregivers for their time and emphasised how much she learned from doing the study.
Following this, we had Dr Niall Pender who spoke about Cognitive and Behavioural Changes in MND. He then spoke about the psychological difficulties that are due to changes in brain function, and he also spoke about cognitive domains in MND such as memory. He spoke about how the brain function interacts with the world around us. He then went on to talk about Cognition and Behaviour Changes in MND. He spoke about the proportion of cognitive Impairments and the traits that come with this. He then went on to talk about cognitive difficulties: assessment & strategies and what they can lead to. And finally he spoke about self-management; Individual Self-Care, from some basics on good sleep hygiene…to reducing stress

And then we had Lesley Doyle and Ciara Fitzsimons who are both Speech and Language Therapists in Beaumont Hospital and CRC and they did their presentations on Voice Message Banking. They spoke about communication in MND and what can help. They talked about speech output technology and what message and voice banking is and how to Bank Your Speech. They spoke about the collaborative project and how this work came about. They talked about toolkit documents than can guide you through voice message banking and why you might want to bank your voice and also why you might not want bank your voice. They talked about message banking process and generating messages.
They concluded by thanking everyone and also directed us to where more information can be found. The toolkit documents can be downloaded from the 'Clinic-related Support' section of www.rmn.ie
And then we had Lillian who presented people with the Thumbs up Appreciation Awards. And finally a recap and thank you from Norman Hughes.
The virtual AGM was a great success and we would like to thank everyone for attending. For those of you who missed out on the conference, the slides from all the speakers are all available from our website www.imnda.ie under the news section.

PATIENT'S DESERVE BETTER

The NAI (Neurological Alliance of Ireland) are running a campaign "Patients Deserve Better - Ireland Needs an extra 100 Neurology Nurses." They want to bring awareness and attention to media and politicians in order to get changes made in neurology services in Ireland and we are supporting them with this campaign.

The issues are patients with neurological conditions are waiting longer, delaying diagnosis and treatment and they deserve better!

100 extra neurology nurses will reduce waiting lists, free up hospital resources and deliver real improvements for neurology patients

Importance of Nurses
Why are more neurology nurses needed?

The number of people on the neurology outpatient waiting list is continuing to rise and the number waiting more than 18 months has increased by 30% in the last year.

Currently 23,979 patients are on the neurology waiting list. In addition to this, people with long-term neurological conditions have limited access to the services that help them manage their condition, this results in unnecessary hospital admissions and delays necessary adjustments in medication.

Neurology nurses have a very significant impact on patients, increasing accessibility of healthcare and improving condition management. Currently Ireland only has 41.5 whole time equivalent (WTE) neurology nurses. Based on local and international recommendations there should be 142 neurology nurses

Better for Patients How will this benefit patients?

Increasing the number of neurology nurses will ensure that people with neurological conditions have improved access to healthcare supports and reduce the time they are waiting for appointments.

Patients who have access to neurology nurses have reported improved psychological well-being and improved sense of involvement in their care, being more prepared for tests and investigations. Their knowledge of their condition and related issues increases and they have more confidence to self-manage their condition.

More neurology nurses will also ensure that patients get quicker access to outpatient appointments, thereby reducing waiting lists and ensuring that any deterioration in the patient's health status can be mitigated. This will also ensure that additional hospital resources can be focused on those that need it.

NAI are calling on all of us to take part and help bring about changes! So here is what you can do!

Please take this opportunity to contact the Oireachtas members that represent constituents in the catchment area for your local neurology centre and highlight to them that neurology patients deserve better. Take action now. For More information on the campaign, please visit
www.patientsdeservebetter.ie

HOW CAN A PRIMARY CARE OCCUPATIONAL THERAPIST (OT) HELP YOU?

By Geraldine Canning

Occupational Therapy is a client-centred health profession concerned with promoting health and well-being. The primary goal of Occupational Therapy (OT) is to enable you to participate in the activities of everyday life that are important to you. Your OT will assess how MND affects your ability to carry out these activities and will help you manage the difficulties that arise.

Motor neurone disease affects different people in different ways and your OT recognises that you are an individual with a lifestyle, family, home, and work life that is unique to you.

Meeting with you as soon as possible following your diagnosis is important to us so that we can establish a supportive relationship with you and your family early on. Following an assessment in your home your OT will help you plan for the future. We will consider all of your needs-physical, psychological, social and environmental, as well as those of your family. We will focus on your goals and your priorities. We liaise closely with the IMNDA association and in particular the MND nurse who may visit you. We always promote a team approach to your care and engage regularly, with your consent, with other services who may be involved with you e.g. Physiotherapy, Speech and Language therapy, Public Health Nurse and GP.

There are many practical and emotional issues that we can help you with which at first may seem overwhelming. We are here to support and guide you in this process.

Here are some of the areas we can help you with;

Looking to discuss your experiences with other people?

- **Giving advice on new ways and techniques for helping you manage daily activities e.g. washing and dressing, preparing meals and drinks, completing household tasks such as laundry, housework, shopping, child care etc.**
- **Assessing movement i.e. your ability to mobilise, get in and out of bed, on/off toilets, chairs, in/out of a bath/shower, car etc.**
- **Giving advice on more supportive seating and other aids to independence in order to support you in the home and workplace.**
- **Assessing the home environment for potential hazards to tripping/falling and giving advice to prevent accidents.**
- **Advising on the management of fatigue and demonstrating techniques for pacing activities in order to conserve energy.**
- **Advising on how to manage work related activities and environments.**
- **Educating and advising on how to maintain good posture in sitting and in sleeping to support digestive and respiratory health and reduce muscular pain and stiffness.**
- **Education on how to look after your skin if you find you are sitting more than usual. Assessment and provision of pressure relieving cushions and other products.**
- **Assisting with plans and designs to adapt your home e.g. installing wet-floor showers, ramps etc. Assisting you in applying for grants from the local authority and making recommendations for changes.**
- **Providing wheelchairs and powered mobility to enhance independent movement, if required.**
- **Advising on memory strategies and memory aids.**

You can ask you GP or Consultant for a referral to your local Primary Care OT. Some OT services accept referrals directly from the service user and/or family members.

This article has been written by Geraldine Canning, who is a Senior Occupational Therapist, in Primary Care, Community Healthcare Network, Inishowen, Co Donegal.

PUTTING THE PATIENT FIRST: ANSWERING THE BIG QUESTIONS WITH PATIENT-DERIVED CELL

by Gráinne Geoghegan

Academic Unit of Neurology, Trinity Biomedical Sciences Institute, Trinity College Dublin

One of the most frustrating aspects of a diagnosis of Motor Neuron Disease (MND) or Amyotrophic Lateral Sclerosis (ALS) is the lack of definitive answers to the big questions. 'Why did this happen to me?' 'Could I have prevented this had I known earlier? ''What can be done about it?'. For scientists and clinicians, finding the right answers to these questions can sometimes feel like finding the needle in a haystack. 90% of ALS/MND cases occur sporadically, meaning that there is no clear underlying cause for disease onset, although there are likely a variety of different genetic and environmental risk factors involved (1). So without knowing the answer to 'why did this happen', it's very difficult to develop the treatment options to 'do something about it'.

Barriers to New Therapies

Research is ongoing to try to more conclusively determine the underlying causes and risk factors for developing ALS/MND in order to improve diagnoses and develop new treatment options. However, a significant stumbling block for new therapies is the lack of accurate disease models available to scientists to test their hypotheses.

A 'disease model' is a laboratory representation of some, or most aspects of a particular disease. These models can be anything from special cells in a dish, to animal models like mice, fish, flies and worms whose genome has been altered to express multiple copies of specific genes responsible for some aspects of the disease, or even organotypic cultures, which are pieces of tissue taken from patients or animals and kept alive in nutrient-rich media. Although all of these types of disease models have helped improve our understanding of ALS/MND, it is important to note that even the best model can only mimic certain aspects of the disease, and none can truly encapsulate everything going on at both cellular and behavioural levels.

Moreover, ALS/MND is very difficult to model in a laboratory environment because it is such a complex disease. Great progress has been made in identifying genetic causes for ALS/MND in many different types of animal models like zebrafish, rats and mice, and in cell-based models. However, all of these models have limitations as they are based on manipulating the genome of these animals in order to get them to display symptoms of a disease which they do not get naturally. Furthermore, these models are based on the inherited form of ALS/MND, which only accounts for approximately 10% of cases (1).

Patient-Focused Solutions

To overcome some of these limitations, researchers have developed new, more specific models of ALS/MND based on patients themselves. Using advanced cell reprogramming technologies, scientists can take a small skin biopsy from a patient and grow skin cells called fibroblasts from it in the lab. These cells can then be reprogrammed to become neurons (outlined in Figure 1), or other cell types found in the brain which are also involved in ALS/MND disease progression (2). These unique cells retain the genetic make-up of the patient, making them a highly specialised model that more closely resembles human disease and can mimic both inherited and sporadic forms of ALS/MND. Furthermore, as ageing is the biggest risk factor for all neurodegenerative diseases, advances in this technology has allowed these cells to retain their ageing signature (2). Scientists can then test their hypotheses using this model, which produces more accurate findings.

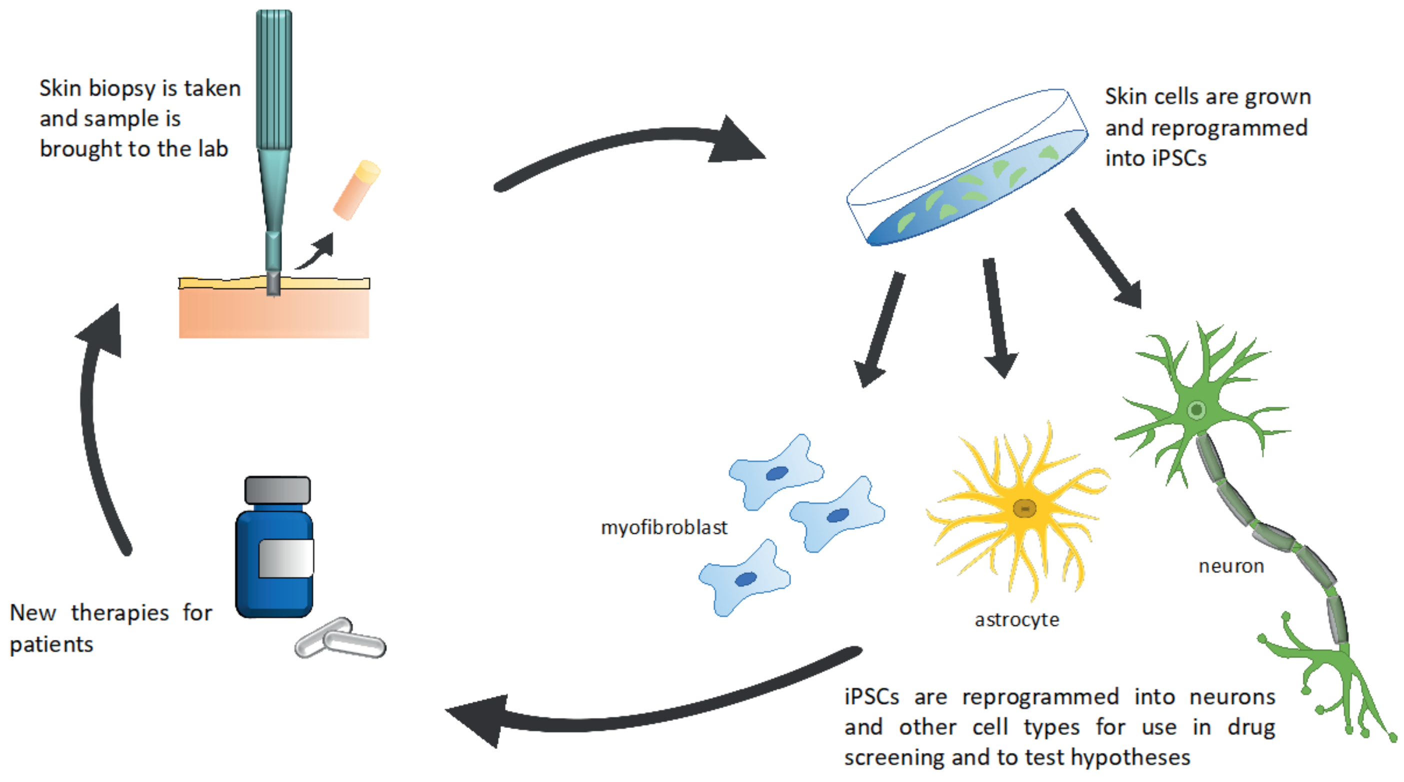


Figure 1. Overview of how skin biopsy samples are used to make induced pluripotent stem cells (iPSCs), which can be used as a valuable drug screening tool.

This technology is based on the ground-breaking development of induced pluripotent stem cells (iPSCs) by Shinya Yamanaka, for which he was awarded the 2012 Nobel Prize in Physiology or Medicine. Using this technology, fibroblasts can be genetically reprogrammed to become pluripotent stem cells, which are a type of unspecialised cell capable of giving rise to all the cell types of the body when grown under the right conditions. This pioneering technology overcomes the highly contentious issues surrounding embryonic stem cells in research and allows for the development of patient-specific cell lines (population of cells with the same genetic make-up) from a simple skin biopsy.

Promising Discoveries

iPSC technology was first used to grow iPSC-derived motor neurons from patient samples in 2008 by Dimos and colleagues, and since then, many pioneering discoveries and breakthroughs have been made (3). iPSC-derived motor neurons were used to confirm the importance of other cell types in the brain for disease progression, an important discovery which could lead to the development of new targets for therapy (4). In 2014, three separate studies using iPSC-derived motor neurons identified shared molecular pathways leading to ALS/MND which were common to patients with different genetic backgrounds (5). This means that patients with different genetic mutations known to cause ALS/MND, for example C9orf72 and SOD1, could benefit from similar therapies, if the underlying pathway to disease is the same.

Furthermore, many potential new drug candidates for ALS/MND have been identified using patient-specific, iPSC-derived cells. Three drugs, ropinirole (6), retigabine (7) and bosutinib (8) were identified as potential new therapies for ALS/MND in drug screenings using iPSC-derived motor neurons, all of which were then tested in clinical trials. All three drugs are already approved and used in the treatment of other conditions, namely Parkinson's disease, epilepsy and chronic myeloid leukaemia, respectively. This illustrates that iPSC-derived motor neurons could be used to test drugs which are already approved and repurpose them for the treatment of ALS/MND, dramatically shortening the time it would take for patients to gain access to new therapies.

These developments have also opened the door to the possibility of personalised medicine in ALS/MND. As iPSC-derived motor neurons retain the genetic signature of the donor patient, it's possible to identify potential new therapies which will be more efficacious for certain subgroups of patients, based on the genes these patients express. Furthermore, it is conceivable that patients could give a skin biopsy sample from which iPSC-derived motor neurons are grown, and are then used to predict that patient's specific response to treatment. This would help to ensure that the right drug is given to the right patient, not only leading to better treatment outcomes, but also reducing unwanted side effects.

iPSC-derived motor neurons are already helping us to answer some of the big questions in ALS/MND research, from identifying underlying causes and developing new biomarkers, to discovering new therapies. The use of iPSCs has exploded in popularity since their development just 15 years ago for a good reason. Scientists conduct their research to better understand the human body and how to treat it when things go wrong. Therefore, when the patients themselves are put at the forefront of this great effort, more accurate findings and bigger breakthroughs are made.

Our Work in Trinity College Dublin

Professor Orla Hardiman's group in Trinity College Dublin and Beaumont Hospital is setting up a new biobank of skin cells with funding from FutureNeuro, the Science Foundation Ireland Research Centre for Chronic and Rare Neurological diseases, and in collaboration with researchers in NUIG, RCSI and the University of Sheffield. A small piece of skin, smaller than the top of a pencil (4 mm) is taken from a numbed area on the inner forearm using a circular 'punch' blade and heals without a scar. The biopsy is then taken to the lab where researchers grow skin cells from it, which are then ready to be stored in the biobank. This valuable resource will be used to investigate the underlying causes of ALS/MND and to develop and test new treatment options in the future.

We are very grateful to everyone who has taken the time to donate a sample of any kind so far. If you or your family members are interested in donating a sample to the biobank, or would like more information, contact Mark Heverin, Research Manager to Prof. Hardiman (mark.heverin@tcd.ie) or Gráinne Geoghegan, Research Assistant (grainne.geoghegan@tcd.ie).

References and Further Information:

1. Hardiman O, Al-Chalabi A, Chio A, Corr E, Logroscino G, Robberecht W et al. Amyotrophic lateral sclerosis. Nature Reviews Disease Primers. 2017;3(1).
2. Myszczynska M, Ferraiuolo L. New In Vitro Models to Study Amyotrophic Lateral Sclerosis. Brain Pathology. 2016;26(2):258-265.
3. Dimos J, Rodolfa K, Niakan K, Weisenthal L, Mitsumoto H, Chung W et al. Induced Pluripotent Stem Cells Generated from Patients with ALS Can Be Differentiated into Motor Neurons. Science. 2008;321(5893):1218-1221.
4. Meyer K, Ferraiuolo L, Miranda C, Likhite S, McElroy S, Renusch S et al. Direct conversion of patient fibroblasts demonstrates non-cell autonomous toxicity of astrocytes to motor neurons in familial and sporadic ALS. Proceedings of the National Academy of Sciences. 2013;111(2):829-832.
5. Matus S, Medinas D, Hetz C. Common Ground: Stem Cell Approaches Find Shared Pathways Underlying ALS. Cell Stem Cell. 2014;14(6):697-699.
6. Fujimori K, Ishikawa M, Otomo A, Atsuta N, Nakamura R, Akiyama T et al. Modelling sporadic ALS in iPSC-derived motor neurons identifies a potential therapeutic agent. Nature Medicine. 2018;24(10):1579-1589.
7. Wainger B, Kiskinis E, Mellin C, Wiskow O, Han S, Sandoe J et al. Intrinsic Membrane Hyperexcitability of Amyotrophic Lateral Sclerosis Patient-Derived Motor Neurons. Cell Reports. 2014;7(1):1-11.
8. 8. Imamura K, Izumi Y, Watanabe A, Tsukita K, Woltjen K, Yamamoto T et al. The Src/c-Abl pathway is a potential therapeutic target in amyotrophic lateral sclerosis. Science Translational Medicine. 2017;9(391):eaaf3962.

HOW CAN WE IDENTIFY ENVIRONMENTAL RISK FACTORS FOR ALS?

Author: Dr James Rooney[1,2]

What are risk factors anyway?

We often hear about certain diseases as being caused by, or resulting from, environmental exposures [1]. The most common and well-established example being that of lung cancer caused by cigarette smoking. Other well-known examples include cirrhosis of the liver caused by excessive alcohol consumption, and skin cancer caused by excessive sun exposure (or UV light more specifically). In scientific research it is typical to refer to the exposure in question as a 'risk factor' [2]. Researchers will typically say something like: 'UV light exposure is a risk factor for skin cancer'.

These examples have several features in common:

1. The effect of cigarette smoke, alcohol, UV light on the lung, liver or skin retrospectively is a strong one. That is – the chances of getting any of these diseases are heavily impacted by the particular exposure associated with each disease.

2. The diseased organ gets a high dose of the exposure in question – i.e. cigarette smoke is inhaled directly into the lung, the liver breaks down almost all the alcohol in the body, and the skin is directly impacted by UV light.

3. The diseases in question and also the corresponding exposures are all relatively common within the population.

These features mean that if you are carrying out a study on one of these diseases, and your study includes the risk exposure in question, and assuming the study is otherwise well designed, then there is a reasonably good chance that your study will correctly identify the dangerous exposure for the disease in question!

However, what happens when the effect the exposure has on a disease is not as strong as that of cigarettes on lung cancer, or the organ in question is not directly exposed to possible risky exposures, or the disease, the exposures, or both, are less common than those discussed above? Unfortunately, in this case, finding the risky exposure (or exposures) for the disease in question can become extremely difficult. This is where we find ourselves when trying to identify risk exposures for ALS.

Environmental risk factors for ALS

In terms of the causes of ALS the picture is somewhat complicated. A subset of ALS cases are known to be caused by genetics. The most common of these is called C9orf72[3] and it explains about 10% of cases in Ireland. A large number of other genetic causes have been identified that explain smaller numbers of cases. Recently, highly detailed studies of Irish families showed that there may be inherited risk in up to 50% of ALS cases (https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6646974/). So, if that is true, what is causing the other 50% of cases? Well, there are a variety of opinions on this. Some believe that all cases are genetic, but that we have not yet discovered all the causative genes yet. Others believe that is caused by multiple genes acting in concert (i.e. polygenic). Still others believe that a wide range of environmental exposures might be responsible for the unexplained cases. And finally, others believe that genes and environmental exposures acting in combination are the root cause.

In summary -> its complicated! But we won't let that stop us. Given all the above, if we want to try to identify environmental exposures that might be causing, or contributing to the risk of getting ALS, how would we do it? The first thing we must do is have a way to measure people's exposures. There are many approaches to this, but some examples include the following strategies:

- Suppose we want to know whether cigarette smoking causes a disease, how might we do it? Well one approach is to survey people with the disease, and people without the disease on their smoking habits. This works reasonably well, because cigarettes come in fixed packet sizes, and as they are expensive and people need to budget for that, people tend to be quite aware of how much they smoke - although in general people do underestimate this. We know this because another way we can measure people's cigarette smoking habits is by measuring a chemical in the blood called cotinine that will only be found in smokers and is found in concentrations proportional to the amount of cigarettes smoked. Such a chemical is a biomarker of exposure. So, we have now identified at least two methods of assessing environmental exposures – by survey of people's consumption habits, and by measurement of biomarkers in the blood (or we could use urine, or hair, or nails – depending on the exposure of interest).

- However, suppose we wanted to know if exposure to diesel fumes was an important environmental exposure for a disease? People generally have no idea how much diesel fumes they are exposed to, and it is not something you can easily measure in a blood sample. But we do know that people in certain occupations have higher exposure than others. For example: farmers, truck drivers and mechanics will have higher diesel fume exposure on average than people working in an office. This approach has been used extensively in the past for respiratory diseases in particular, and industrial hygienist and epidemiologists have developed job exposure matrices to link many thousands of jobs with various exposures. Therefore, by surveying people's employment history, they can generate estimates of their exposures to a variety of chemicals or radiation.

- What about exposures like air pollution? Again, this is something people are generally unaware of on a daily basis (unless air pollution levels are extremely high). Although one can now purchase their own air pollution monitor, and wearable devices are becoming available to measure such things in real time, this doesn't help us as researchers if we want to know about someone's exposure 5 or 10 years ago. However, extensive satellite air pollution data is available from NASA (https://airquality.gsfc.nasa.gov), and Copernicus (https://atmosphere.copernicus.eu). Therefore, it is possible to look up a given persons home GPS coordinates and estimate their exposure over a time period to different air pollution measurements (i.e. particulates or various gases).

A number of studies into environmental exposures and risk of ALS have been carried out in Ireland. The EURALS study (2008 to 2012) surveyed ALS patients and age and gender matched healthy volunteers (commonly called 'controls' in studies) about their lifetime exposures. This was followed by the EuroMOTOR study (2011 to 2014) which built on the design of EURALS and expanded the survey to include additional possible exposures including a broader medical history and very detailed occupational history. Both studies were carried out across multiple European countries to include as many people as possible. Some of the findings from these studies included:

- EURALS found coffee consumption was associated with decreased risk of ALS **(https://academic.oup.com/aje/article/174/9/1002/168671)**
- EURALS found that repeated trauma and severe trauma were associated with increased risk of ALS **(https://www.tandfonline.com/doi/abs/10.1080/21678421.2017.1386687?journalCode=iafd20)**
- EuroMOTOR found that occupational exposure to a range of chemicals was associated with increased risk **(http://www.tara.tcd.ie/handle/2262/85062 - Chapter 5.5)**
- EURALS found that physical activity was not associated with a higher risk of ALS **(https://onlinelibrary.wiley.com/doi/10.1002/ana.24150)**
- EuroMOTOR found that physical activity was associated with increased risk for ALS **(https://jnnp.bmj.com/content/89/8/797.long)**

1 Academic Unit of Neurology, Trinity Biomedical Sciences Institute, Trinity College Dublin
2 Institute and Clinic for Occupational, Social and Environmental Medicine, University Hospital, LMU Munich, Munich, Germany

So given such findings, why do we not tell ALS patients to drink lots of coffee for example? Well, you might have noticed that the findings of EURALS and EuroMOTOR disagree with regard to physical activity. EURALS found that physical activity was not associated with increased risk for ALS, while EuroMOTOR found the opposite. How can this be? There are several possible answers here, including random chance, measurement errors or even differences in study design. Another possibility is that something else might be associated with both exercise and ALS, such as a gene that is associated with being a good athlete and could also be involved in ALS. However, the take home point here is that we cannot rely on a single study to identify a risky exposure, no matter how well designed or how many participants are involved. Because of this, every few years experts perform 'systematic reviews' of the research and consider all the papers on a given topic. This should be a highly organised process involving grading each paper by its design, number of participants and so on. Then it is possible to make a more general decision about a risk factor using special statistical methods to combine study results. Currently, the only environmental exposure widely recognised to increase the risk of getting ALS is cigarette smoking, adding to the list of reasons why everyone who smokes should take action to cut down and quit the habit.

The MetALS study

Currently, a study on environmental exposures known as the MetALS study is running in Ireland. This study is designed to further evaluate the role of metals as risk factors for ALS. The metals being studied are: aluminium, arsenic, cadmium, chromium, copper, lead, manganese, mercury and selenium. Some of these metals such as lead and mercury are always considered toxic to humans, while others such as copper and selenium are nutrients that are required by the body in low doses, but also can be dangerous at too high a dose. In MetALS, we are combining a survey approach with the collection of blood and urine samples from volunteer patients and controls. Using these samples, together with samples from German and Italian patients and controls collected by the MND-Net organisation in Germany, and the PARALS register in Turin, we are measuring the concentrations of blood and urine metals, standard hospital blood tests such as liver and kidney function tests, and the measurement of heat shock proteins. Heat shock proteins are special proteins that help our cells to cope with stressful events. For a human cell, stressful events can mean many things, but includes exposure to heat (hence the name heat shock proteins), and also chemical exposures to the cell, such as that of toxic metals. The heat shock proteins function to help the cell continue its normal functions in spite of such stresses. We also hope that some of our volunteers will return to give repeated blood samples so that we can determine trends over time of our measurements.

When we have completed all of the measurements, we will use statistical methods to make sense of all this data. We are interested in seeing whether metal or heat shock protein concentrations differ between people with ALS and volunteer controls, to see if there might be associations between metal concentrations and heat shock protein concentrations, and to see if any of these measurements might be correlated with disease progression (measured via the ALSFRS). Right now (September 2021), we are carrying out measurements on samples from the first recruits to our study. However, recruitment of volunteers for MetALS is still ongoing through the ALS clinic at Beaumont Hospital. We are really grateful for the interest of the ALS community in this work, and we would be really happy to hear from any volunteers wishing to take part in the MetALS study, either with or without a diagnosis of ALS. I hope that this overview has been of interest for the wider ALS community. If you'd like to hear more information about our results so far or taking part in future research, please email me at rooneyj4@tcd.ie or Gráinne Geoghegan at Grainne.Geoghegan@tcd.ie.

I'd like to thank Professor Orla Hardiman and Magdalena Kotalla, MSc, for feedback on this article.

[1] In scientific research "environmental exposures" can refer to air pollution, chemical exposures, radiation exposure, or even behavioural qualities such as diet and exercise

[2] Risk factor is a somewhat controversial term in that it can have different meanings in different contexts, however in this article we take it to mean an environmental exposure that can cause a disease. More on this topic can be read here: **https://www.bmj.com/content/355/bmj.i6536**

[3] Technically, an expansion of the C9orf72 is responsible. Everyone carries the C9orf72 gene, but in some individuals it is extra-long (hence 'expansion'), and it is the expansion that is associated with ALS and FTD (fronto-temporal dementia).

This project has received funding from the European Union's Horizon 2020 research and innovation programme under the Marie Skłodowska-Curie grant agreement No 846794

IMNDA Online Community Hub

Did you know that the IMNDA has set up a Community Hub for people affected by Motor Neurone Disease (MND), their caregivers and families?

The IMNDA Community Hub is an online support community for people affected by Motor Neurone Disease (MND). It is a safe and supportive online discussion site for the MND community.

- Looking to discuss your experiences with other people?
- Interested in finding, receiving and providing support?
- Want to connect with others at a time convenient for you?

Our community page allows you to post questions, share tips or advice, and interact with people with MND and their loved ones from around the country.

Registration is free and your contact details are kept confidential. You can submit your own questions and use the answers provided by the community to help support you with MND. You will find our online community hub here at http://community.imnda.ie/

Once registered, you will have access to the following services:

Forums

Our forums can be read by anyone, but in order to interact with others and post messages of your own, you will need to register with this site.

Blogs

A blog is a shared online journal where people can post diary entries about their personal experiences. We will also share entries by health professionals and those involved with research.

Connect

Reach out to people living with MND. Registered members can connect to freely discuss topics in a private and safe area.

The online community is open to people affected by Motor Neurone Disease and provides a place to connect, and find support in a safe space. For more see: http://community.imnda.ie/

IMNDA – PALLIATIVE CARE AND PRACTICAL HELP FOR PEOPLE LIVING WITH MOTOR NEURON DISEASE

by Maria Clarke

- **Outreach nurses** – a bridge to the network of community health care professionals
- **Home care support grant** – helping people do the things that others take for granted
- **Flexibility, nimbleness** – part of the association's DNA

Amyotrophic lateral sclerosis/motor neuron disease

MND is a relentlessly progressive disorder culminating in complete dependence of others for all activities of daily living. The clinical management of ALS/MND is palliative from the time of diagnosis and is focused on symptom control and adjustment to the progressive loss of neurological function.

Source: Bernie Corr. Clinical Nurse Specialist, Beaumont Hospital.

The IMNDA provides a wide range of services that are specific to the needs of people diagnosed with ALS/MND. The association provides palliative care as the disease progresses. Two key services, which improve people's quality of life and help them remain in their own homes, are:

- the four-strong team of outreach nurses that integrates health and social care, and
- the home care support grant that helps people self-manage their daily difficulties.

Fidelma Rutledge, an outreach nurse with the IMNDA who has carried out some 2,560 home visits over the last 14 years, describes the impact of these services on people's lives. Johanna McGrath, information and support officer, provides background information on the home care grant and how it is administered.

Table 1 Support services for people diagnosed with ALS/MND - benefits and savings

	Who /what	How	Benefits
1	Person living with ALS/MND	Enhances mental and physical wellbeing	Intangible
2	Family/informal caregiver	Relieves stress, gives them a break	Intangible
			Potential savings (€)
3	Hospital system	Fewer hospital /A&E admissions/ shorter hospital stays	€5,000 per bed per week (acute hospital)
4	Nursing/care homes	Reduces need	€1,300 per person per week

Source: IMNDA. Nursing Homes Ireland

These two support services impact the lives of well over a thousand people. Not only do they help the 563 people living with ALS/MND but they also lighten the load of the army of family caregivers that provides care on a 24/7 basis. These extra supports reduce unnecessary hospitalisations and ease the strain on an already overstretched hospital system. Fidelma notes, "The more care that is available in the community, the fewer people attend hospitals for care". The IMNDA programmes help delay or avoid the need for more expensive institutional care - such as nursing homes. Fidelma points out, "All research shows that people everywhere want to stay in their own homes for as long as possible".

Filling gaps IMNDA fills some of the gaps in health and social care which people, diagnosed with ALS/MND, encounter. Some of these result from the structure of the health care system while others are due to the nature of the disease. The health care system can be a labyrinth for the average layperson which, due to its size, moves slowly with a tendency to inflexibility. Motor neuron disease creates complex needs that straddle both health and social care and can run the risk of being met by neither.

Nurses - a bridge to the network of community health care professionals

Table 2 -The IMNDA outreach nurses -in figures

Outreach nurses	Figures
Number of outreach nurses employed by IMNDA (2021)	4
Number of home visits made by IMNDA outreach nurses (2020)	727
IMNDA spend on outreach nurses (2020)	€380K

Source: IMNDA

Outreach nurses are an efficient way to meet the high needs of people living with ALS/MND who are geographically dispersed. They play a pivotal role in delivering services and support. Nurses take a personalised and face-to-face approach and visit people in their own homes. They understand the individual, their different circumstances and the wide variety of needs that exists.

Nurses are best placed to act as a bridge to the network of community health care partners. They can navigate - because they understand - the complex and stratified health care system, they know which services are available locally and which are not - for whatever reason. Fidelma sums up their role, noting "The IMNDA nurse is useless on their own but they know where to go to receive the support that is needed". The nurses work closely with clinics and health partners in the community to integrate health and social care.

Hospital clinics

The IMNDA nurse team works with the MND clinics in Dublin, Cork and Galway. Here nurses and multidisciplinary teams - clinical nurses, dietitians, OTs/PTs, respiratory technicians, social workers, and psychologists - share expertise and experience. Bernie Corr, clinical nurse specialist, writes, "Multidisciplinary teams can enhance quality of life and improve survival". The National Motor Neuron Disease clinic in Beaumont Hospital is the largest one in the country, seeing 80% of the people in Ireland who have contracted the disease. The Beaumont Hospital clinic is held three times a month and is run by consultant neurologist Professor Orla Hardiman.

Community health care partners

Self-feeding As the disease progresses, it impacts people's ability to independently self-feed. The simple task of eating becomes a major chore as grasping and manipulating utensils – forks, knives, spoons – become ever more difficult. The outreach nurse makes the referral to the OT as only they can decide on the specific adaptive cutlery and utensils which will help the person to continue to independently self-feed.

Swallowing People living with MND can experience difficulties drinking and swallowing which, if left untreated, can lead to other serious problems, such as pneumonia and lung infections. One solution is to modify the texture of foods and fluids that are consumed. Fidelma explains "Some people have difficulty swallowing their food. In some cases their food must be thickened slightly or, in other cases, substantially". But only a speech and language therapist can make that decision and it is the outreach nurses who makes the referral.

Pulling it all together

The outreach team deals with inequities in accessing palliative care services and equipment. Functional inaccessibility is a perennial problem: People live too far from the MND clinics, suitable transport may not be available, or what is available may be too expensive. Charges of €200 to €300 for wheelchair accessible transport to hospital appointments are not unknown.

The expert

One solution is to switch roles – it can be the more mobile health care expert who visits the house-bound. Fidelma points out, "There are people living in remote areas unable to attend appointments they have been allocated. The hospital does not know that their condition has sharply deteriorated since the last appointment or there's no wheelchair accessible transport. An advanced nurse practitioner now accompanies me on these visits. They can report back to the consultant, it's a two-way collaboration. The consultants now look for feedback from the ANP. It's a form of troubleshooting".

The device

There are geographic variations in the availability of special medical devices. Those living far from urban centres can find themselves at a disadvantage as the technicians, who set up these machines, are not always able to travel long distances. One example is the NIPPV (non-invasive positive pressure ventilation) device which supports breathing muscles. Respiratory muscle weaken as MND progresses can make breathing more of an effort and can lead to lung infections. The solution has been to train outreach nurses to set up NIPPV devices and improve people's quality of life in a more timely fashion.

Chairs and beds

The IMNDA steps in and fills gaps when special equipment, needed by people living with ALS/MND, is not provided by the HSE. Powered wheelchairs that cost in excess of €7,000 are one example. But it is not always about cost, there are other items for which people may have to endure a lengthy wait due to HSE procurement systems. In these cases community healthcare professionals use the IMNDA which is known to be more responsive. The association provides electric wheelchairs, chairs with built-in tilt-in-space and even double size electrical hospital beds when needed. Fidelma explains, “The HSE supplies single hospital beds which it bulk buys but not double beds which are the ones that young people prefer”. A community physiotherapist notes,” It's a strange thing to say but one of the best things about this diagnosis is the practical help that you get from the motor neuron disease association”.

(Note: The impact of electric wheelchairs on people's lives has been described in a previous issue)

Local decision-taking Varying interpretations of regulations can create inequities in the provision of palliative care. Local decision taking means that people with ALS/MND admitted to nursing homes in some areas can find themselves in a virtual care limbo, unable to access community healthcare services. Fidelma explains, “The HSE will not sign off on referrals for people in nursing homes. It is absolutely no reflection on the homes, some of which are excellent. It is just the system. People discharged from hospitals get follow-up but not people admitted to nursing homes!”.

Home care grant - helping people “do the things that others take for granted”

The other key support provided by the IMNDA is the home care grant, which allows for 3 to 5 hours of home care per week. Fidelma explains, “It is used to pay to do the things that everyone else takes for granted”. Johanna notes the grant is freely available, saying, “Whoever contracts the disease and whoever needs help is offered the grant”.

The outreach nurses, who know the people and their needs, are involved in this project and have responsibility for getting the ball rolling. Johanna says, “It is the nurse's visit that initiates the home care grant”. The lion's share – 80% - of the home care grant is spent on personal care - the usual ‘bed and bath’ tasks. Fidelma explains “We are looking at things needed in the home and used in the home”. But, as there is more to living than washing and dressing, the grant is used for a wide variety of social activities.

Table 3 - The IMNDA home care grant 2021– in figures

The home care grant	Figures
Number receiving the grant (2021)	140 people (approx)
How the home care grant is used	Personal (80%) and other (20%) care
Value of home care grant per week per person in currency	€80 - €120
Value of grant in care hours per week	3 - 5 hours
Years the grant has been in operation	1990s
Number of care hours funded (2020)	19500
IMNDA spend on home care grant (2020)	€511,028

Source: IMNDA

Helping those who help others

Family caregiver are the backbone of the healthcare system. Caring for a person with ALS/MND can be a full-time responsibility and, like any never-ending difficulty, wearing. Without support and help, the caregivers can themselves end up physically and emotionally exhausted. These primary caregivers – informal, unpaid - are sometimes referred to as “hidden patients”.

HSE and IMNDA: Two care grants, different approaches

The IMNDA grant fills some of the gaps that exist in the Irish social and health care system. It complements the HSE Home Support Service which is usually the first port of call for people. Most recipients opt to stay with same care agency used by the HSE as this arrangement is mutually beneficial. The parties involved already know each other, the care visit can be extended by combining both grants and travel time reduced.

Different criteria The HSE imposes rigid usage criteria. The support only covers intimate care: 1) helping into/out of bed 2) washing and dressing and 3) bringing to the toilet. In contrast, the IMNDA allows the people - the patient and family who know what is needed - freedom to decide how the grant is used. They can tailor the help to meet their specific needs.

Fidelma describes some of the different ways the home care grant is used:

Loneliness

The grant is used to cover a 30 minute care visit at midday. This visit helps breaks the monotony of the long stretch – up to 12 hours – when people can be left on their own when the rest of the household is at work. The carer can check on the person and bring them to the toilet.

It can be loneliness that propels people into care homes. These mid-day visits give family members, who work outside the home or live at a distance, peace of mind. Fidelma says “They have the reassurance that someone is going to the house between morning and evening HSE care visits”.

*Mark - cycling club companions

Mark is a young man who used to belong to a cycling club. He lives in a rural area where it is difficult to get a carer for short periods of time. Mark saves up his hours and uses them in one block. The grant is earmarked to pay for a carer who gets him out of the house and brings him “somewhere nice”. Cycling was Mark's hobby. These excursions are an opportunity for him to meet up with his cycling companions. Although he can no longer ride a bike, he retains contact with and feels part of the club.

*Diarmaid - one night off for his family

Diarmaid is in his late sixties. He no longer has use of his upper limbs and cannot press a bell. Neither is he able to communicate or to call for help. Diarmaid's family take turns to sleep on a camp bed in his room at night as he occasionally suffers from coughing fits. They are able to help him but they themselves do not get a good night's sleep which concerns Diarmaid. He uses the grant, which he tops up with his own money, to pay for a carer so his family can get at least one night off a week.

*Anna - Peace of mind

Anna is an elderly lady living on her own. Gardening had been her hobby but she was no longer able to keep her garden in good order. Anna was fretting that, with the lawn overgrown, her house would be a target for burglars. She uses the grant to pay a carer to keep the lawn mowed. Anna has peace of mind and no longer worries about the overgrown grass and unkempt appearance attracting unwanted visitors.

*Margaret - WhatsApp

Margaret is in her late 70s and very mentally alert. She cannot speak and uses the grant to pay for a carer to do all her phone business – including WhatsApp calls, online banking and bill paying. Margaret has all her tasks organised and lined up for the carer when she arrives. Family members know the carer's schedule and can time their calls accordingly and friends who live abroad can see her. Fidelma notes that this carer “does an amazing job. It's horrible for the phone to be ringing away and the person is unable to answer because they can't move or lift it”.

*Lily - Painting

Lily was an art teacher. Art is Lily's hobby and she uses her grant to pay someone who can help her paint. The carer gets everything ready from preparing brushes and paints to collecting the canvas from the local art supplies shop. Lily's shoulders are weak and she cannot raise her arms herself so the carer holds Lily's arms as she paints. Old telephone directories are used to prop up and balance Lily's arms. Although Lily still has enough power in her hands to hold and use a paint brush, she knows her work is not up to the same standard as before. The grant allows her not only to continue to paint but - as she explains her work to the carer - to also continue to teach art.

Family caregivers get a break

The grant gives the families a real break from caregiving. Two people are required to operate hoists, used to move patients from bed to commode. This is usually done by the HSE carer and the family caregiver. It is the IMNDA grant that allows for another carer to be hired and for the family to have a little free time. Fidelma explains, "The families need a break. There are a few mornings a week that the family member doesn't have to be the second carer and can have some free time". This is time that they can call their own and do what they want to do - usually something very simple. Fidelma summarises, "Some people get their hair done or meet a friend for a coffee. Others will simply go to bed for a few hours, they tell me that is what they need".

Person-centered care

High quality care Person-centered care is the highest quality of care. It is a win-win situation for both care recipient and caregiver. The former experience greater levels of satisfaction while the latter benefit in terms of personal accomplishment. Care is humanised, that is, the person is known as a person and not just a passive recipient of care. The three features of person-centered care are:

Continuity Continuity of care creates the environment in which trust can be built up. Fidelma points out, "The IMNDA carers are always the same. They only work a set number of hours. They live locally, they're special". The association provides the grant for as long as it is needed to guarantee continuity. Johanna explains, "We try to get the grant in place and started before it is desperately needed. It then continues for as long as there is a need"

Conversation A conversation – the chat – is an integral part of care. People are social beings and talking to someone - and being talked to - is a very basic human need. There is a psychological benefit from being and interacting with others, people are happier. Fidelma notes, "The grant is used to pay someone to come in, sit together, and have a chat. It allows someone to stay up late just one night a week, watch the Ryan Tubridy show with someone, have a glass of wine and talk".

Connectedness Person-centered care allows for a relationship to develop between the paid carer who cares and the person who is cared for - connections are forged. Fidelma notes, "Great friendships have come out of this. People prefer to wait for the carer they know, so many times I will hear that no carer has been in as the regular carer is not available".

Lack of continuity results in a poorer quality care, which is less effective. The delivery of intimate care services – such as showering – is awkward for the caregiver and care recipient when they barely know each other. It is a monumental waste of time and energy to explain the same thing over and over again with some visits lasting only 30 minutes. Neither - with social care costing €27 per hour - is it an efficient use of money.

***All names have been changed to protect people's privacy.**

The Cinderella of health care

Social care is universally undervalued and widely regarded as the poor relation of health care. Challenges facing the social care sector include:

Staff retention and recruitment high rates of carer turnover result in a downward spiral with ever decreasing job satisfaction and personal accomplishment.

Widespread burn-out Some carers may be rostered for to 12 care visits a day with travel time not always included as work time, nor the mileage costs incurred always reimbursed. There is job insecurity with hours not guaranteed.

Flexibility, nimbleness – part of the association's DNA

The very nature of care requires flexibility – a one-size-fits-all approach is never going to work. The IMNDA, as always, keeps bureaucracy to a minimum so it can be nimble and responsive to the needs of care recipients and their caregivers. Flexibility is needed due to:

Supply constraints Care provision is determined by the availability of caregivers. Short and frequent care visits are not feasible outside the larger urban areas as there are simply not enough caregivers. Johanna explains "What works in Dublin won't work in Mayo or Donegal. It's easier to get a large block of hours in most rural areas rather than shorter and more frequent slots".

Autonomy The people themselves decide – along with nurses – how the grant is to be used. It is impossible for those without direct knowledge of the person to take decisions on their behalf. Everyone is different - their needs are complex and cannot be generalised. Autonomy – freedom of choice, to take the decision - is empowering and increases satisfaction. Johanna notes, "There is no requirement to specify how the hours will be used. That is decided by the care recipient, the family and the nurse".

Unpredictable events Flexibility is needed when unexpected events, such as the pandemic, up scuttle lives and routines. People's needs can change overnight. Fidelma notes, "There has been a big increase in people using the grant for shopping during the lockdowns". Illness also requires a fast response. "Some families are excellent and can manage till a crisis arrives. If I find out that the primary carer has caught COVID. I send the association an email and can get the go-ahead within two hours. The carer can start the next day.

Administration

The association deals with all administrative issues. The care recipients only have to decide on a care agency and agree on the duties to be discharged. The grant, for insurance reasons, can only be paid to an approved home care agency.

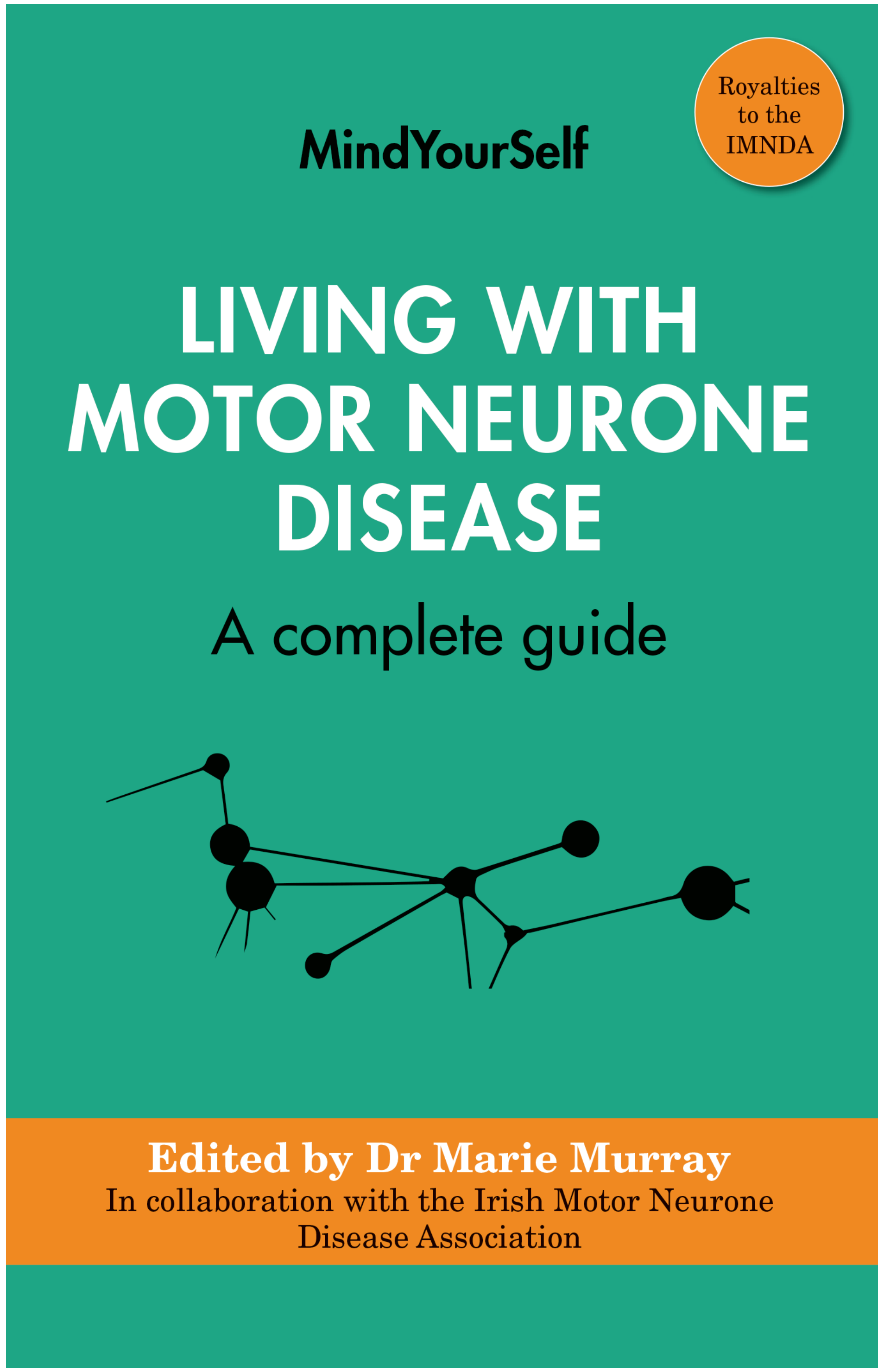
The duration of the grant depends on the speed of the progression of the disease. Some people rely on the grant for years while others, who are in the later stages, may only require the grant to be paid for months.

Table 4 Grant administration – Keeping it simple

Responsibilities			
	IMNDA		Care recipient/family
1	Initiates the home care grant via the nurse		
2	Processes the application	4	Decide on which home care agency to work with
3	Informs patient of grant approval	5	Determine the specific care to be provided
6	Deals with invoicing and payment		

Source: IMNDA

LIVING WITH MOTOR NEURONE DISEASE: A COMPLETE GUIDE



Royalties to the IMNDA

MindYourSelf

LIVING WITH MOTOR NEURONE DISEASE

A complete guide

Edited by Dr Marie Murray

In collaboration with the Irish Motor Neurone Disease Association

Every two days someone on the island of Ireland is diagnosed with motor neurone disease MND which is a neurodegenerative condition in which the nerves that control voluntary muscles stop working. This means that messages gradually stop reaching the muscles, which leads to weakness and wasting that affects the ordinary everyday activities that we take for granted. This is why Living with Motor Neurone Disease: A complete guide is designed to help anyone diagnosed with the disease, their family and friends to navigate their way through the progressive complexities that living with MND poses for everyone. It is also a must-read book for all health care professionals.

While MND is a rare disease it is a devastating diagnosis so good quality information from people who understand MND is vital. It takes time to learn about MND, to absorb the implications of it; to talk about it; to let family adjust to it; to help friends understand it and to learn to live a life that is altered in which the future is changed and the present is challenging. Living with Motor Neurone Disease: A complete guide is a practical and reassuring book at this time. Written in collaboration with The Irish Motor Neurone Association, IMNDA by many of the most distinguished Irish experts on MND it is a book that shows the extraordinary power of multidisciplinary professionals working together to support people diagnosed with MND and their carers. It is a guide on how to live 'with' MND with the highest quality of life that is possible for as long as possible.

Living with Motor Neurone Disease is a step-by-step guide. It explains what MND is, how it is diagnosed and managed; how it affects the individual and the family; the psychological dimensions of the condition; the caregiver experience; living with the condition and facing the future too. It shows how to talk to children and adolescents, how to tell family and friends, how to adapt working conditions and home life. It describes all the supports; medical, psychological, mechanical, technological and practical to cope with the daily impact of living with MND particularly the crucial supports provided and coordinated by the Irish Motor Neurone Association of Ireland IMNDA.

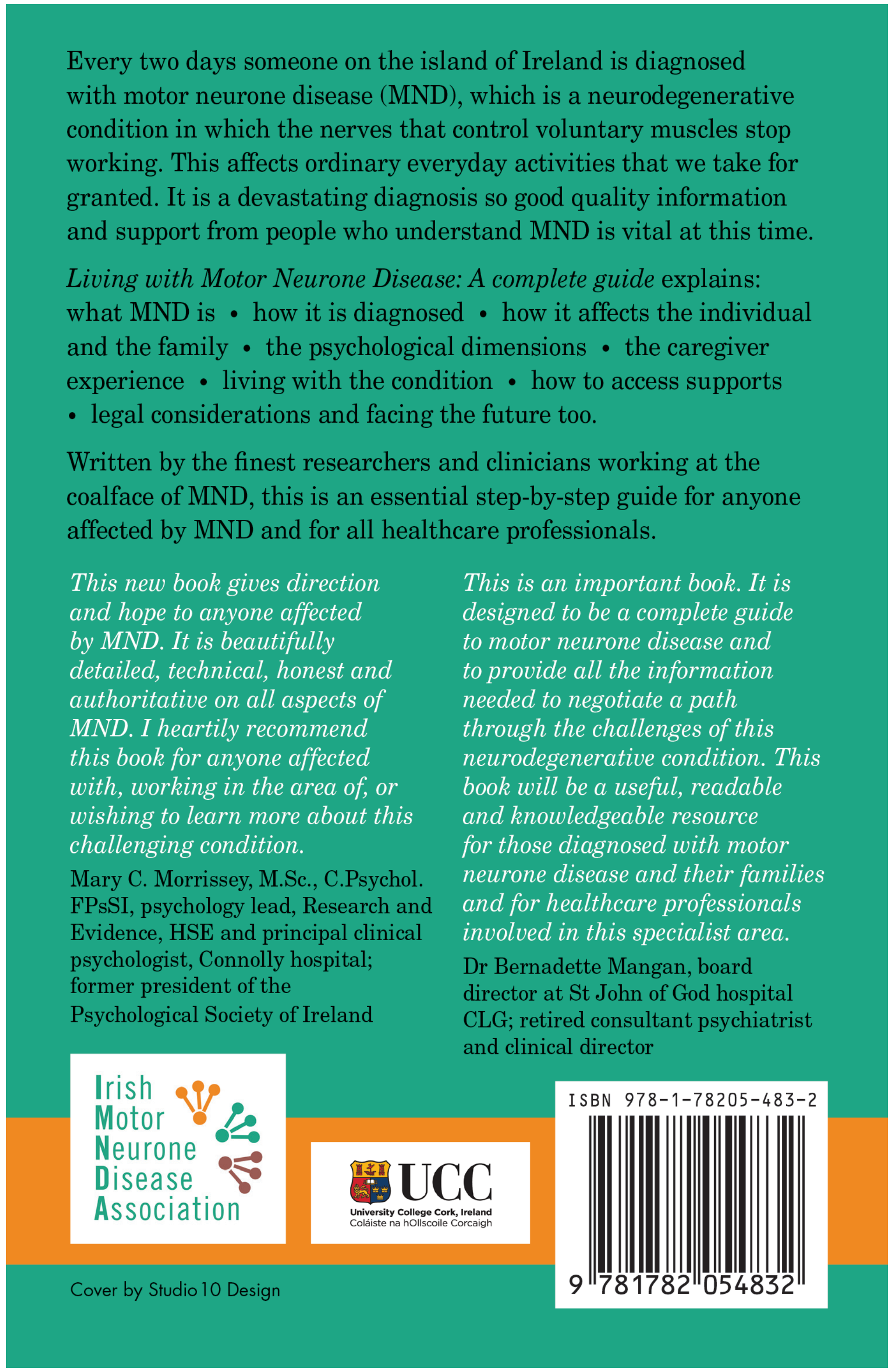
With chapters by acclaimed authorities on MND such as Professor Orla Hardiman; Professor Peter Bede, with Dr Stacey Li Hi Shing and Dr Jasmin Lope on diagnosis and management; clinical nurse specialist Bernie Corr on the profound impact of the diagnosis, and neuropsychologists Dr Niall Pender and Dr Marta Pinto-Grau on cognitive changes, the book also has advice on accessing services, on family dynamics, on the role of carer, on legal matters and most poignantly a chapter by the late Andy Minogue whose life may have ended but whose legacy on how to cope with MND lives on.

Having read the book readers must be profoundly moved by the resilience of those who have received a diagnosis, the professionals who support them, the families who care for them, the researchers who seek a solution and the exceptional way in which people live their lives with MND and fight to fundraise and help others who will come after them

(www.wwyc.ie)

(https://www.youtube.com/watch?v=P9tSlqQSCXE)

We are very grateful for the support of many individuals during the preparation of this volume. In particular, we want to thank Dr Marie Murray, MindYourSelf Series Editor for her outstanding support and belief in this project. This volume would never have seen the light of day, if it wasn't for Marie's expertise, drive, determination and enthusiasm



Every two days someone on the island of Ireland is diagnosed with motor neurone disease (MND), which is a neurodegenerative condition in which the nerves that control voluntary muscles stop working. This affects ordinary everyday activities that we take for granted. It is a devastating diagnosis so good quality information and support from people who understand MND is vital at this time.

Living with Motor Neurone Disease: A complete guide explains: what MND is • how it is diagnosed • how it affects the individual and the family • the psychological dimensions • the caregiver experience • living with the condition • how to access supports • legal considerations and facing the future too.

Written by the finest researchers and clinicians working at the coalface of MND, this is an essential step-by-step guide for anyone affected by MND and for all healthcare professionals.

This new book gives direction and hope to anyone affected by MND. It is beautifully detailed, technical, honest and authoritative on all aspects of MND. I heartily recommend this book for anyone affected with, working in the area of, or wishing to learn more about this challenging condition.

Mary C. Morrissey, M.Sc., C.Psychol. FPsSI, psychology lead, Research and Evidence, HSE and principal clinical psychologist, Connolly hospital; former president of the Psychological Society of Ireland

This is an important book. It is designed to be a complete guide to motor neurone disease and to provide all the information needed to negotiate a path through the challenges of this neurodegenerative condition. This book will be a useful, readable and knowledgeable resource for those diagnosed with motor neurone disease and their families and for healthcare professionals involved in this specialist area.

Dr Bernadette Mangan, board director at St John of God hospital CLG; retired consultant psychiatrist and clinical director

Irish Motor Neurone Disease Association

UCC University College Cork, Ireland Coláiste na hOllscoile Corcaigh

Cover by Studio 10 Design

ISBN 978-1-78205-483-2

Living with Motor Neurone Disease: A complete guide is edited by Dr Marie Murray, and published by Cork University Press as part of its MindYourSelf series https://mindyourselfbooks.ie All royalties are dedicated to the IMNDA

To get a copy of the book which will be available soon, please contact info@imnda.ie

DRINK TEA FOR MND

Back last year when Drink Tea for MND went digital we were sure we would be having tea parties in homes, offices, restaurants and community centres in 2021. Alas June was a month that fell between different levels of restrictions and Ireland wasn't quite ready for large physical events.

That been said there were some fantastic outdoor tea parties, quirky event ideas and once again drinking tea online proved to be a massive success. As ever we are continuously blown away at your ability to think outside the box and support the IMNDA despite the obstacles in our way. So an enormous thank you to everyone who had a cuppa this June and helped to raise over €200,000!!!!

We must say a big thanks to our wonderful Drink Tea ambassadors who bravely told their stories to the media through the month; thank you Gerard, Todd, Denis and Roisin and everyone else who took the time to speak with journalists and radio stations – we literally could not do this campaign without you.

Lastly a special mention to our long-time corporate friend and Drink Tea supporter, SuperValu. They absolutely smashed the funds raised for the IMND in previous years and MD Michael Morgan handed over a cheque for €40,731 to our CEO Lillian and Board Member Jonathan. Now that's what we call tea-tastic!!!!!!!!!!!

This is my mum Mary Corkery to those of you from Cahersiveen and Mary Finola to those from her native Waterville. She and my father have ran the family business Corkery's Hardware in the town of Cahersiveen for over 40 years. She loves people, serving her community and GOLF.

Mum was diagnosed with MND In September 2020. After months in lockdown and a couple of falls she went about getting her hip done but knew her foot was not working properly. She was sent for tests and was diagnosed with MND on her 68th birthday. We were all absolutely devastated. The hardest part was telling my sister and brother who both lived oversea's. It was just dad and I for the first few months. My husband and work colleagues were so supportive and enabled me to be with mum as much as possible. Lockdown ment that she had no callers, no one else to support her or us. Friends and family really wanted to be there for us but the restrictions prevented this from happening. The human touch she craved so much from others was against the rules and that left a massive void for her.

Mum cried solidly for the first 4 months. She could not accept her diagnosis. Seeing such a strong independent, hardworking woman crumble due to this diagnosis was terrible for us all.

My father Michael has been an absolute tower of strength and has left no stone unturned when it came to adapting the house to prepare for the future and caring for mum so attentively every day.

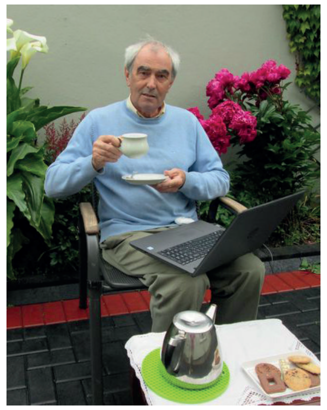
Since restrictions have eased our friends, family and neighbours have been a huge support. The baking and dinners we have received has been so appreciated. Mum's friends are so incredibly supportive. They take her out a couple of days a week and she loves the fun and laughter that they have. It makes her really happy. We are so grateful for those ladies.

With the fantastic help of IMNDA we received great support and guidance to navigate the hard times. Katie Kinsella the IMNDA nurse has been an absolute gem when it comes to listening to our concerns as a family. Just knowing we have someone to listen, advise and support us regarding the care needs and equipment for mum has been so helpful.

In June, Mum asked Ruth and I to set up a fundraiser for 'Drink Tea for MND'. We were absolutely blown away by the support from everyone who donated. It gave mum a great lift and kept her spirits high. So far the fundraiser has donations exceeding €31,000.

We would like to thank every single person who donated in Mum's name. Thank you too to all the local businesses who fundraised and helped us to fundraise by supplying gifts to raffle. We have an amazing community here in South Kerry and are so grateful for their support.

By Supporting 'Drink Tea for MND' you are supporting families like ours to receive the care, advise and support which is so valuable when coming to terms with an MND diagnosis. It is a family disease and certainly IMNDA approach every patient and family member in a holistic manner, for that we are extremely grateful.



WALK WHILE YOU CAN

Walk while you can this September, was all about the communities of Ireland. It was truly heart-warming to see so many people come together across the whole country and walk 5km to raise funds and awareness for the IMNDA. The spirit of Walk While You Can lives on because of all of you!

September was an amazing month of walks in every corner of Ireland and we really cannot thank you all enough for your support. A special mention to those who took on 5k a day for the whole month!

Walk While You Can has really grown into a community event embodying the true spirit that Fr Tony Coote represented when he came up with his idea after been diagnosed with MND in 2018. What a wonderful way to continue what he started and raise much needed funds for over 400 families dealing with MND every day.

We are beyond delighted that this year's campaign has so far raised a remarkable €140,000! Every step has really made a difference. See you all in 2022.

Hope starts with one step, change happens with many.

WALK WHILE YOU 5K CAN

Hope starts
with one step.
Change happens
with many.

WOULD YOU LIKE TO BE AN IMNDA COMMUNITY VOLUNTEER?

As a small organisation we lean heavily on our wonderful community. Unfortunately, staff and board members are not always available to travel to events and cheque presentations across Ireland. To have IMNDA representatives located in numerous areas means we can continue to provide a high level of fundraising support to as many of our supporters as possible.

We need trustworthy and flexible people in all areas of Ireland to act as a representative of the Association with the upmost professionalism.

Fundraising events take place sporadically and whilst we will always endeavour to give as much notice as possible, requests are occasionally made at short notice. They are also often in the evening and/or weekend and may involve some travel outside of your local area.

Tasks involved for Community Volunteers vary but can include photo opportunities with cheques to be sent to local media, attendance/volunteering at a fundraising event, saying a few words on our behalf about the IMNDA at an event (if you are comfortable to do so).

There is no minimum or maximum amount of time we ask you to give to the IMNDA, everyone's circumstances are different, and we appreciate all offers of help!

Please note the minimum age to be a Community Volunteer is 21 years of age. We request that volunteers are over 21 because of the nature of the work we do and people we support. Meeting families affected by Motor Neurone Disease can be very challenging and emotional at times as well as hugely rewarding and inspirational.

Life experience, warmth and empathy is essential.

Our Community Volunteers are:

- Personable
- Comfortable been placed in an environment where people are dealing with a terminal illness and/or loss
- Strong communicators & confident
- Available and easy to contact
- Organised and flexible
- Reliable and trustworthy
- Drivers or have access to good public transport links
- Experienced in motor neurone disease or an understanding of how the disease affects families.

If this sounds like you please contact Gemma or Jackie at fundraising@imnda.ie or call 01 670 5942

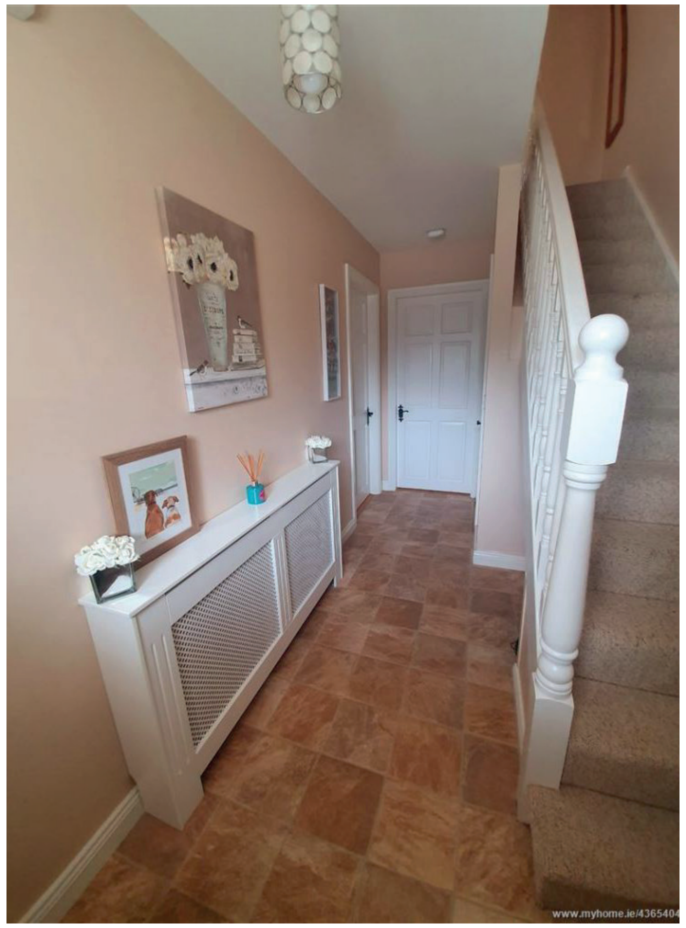
PRIZE HOME KILKENNY IS OFFERING YOU THE CHANCE TO WIN YOUR DREAM HOME....

Hatch House Digital approached **IMNDA** during the summer with an amazing offer to raffle a fully furnished home in Kilkenny. The raffle is called Prize Home Kilkenny and is a wonderful opportunity for IMNDA to be the beneficiary of **€100,000** the proceeds of which they hope to raise from the raffle of a beautiful home!

Located in the stunning village of Kells, Co. Kilkenny, this fully-furnished two-story house has three bedrooms and three bathrooms. The ground floor has an entrance hallway, with a spacious front sitting room, beautiful open plan kitchen, downstairs bathroom and private garden.

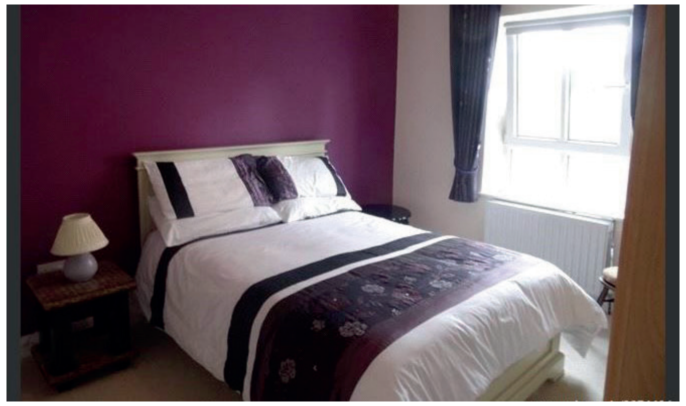
Upstairs there are three bedrooms, two bathrooms with brand new floors and a large attic space. The house also comes with comes with new appliances including washing machine, dryer and dishwasher and fully installed oil central heating system.

Kilkenny is a tourist destination, known for its historic buildings such as Kilkenny Castle, St Canice's Cathedral and round tower, Rothe House, Shee Alms House, Black Abbey, St. Mary's Cathedral, Kilkenny Town Hall, St. Francis Abbey, Grace's Castle, and St. John's Priory.



So what's in it for you? Enter Prize Home Kilkenny raffle to win a house located at only 8 km away from the city centre, so you can enjoy the beautiful surroundings of Kilkenny every day! In addition to this, you will win a cash prize of €20,000, all while donating €100,000 from the ticket earnings to the IMNDA.

You can buy your ticket for only €100 and enter as many times as you like. All entrants must be 18 or over.



The main draw will take place on the **17th of December 2021** or 7 days after the last ticket is sold. Every entry counts, please share the details of this raffle with friends and family on social media, for more information visit **www.prizehomekilkenny.com**

IMNDA STAFF UPDATES

Welcome to Lillian!

We would like to introduce our new CEO Lillian McGovern who joined the IMNDA in June 2021 and comes with a wealth of experience. She has worked at a senior level in the voluntary sector for the last twenty five years. Her previous experience includes a number of Chief Executive Officer roles with Victim Support in supporting victims of crime nationally and the Marie Keating Foundation cancer charity.

Lillian also worked at the National Children's Hospital Foundation, based at Tallaght University Hospital where she managed the affairs of the foundation. Her voluntary contribution has included membership of the National Crime Council, the Irish Parole Board and the Irish Motor Neurone Disease Association. She is currently a Board member of Tallaght University Hospital Foundation. Welcome Lillian, we know you will be a great asset to the IMNDA!

Congratulations to Maeve!

We would like to congratulate our PR & Communications Executive Maeve Leahy who gave birth to a beautiful baby girl called Caoimhe earlier in the year! Both Mum and baby are doing well and we hope to see Maeve back in the hot seat sometime in 2022!

THANK YOU

2021 has been another challenging year for fundraising. The first 6 months of the year saw more lockdowns and restrictions and not the return of physical events we had hoped for.
However, once again you, our community, have found wonderfully innovative and creative ways to support the IMNDA.
Covid 19 has stopped many things but it can't curtail sea swimming, cycling, walking, running, head shaves, Zoom tea drinking, donations, sponsored silences etc etc and the generosity and kindess of the people of Ireland.
As we - hopefully - come out of the other side of the Pandemic we want to thank each and every one of you for your unwavering support during such uncertain times. The only certainty over the last 18 months is that we are so lucky to have a supporter base who will go above and beyond during such tumultuous times. We have been blown away by the fundraising that has been carried out which allows us to continue to provide our vital services to over 400 families living with MND in Irreland.
We salute you all!

Marie Reavey a Tribute By Christy Lehane

It is with some sadness that I write a few lines about my friend Marie Reavey who has departed the Irish Motor Neurone Disease Association recently. The first time I met Marie Reavey was at an open meeting held in Killarney on the 15thFebruary 2011 hosted by by the IMNDA. A Consultant Neurologist along with the Manager of the IMNDA Larry Joyce and Marie herself who was the Regional Development Officer addressed the meeting. In attendance that night were MND sufferers and their families. The purpose of the meeting was to set up a group in Kerry to create awareness of MND and to do some fundraising as well.

Recently diagnosed MND sufferer John Reidy (rip) was in attendance, and he was very keen to do some fundraising for the IMNDA in lieu of all the help and support he had received from the Association in recent times.

Kerry Friends of Motor Neurone were launched on the 11th May 2011 and quickly planned a walk around the Lissivigeen Loop which was held on 26th June 2011, and we were finally able to hand over a cheque for €45,000 to Marie on the 19th July 2011.

From that time on Marie was with us on many occasions for Information Meetings, Eye Gaze Demonstration, Cheque Presentations and the Ring of Kerry Charity Cycle held in 2014. These are just a few of the events that Marie and Kerry Friends of Motor Neurone participated in together.

Since our very first meeting in Killarney when very few of us knew anything much about MND I think it is fair to say that both Marie and all of us have come a long way on this amazing journey. Marie it was great working with you, thanks for all you did for us, and I look forward to talking to you soon again.

On behalf of all our friends at KFMN I wish you all the best for the future in whatever path you may take.

Photo below was taken at our last information meeting in the Plaza Hotel Killarney in late 2019 where Christy presented Marie with a cheque.

On behalf of all the IMNDA team, the board, clients and supporters we would like to thank Marie for all her hard work, passion and commitment over the last 11 years. Marie brought joy and enthusiasm to her role and made wonderful friendships throughout her time in IMNDA. We will miss Marie.

TOUCHING POEM BY LATE MND SUFFERER BETTY

Love is all around me
Through the mist
I can see it
I can hear it
I cannot touch it
It cannot touch me

Pain is my lover,
My gaoler, My keeper
It plays with me
It teases me
It will not let me be
It will not set me free

Where are my husband,
my children, my friends?
They're out there beckoning
with open arms
I run to the door
Where is the key?
It is hanging inside
Why can't they see

Often I think of a wild lonely place
With the sun on my body
Bringing me to life
And the wind on my face
Blowing away the pain
That makes me feel old before my time

I would shatter into a million pieces
Like the stars
And scatter
Throughout the universe

Someone, touch me,
Heal me, help me
Set me free

A LITTLE BOOK OF CALMING AFFIRMATIONS

Healing Whispers is a little book of calming affirmations combined with soothing photography all rolled up in one bite size package of happiness and peace…

On Sunday 3rd October, Lisa Doyle, Niamh Ryan and Liz Phelan launched their very special photography book 'Healing Whispers' and calendar in aid of IMNDA at Bloom HQ in Mountrath, Co Laois. These beautiful items can be bought online at https://healingwhispers.ie or in the following shops: Crafts By Edwina & Phelan's Mountrath, Nook & Cranny and Allbooks & News Portlaoise.

This book was the brainchild of Liz Phelan. It is something that she has wanted to do for so long, so when the stars aligned and she met Lisa & Niamh, it all fell into place. Each lady brought their own set of skills to the table, Liz – affirmations, Lisa – photography, and Niamh – graphic design. And added to that mix was the need to help a very worthy cause – Irish Motor Neurone Disease Association, in the name of a very special lady – Aine Purcell. Aine sadly passed away on 4th May 2021 from MND.

They would like to thank their sponsors, without whom this book would not have been possible. Thanks also, to Aine's family, for allowing them to dedicate this book to Aine, and to use some of her beautiful photographs.

CONGRATULATIONS

We would like to take this opportunity to congratulate Ger Tracey & his beautiful bride Laura who got married over the summer!! We wish them all the luck for the future.
Ger was the face of this summer's Drink Tea for MND campaign.

DÉBUT POETRY COLLECTION BY IRISH SOLICITOR & POET OFFERS READERS A PROFOUND INSIGHT INTO MOTOR NEURON DISEASE

Having just completed her LLM degree in UCD back in 2017, solicitor, devoted wife and loving mother Vicky McCarthy Keane received some crushing news; she had motor neuron disease. MND is a terminal neurological condition that causes the patient's muscles to gradually lose function. While some poems in Vicky's debut collection, poems like 'The Day it Rained All Day', capture her emotions on that fateful day of diagnosis, others point to future possibilities and hope.

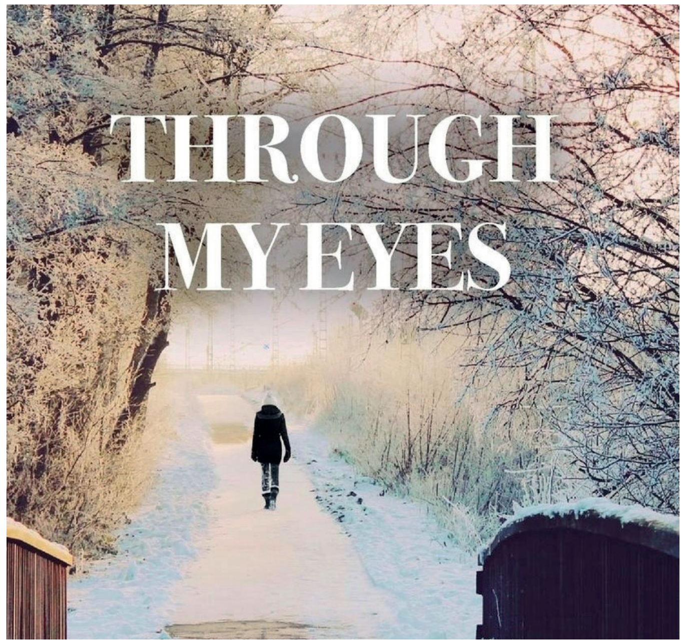
Vicky's language is visceral and profound, rich in symbolism, allegory and imagery, often drawing on the natural landscapes of Ireland. Many MND sufferers describe how the disease makes them feel 'trapped' in their bodies and locked in a battle with time, and nobody articulates this better than Vicky McCarthy Keane. Many of the poems hint at a battle with fate, richly imagined in the form of a journey, while others are dappled with light and hope, with the final poem 'Sunset Over Fanore' hinting at a paradise regained.

Vicky credits the great Irish writer John B Keane as the main inspiration behind her decision to take up writing after her diagnosis. Having watched a documentary where John B Keane's son, Billy Keane, discovered an old copybook owned by his father, Vicky wrote her first poem. Since that day, she has written poetry regularly through the assistance of an eye-gaze computer. The computer is the inspiration behind the collection's title, Through My Eyes.

Billy Keane, an early champion of Vicky's work, remarks, 'Vicky McCarthy Keane writes pure, tender, lucid poetry of the finest kind'. While award-winning writer and filmmaker Csilla Toldy has written, 'Vicky McCarthy Keane's poems celebrate love and life with a wistful gratitude only someone in her condition can know'.

The book is being published by JM Editing & Literary Agency, a publishing consultancy based in Ireland. The collection will be available in three editions, international paperback, deluxe edition with 'French flaps' and eBook. The international paperback and eBook will be available through all major online retailers, including Amazon, Barnes And Noble, Kobo, Apple Books, Google Books and more . The deluxe edition will be available in some Irish independent bookstores, Irish websites like buythebook.ie, or directly from the publisher. If you would like to order a copy directly from the publisher, or you are interested in stocking Through My Eyes, please contact Jeremy Murphy of JM Agency at jm.murphy@outlook.ie

Most importantly, Vicky McCarthy Keane has requested that all her proceeds from Through My Eyes be denoted to the Irish Motor Neurone Association, IMNDA.



We miss our loved ones all year round but at Christmas we miss them that little bit more. It's a time to keep their memories shining brightly even though they are no longer with us.

Lighting up a star on our online Memory Tree is a small way of remembering someone special during the festive period.

The stars that light up the darkest night are the lights that guide us.

To light up a star please visit https://fundraise.imnda.ie/event/christmas/home

Create a lasting tribute

When someone close to you passes away, keeping their memory alive becomes more important than ever.

Our dedicated In Memory site allows you to create a tribute page in memory of your loved one. You can share stories, photos and memories and ask family and friends for donations at special times of the year; anniversaries, birthdays and Christmas.

Honouring their life, through a donation to the IMNDA, is a special way to keep their legacy alive, while also helping other families in the MND community. This truly is a unique and special gift.

Whether you wish to set up an online tribute page to celebrate the life of someone you have loved and lost or give a once-off personal donation, each special gift in memory of your loved one is a gift of hope for the future.

Create your tribute page by visiting https://fundraise.imnda.ie/in-memory and allow friends and family to join together and mark the memories of those we treasure so fondly.

This event is dependent on Government advice in relation to Covid 19

The Pandemic has been so tough for numerous reasons. Losing a loved one and holding a funeral during lockdown with so many restrictions in place has been particularly challenging for our families.

We are delighted to announce that this year, our 2021 Annual Memorial Service will be an in-person event taking place at the beautiful O'Reilly Hall, UCD, Belfield, Dublin 4 on **Saturday 27th November at 3pm**. Light refreshments, tea and coffee will follow the service.

After not been able to come together and remember last year we look forward to the opportunity to do so at this special venue. This special Remembrance Service gives us the opportunity to honour and celebrate the lives of those we love but who are sadly no longer with us. This years' service will include readings from Fr John Kelly and with music from renowned Singer Mary Flynn and Harpist Siobhan Flynn.

If you would like to attend the service, we do ask that you RSVP by emailing info@imnda.ie with the number of people attending and the name of your loved one

LEAVE A LEGACY AND MAKE LIFE MORE MANAGEABLE FOR SOMEONE WITH MOTOR NEURONE DISEASE.

You don't need to be wealthy to give a significant gift to people affected by MND and you can make a substantial contribution that costs nothing during your lifetime.

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

Some people leave their entire estates, but most leave a modest sum. Once you have made provisions for your nearest and dearest you might choose to leave the remainder, or part of the remainder of your estate to one or more preferred charities.

However, much you choose to leave is up to you but please be assured that every legacy counts, no matter how large or small.

Member of my legacy

November is
My Legacy month,
to find out more
please visit
www.mylegacy.ie

TYPES OF LEGACIES

Having a Will ensures that what you own goes directly to the people and causes you care most about. If you are considering remembering the IMNDA in your Will, we are honoured and want to say a heartfelt thank you.

The first step is to speak to your solicitor to make sure that your wishes can be carried out in the way you would like.

Pecuniary Gift

A pecuniary gift in a Will is a gift of a specific sum. Remember, any amount, whatever you can afford after family and friends are taken care of, is greatly appreciated.

'I give the sum of €__ to the Irish Motor Neurone Disease Association (R.C.N 20021009) and I direct that the Treasurer or other proper officer for the time being of said Organisation shall be proper and sufficient discharge for the same'

Residuary Gift

A residuary gift in a Will is a gift of part of an estate. This is a share of your estate that hasn't been promised to family or friends. These kind of gifts are enormously valuable in supporting our work.

'I give to the Irish Motor Neurone Disease Association (R.C.N 20021009) a fraction (insert fraction) of the residue of my estate, and I direct that the receipt of the Treasurer or other officer for the time being of the said Organisation shall be a full and sufficient discharge of the same'

Specific Item

This is where you generously select a specific item of value like stocks, shares, jewellery, property, the proceeds of a life assurance policy or other valuable items.

'I bequeath (the item specified) to the Irish Motor Neurone Disease Association (R.C.N 20021009) and I direct the Treasurer or other proper officer for the time being of the said Organisation shall be proper and sufficient discharge for the same'

Codicil to a Will

A codicil to a Will is an addition to a will. If you have already written a will but decide you would like to leave a gift for the IMNDA in your will you can ask a solicitor to add a codicil, or an addition to your original will. A codicil is simple to add and is signed in the same way as your original will, with a witness present and will be added to a permanent part of the will.

WHY SHOULD I MAKE A WILL?

Making a Will is the only way for you to limit inheritance taxes, say how you want your assets and belongings distributed after you pass, and outline any legacy you want to leave behind. Without a Will to give your final instructions, those decisions will be made for you by others. Getting started is as easy as a phone call: Will-making is a basic service almost every solicitor provides.

Inheritance tax rates have jumped from 20 to 33%. Because of these significant changes even modest estates will suffer the taxman's share, shrinking your estate and creating needless tax bills, especially for children. A proper Will helps protect you from this.

CARE UNTIL A CURE – WHY LEAVE A GIFT TO THE IMNDA?

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

Leaving a gift in your will (a 'legacy') to the IMNDA offers much needed financial security on a long-term basis and will ensure families affected by this incurable disease have access to our vital services regardless of their location or means for as long as is required. Over 80% of our income comes from people like you.

After providing for family and friends, leaving a legacy to the IMNDA in your will is a thoughtful way of ensuring that families coming to terms with this life changing diagnosis have as much support as possible.

You don't have to tell us that you have decided to leave a gift in your Will but we would love you to. Informing us lets you direct your legacy to a part of our work that is closest to your heart, which may add meaning for you.

It also lets us thank you, in your lifetime…

To get in touch email fundraising@imnda.ie or call 01 670 5942.

To read more about My Legacy – visit www.mylegacy.ie

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
Phone: 01 670 5942

Thank you for your support and co-operation.

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

Irish
Motor
Neurone
Disease
Association

To Contact Us:
Irish Motor Neurone Disease Association
Unit 3, Ground Floor
Marshalsea Court
22/23 Merchant's Quay
Dublin 8

Freefone: 1800 403 403
Email: info@imnda.ie

www.facebook.com/irishmnd2011
@IMNDA
@IMNDA

Contributions to the next edition of Connect:
If you would like to submit a story, photo, or something you would like to share then please contact the office.

Unsubscribe from Newsletter Mailing
If at any stage, you no longer wish to receive the Connect Magazine simply email pr@imnda.ie or call 01-670 5942. We will remove you immediately from the mailing.

Disclaimer

This newsletter provides information only. The authors have no medical qualification whatsoever unless otherwise stated. No responsibility for any loss whatsoever caused to any person acting or refraining from action as a result of any material in this publication or any advice given can be accepted by the IMNDA. Medical advice should be obtained on any specific matter.

MEDICAL PATRON: Prof Peter Bede MD. PhD. MRCP Associate Professor Trinity College Dublin
DIRECTORS: Declan Mac Daid (Chair Person), Alison Gray (Hon Treasurer), Katie Hallissey, Bernie Conolly, Jonathan Healy, Angela Hogan, Norman Hughes

CHY 8510 R.C.N: 20021009

CHRISTMAS IS COMING...

Send a Card

Spread a little bit of IMNDA festive spirit this Christmas by purchasing a pack of our charming Christmas cards. BRAND NEW DESIGN FOR 2021!! The cards are €10 per pack of 12 cards and each pack has 6 different designs (2 of each design in each pack) and postage will be added at time of order. Buying a pack and sending our cards is a simple and effective way for you to help us raise awareness.

Hang a Star

Our special Irish 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.

Christmas Cards and stars are available to purchase
from our online shop: www.imnda.ie
or by calling the Fundraising Team on 01 670 5942.
Please note postage fees will vary depending on quantity ordered.