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'MS News' is the magazine of MS Ireland. It exists to foster informed debate and comment about all issues relating to MS. The view of contributors are not necessarily those of the Society. No treatments or therapies should be attempted or products used without qualified medical or professional advice.

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Dear Friends,

Welcome to MS News 111. How things have changed since our last edition of MS News! Thankfully, we are able to organise in-person events and the isolation that a pandemic brought is easing for many people. In MS Ireland, this change has prompted us to reflect more broadly. As we move forward, it can be useful to look back. For all of us, the sheer amount of change we want to make and work we want to do can seem that it is insurmountable... but it's not! When we look back and see how far we have come, it is easier to understand that the work ahead can, and will be done! The MS community is one that has seen some wonderful developments, both in the understanding of the condition and also in treating it. In parallel with these developments, social supports have been enhanced and within MS Ireland, additional services have been created to meet the changing needs of our community. We have highlighted a small number of key developments which you can read about on **page 22**. We can't stop here and will ensure that everyday, we work to improve the position of the MS community in Ireland. However, we cannot do that without your support! We invite you to read our pre-budget 2024 asks on **page 18**. We ask that if possible, you make contact with your local TD's asking for their support with our asks.



MS Ireland's Information Service works to ensure that people have access to the information they need, when they need it. Themes in information requests are routinely reviewed to understand the needs of our community. One issue that comes up regularly is guidance for those supporting a loved one through a diagnosis. This most frequently comes in as an ask from a parent to an adult who has been newly diagnosed. In this edition, we include a piece written by a mother living with MS who details her thoughts on her daughters diagnosis. You will find this on **page 8**. Additionally, you will find an information resource on **page 15** which outlines some steps that people can take to support those who are newly diagnosed.

This year, we are incredibly excited about World MS Day. The theme this year is 'connections'. The theme changes every 3 years and this is the final year we will be working in line with this theme, so our team have been incredibly busy working to ensure this is our best World MS Day yet. You can read about MS Ireland's World MS Day plans on **page 10**.

As in the last edition of MS News, we have used QR codes in this publication. These little black and white squares, similar to a barcode can be scanned on a smartphone, simply by opening the camera and holding it over the code as if you are going to take a photo of it. You must ensure the four corners of the code are visible on your screen. Your phone should then automatically scan the code and provide a link which you can click, taking you directly to the item we provide the code for.

We hope you enjoy this edition of MS News. As always, if you have any comments or would like to contribute, our Editor, Aoife Kirwan would be more than happy to hear from you –
aoifek@ms-society.ie

Ava Battles
Chief Executive

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Sativex update



MS Ireland is delighted to share that Sativex has been recommended

for reimbursement, subject to a managed access programme. Details of the managed access programme are yet to be shared but MS Ireland will be monitoring this closely and liaising with the Department of Health for updates which we will be sharing with our community. If you think that this medication would be suitable for you, we recommend speaking to your neurologist.

Ava Battles Chief Executive of MS Ireland welcomed the news saying “This is wonderful news for the cohort of people living with MS who benefit from this treatment but have been struggling to self-fund or those who have been unable to access it due to the prohibitive costs.

“MS Ireland have been advocating for this medication to be made available for many years. 10 years ago MS we were supporting a change in legislation which was required before this medication could even be prescribed. Following on from that we made numerous representations on behalf of the MS community including patient group submissions as part of the reimbursement process.”

Consultant Neurologist Dr Hugh Kearney said “Sativex will be an additional pharmacological treatment available for spasticity in MS. Our hope is that with better disease modifying drugs for MS we will see complications like spasticity much less often. This medication option may not suit everyone as it has many possible side effects, so other treatments such as physiotherapy and occupational therapy will still be as important as ever.”

Brain Awareness Week



To mark Brain Awareness Week 2023, MS Ireland researched what the most frequently searched questions in

Ireland about MS and the brain. We sat down with Consultant Neurologist, Dr Hugh Kearney from the MS Unit in St James' Hospital and recorded a series of videos which provide answers to these questions. We released a question and response each day for the week. A video with all questions and responses can be found here <https://www.youtube.com/watch?v=wgT6hWVzDwg> or scan here:



Additionally, we highlighted a number of resources from MS Ireland which may be useful for people when considering their brain health.

Young Scientists Great Achievement

In 2022, MS Ireland were delighted to support three budding researchers with their project which explored the topic of sex bias in chronic illness. We circulated a survey to our members which helped the scientists to gain a greater understanding of the topic in the MS space. We were delighted to later learn that Ellie, Lily and Meadhbh had gone on to achieve great success with their project at the Annual BT Young Scientists competition.

Our many congratulations to Ellie, Lily and Meadhbh on their project. We wish them the best of luck with what are sure to be very bright futures!

Physiotherapy Business Case

MS Ireland recently launched our Physiotherapy Business Case in the National MS Care Centre with Deputy Colm Burke and Senator Martin Conway. We are seeking sustainable funding for a national physiotherapy programme which you can read more about in our pre-budget asks on page 18.





National Conference 2022

In November, MS Ireland were delighted to host a virtual conference. Our speakers included Dr Hugh Kearney who discussed the topic of grey and white matter in MS; Dr Maria Gaughan who covered the topic of MS and Pregnancy; Dr Guido Giunti who discussed involving people living with MS in the design of digital tools with reference to his project More Stamina, a mobile app for fatigue management in people living with MS. The day saw 127 attendees join for the live sessions which were followed by an opportunity to ask the speakers questions. Recordings of the sessions were made and are available here: <https://www.ms-society.ie/what-we-do/video-catalogue> or scan here:



The lunch time session consisted of a pre-recorded conversation Professor Michelle Toshima and Dr Claire Yang and focused on the topic of Sex and MS. The conversation was facilitated by MS & Me blogger, Trevis Gleason. This was the

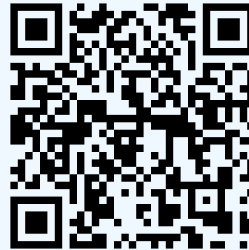
first conversation in a series called the 'Unspeakable Bits' that has since continued, read more below.

Unspeakable Bits



Over the past number of months, MS Ireland has facilitated a number of conversations on some of the elements of MS which tend to be under-discussed. The 'Unspeakable Bits' series has covered topics including: Sex & MS; MS, Food & Exercise and MS & Money. The sessions, bar one, have been live webcasts which are recorded and added to MS Ireland's video repertoire. The series will continue throughout 2023, so keep an eye on our website and social media for additional information, to register for

upcoming webcasts and to view past events. You will find them on our video catalogue page here: <https://www.ms-society.ie/what-we-do/video-catalogue#THE-UNSPEAKABLE-BITS> or by scanning the QR code:



NAI Board Membership

MS Ireland's Research and Advocacy Officer, Alison Cotter was appointed to the Board of the Neurological Alliance

of Ireland. In this position, Alison will be working alongside colleagues in other patient organisations representing those living with neurological conditions in Ireland. This approach ensures that associated organisations are working together with a collective voice to make positive change for our communities.

EMSP Executive Committee Membership



In May, Aoife Kirwan, MS Ireland's Information Officer was appointed to the Executive Committee of the European Multiple Sclerosis Platform (EMSP). This role will last for 4 years and will involve input into the governance and direction of the organisation. The role will help to strengthen our relationship with EMSP and our European colleagues to ensure that we are working to support each other and the MS community in Europe.

EMSP Spring Conference

This year's European Multiple Sclerosis Platform (EMSP) Spring Conference took place in Helsinki, Finland on May 5th and 6th. The theme of the conference was 'Social Policy: A better life for people with MS' which allowed attendees to discuss various advocacy issues on a European scale. It offered the opportunity to explore the impact of various social policies which included employment; family life & parenthood and social exclusion. Experts from around the globe joined to provide knowledge and insight into the various topics explored. A key element of this conference is to hear from representatives of various organisations who are working with people living with MS. Our staff members Aoife Kirwan and Alison Cotter took part to explore these issues with their European counterparts. They engaged in workshops on various topics to contribute and learn from the experiences of others on how best to approach making change on a national and European level. MS Ireland's Information Officer, Aoife Kirwan was also part of a panel of speakers at the conference who explored the topic of 'Family Life and Parenthood' offering her own experience as a mother living with MS and also insight from a professional perspective.

Some of the highlights from the conference included a moving session with professional basketball player, Chris Wright who was diagnosed with MS while he was building his career as a basketball player in the American NBA. His inspiring story of challenges and determination was warmly received by all in attendance.



The launch of the 'Impact of Multiple Sclerosis Symptoms' (IMSS) Survey was also a highlight of the conference. Research from the 2020 MS Barometer highlighted gaps in service across Europe in providing symptomatic care to those living with MS. EMSP along with 25 national MS Societies, including MS Ireland, will be sharing the survey to better understand MS symptoms, their impact, prevalence and management strategies. By increasing our understanding of this, we will be in a better position to advocate for those impacted by MS symptoms.

How to get involved:

Anyone diagnosed with MS in the participating countries, including Ireland are invited to take part in this survey. Those under the age of 18 will require consent from their parent/caregiver.

You can access the survey here:

<https://impactofms.com>

Or by scanning:



The anonymous online survey is now open and will run to the end of July.

Neuromapping

MS Ireland were delighted to have attended the launch of the Neuro-Mapping Project which is a joint partnership between the Health Service Executive, Disability Federation of Ireland and the Neurological Alliance of Ireland recently, launched by Minister Anne Rabbitte T.D.

This project describes the breadth of community services that people with neurological conditions can access from voluntary organisations, and identifies a number of joint service initiatives between voluntary organisations and the HSE.

MS Ireland welcomes this report and look forward to phase 2 of the project.





Octopus

Octopus Trial

Many of the treatments used to manage MS, including one of the earlier licensed treatments for secondary progressive MS treat neuroinflammation which is typically associated with the earlier stage of MS rather than treating MS progression where relapses are not a feature. Traditionally, clinical trials in MS have focused on establishing the effectiveness of a single medication. These factors have contributed to few medications being licensed to treat secondary progressive MS.

A new trial in the UK is aiming to accelerate the speed at which medications could be tested to establish their effectiveness as secondary progressive MS treatments.

The Octopus Trial is the first multi-arm, multi-stage (MAMS) trial in MS. It is currently simultaneously trialling two treatments which are already used in other conditions against a single control group. The control group will be given a placebo (dummy) drug. The name 'Octopus' stands for Optimal Clinical Trials Platform for Progressive Multiple Sclerosis. Additional treatments can be added to this multi-arm trial which will help to accelerate the discovery of potential treatments.

New treatments are assessed for their ability to slow down progression in the first stage of the trial. MRI techniques are used as part of this assessment. Treatments with promising assessment outcomes then move on to the second stage of the trial. This stage involves additional participants, runs for several years and monitors disability progression.

The drugs currently being tested in the trial are metformin, which is used to treat diabetes and alpha lipoic acid, which is used to treat neuropathy. This approach, both in trialling the effectiveness of existing medications and doing so with a multi-arm approach allows for research to progress at an accelerated rate and potentially identify effective and safe treatment options that can be used to manage secondary progressive MS. This revolutionary trial is led by Professors Jeremy Chataway and Max Parmar at University College London.

To find out more about this new approach visit their website:

<https://ms-octopus.mrcctu.ucl.ac.uk>

Getting to know biomarkers



Biomarkers, short for biological markers, are measurable indicators which can provide us with information about what is happening inside the body. In MS, biomarkers can be helpful during diagnosis, monitoring of disease activity, assessing treatment response and predicting prognoses.

When a lumbar puncture is conducted, the cerebrospinal fluid (CSF) that is drawn can be analysed for the presence of a number of things which include:

Oligoclonal bands

These are a type of protein that can indicate inflammation in the central nervous system (CNS). They are a type of antibody species. In MS, antibodies can cross the blood-brain barrier, where they can attack the myelin which coat the nerves in the brain. This means that there are increased levels of antibodies in the CSF of people living with MS. Electrophoresis is a test that shows the presence of antibodies. In this test, a CSF sample is placed on a gel and then voltage is applied. This causes antibodies of the same size to group together in visible 'bands'. One (monoclonal) band forming during this test is normal, When two or more (oligoclonal) bands form it indicates the presence of disease activity. While this is not a direct indicator of MS, approximately 80-95% of people living with MS have oligoclonal banding in their CSF.

White blood cells

These can also be analysed as part of the diagnostic process. Those living with MS can have seven times the typical level of white blood cells in their CSF.

Neurofilaments

Are a useful biomarker in understanding disease activity. They are fragments of the surrounding support of nerve axons. Their presence in the CSF is indicative of disease activity as it can be evidence of myelin damage. Monitoring these can be useful as if someone is on a disease-modifying therapy, fewer neurofilaments in the CSF can indicate that the disease-modifying therapy is effective in protecting the nerves.

MRI

Another important biomarker that is routinely used in MS are MRI's which stand for magnetic resonance imaging. MRI uses magnetic fields and radio waves to determine how much water is in various tissues of the body. It maps the location of the water and then uses this to generate images.

MRI's can be used to visualise MS-related brain lesions. They are used in the diagnosis and monitoring of MS. They can provide useful information when tracking disease activity. It can also determine lesion load and location as well as changes in lesion characteristics. MRI can also be useful in measuring the reduction of lesions and reduction of lesion activity.

While biomarkers are a valuable tool in MS diagnosis, monitoring and indeed research their use is still evolving. Additional research in the space is required to identify more specific and reliable biomarkers. They may help us to understand more about MS but are do not solve the puzzle. Their use continues to be in conjunction with clinical assessments and other diagnostic and monitoring tests to ensure comprehensive care of those living with MS.

FROM THE PERSPECTIVE OF A MOTHER TO A NEWLY DIAGNOSED ADULT

The author of this article wishes to remain anonymous as their daughter, whose real name does not appear in this article has not disclosed her diagnosis openly but is happy for her mother to share her experience in this way.

I will never forget sitting next to my daughter Sarah in the hospital on the day we found out that she was living with MS. I will never forget how helpless I felt. For months, she had been mentioning little things, numbness here and there. Things came and went, she mentioned them but isn't one to make a fuss as such. Her 'get up and go' attitude and approach to things probably masked how severe the symptoms she was experiencing were.

I knew she had been going to the GP about numbness and that they felt it was perhaps some kind of inflammation for which they prescribed medication. I knew it was playing on her mind and I advised that she go back to the GP again to discuss any concerns she had. She was reluctant. Some days after we discussed this, Sarah mentioned that she had an issue with her vision. Sarah had experienced migraines since her teenage years, which sometimes seemed to impact her vision, so it wasn't overly alarming at the time. When it had not gone away but gotten worse by the next day, she agreed to go to the GP and afterwards, arrived home with a letter for the hospital where the GP told her to present to A&E.

I was off work that day and drove her up. We were waiting about an hour before she was triaged. I went in with her. The triage nurse carried out various tests, asking Sarah to read lines on an eye chart. Sarah was able to carry this out normally with one eye but when asked to repeat with the other, she said she couldn't see the chart at all. The nurse continued to ask her to describe items in the room and Sarah continued to say she couldn't because she had no vision. They tried shining a light into her eye and she said she could see that there was light but said even at that she could not see it well. She described it to us as when you have your eyes closed in daylight and cover one with



your hand, you can make out that there is lightness and darkness but there is no vision. I didn't realise it was so bad. The nurse asked someone else to come in and they did some more tests. Finally, she said that Sarah would need to wait to be seen by a consultant.

We waited for hours, until the end of the consultants clinic. While in the waiting area, Sarah told me that she thought perhaps it could be MS as she had looked online and read that the numbness and vision issues were symptoms. I thought she was put two and two together and was miles off. Not for a minute did I think this was possible. There was nobody else with MS in the family and surely at 22 she was far too young.

The consultant took a detailed history, carried out some additional tests and examined the back of Sarah's eye. The conversation that followed will forever be etched in my mind. The consultant said



to Sarah “Ok, you’ve got these symptoms, what you think this might be?”. Sarah confidently said “ I think I have MS” and the doctor said “I think you do too”. I was floored. I really didn’t think for one second that Sarah’s suspicion might be right.

It was all such a whirlwind from that moment, things moved along quite rapidly. Sarah was admitted to hospital for a number of days to have different tests carried out and the diagnosis officially confirmed. Those days were difficult. While Sarah had suspected MS, I don’t think that she actually expected to be right about it. As a family, we tried to do all we could to support her but in true Sarah-style, she was the one supporting us. She had a great attitude about it from the get go. She was happy to have an answer and while she had concerns and fears, she leaned into the fact that knowing what you’re dealing with is actually an empowering thing. I will forever admire her strength in those very difficult and raw days.

From a personal perspective, I was gutted for her. I didn’t know what to do. How could I help her? Your baby is always your baby, no matter how old they are. I just wanted to take it all away for her and not have her have to live with this condition. She was so young, she still is! I didn’t realise that this was quite a common age to be diagnosed. I always thought MS was a condition that impacted people who were maybe 50+. I wanted to be able to support Sarah and talk to her about it all. She was so strong and gracious through the whole ordeal. There were times she just wasn’t able to talk. My husband and I had to feel it out a little bit if we wanted to discuss something MS related with her. We didn’t want to confront her with having to think about it when she wasn’t able but we wanted to support her too. Her feelings on it seemed to come in waves and we let her lead the way. If she wanted to talk, we were there. If she didn’t, we didn’t push her.

When your child is young, you go to the doctor with them. You get their prescription, you administer the medication and you take care of them. But when your child is 22, you’re an observer rather than an active participant. Your instinct in wanting to protect and help them remains but the decision making and action is up to them. So when Sarah was presented myself and my husband with a number of treatment options, we were only able to give an opinion. Sarah came to us with the options and asked if we would pick one for her. We couldn’t. We didn’t know enough about it and didn’t want to make the wrong decision for her. The stakes were too high. It wasn’t our place to make the decision for her and I don’t think she was expecting that. That was a very painful part for me. She needed me in a way I couldn’t be there for her. She is too precious to us to take a gamble not knowing what we would need to know to make an informed choice. We supported her by suggesting she have a conversation with her MS nurse about the treatment options. I went with her to that to act as a second pair of ears. I acted as a sounding board when she was taking through the options and what she thought she was going to go with. Luckily, Sarah did choose an option and 4 years on it seems to be working well for her. She is living a very active and full life and MS is a very small part of that.



World MS Day will take place on Tuesday, 30th May 2023. This day of celebration brings the global MS community together to share stories, raise awareness and campaign for everyone affected by MS. World MS Day activities are taking place throughout the month of May and will continue into early June.

What is this year's theme?

This year, the global theme for World MS Day is 'connections'. In addition to this theme, MS Ireland have been working on a campaign that highlights the range of MS related experiences and also challenges perceptions of what people living with MS look like and are capable of.

What is the campaign?

MS is different for each person impacted by it. They experience different symptoms, with different degrees of severity for different amounts of time. There is no one way to 'have' MS, there is no one way to live with MS. Our aim is to showcase a range of experiences so people will better understand that MS is a very individual condition.

The '**I aM Someone**' campaign aims to show the vast reach that MS has in Ireland and allow our community members the opportunity to lend their picture and story to our vision for the day. This campaign is about building community connections, self-connection and celebrating support networks. So we welcome input by anyone impacted by MS. We have left the 'I aM Someone' element open ended. This prefix could be followed by any number of endings including:

- I aM Someone living with MS
- I aM Someone who loves someone living with MS
- I aM Someone who cares for a person living with MS
- I aM Someone who supports the MS community
- I aM Someone who works with people living with MS

We are all someone and each of us impacted by MS has their own unique story to share. So please join us in sharing yours and making this campaign as visible and impactful as possible. Whether you're a person living with MS, involved in supporting people living with MS, love someone living with MS, or more - everyone is welcome to join in and help spread awareness.

How can I get involved?

The '**I aM Someone**' campaign will showcase the difference faces of the MS community through a photography campaign. We will be encouraging you to share a photo online to spotlight your journey on World MS Day using the hashtags **#MSConnections**, **#IaMSomeone** and **#WorldMSDay** on all social channels.

All you have to do is follow our simple steps and you can be involved in the campaign!

Step one: Take a photo or use an existing photo.

Step two: Write a little about your experience living with MS in Ireland or how you support the MS community.

Step three: Post them on your social media along with the hashtags **#IaMSomeone**, **#MSConnections** and **#WorldMSDay**

Leinster House Briefing

To mark World MS Day, we will be holding a briefing in Leinster House. We aim to raise awareness of MS amongst the members of the Oireachtas as well as the political profile of MS Ireland which we hope will benefit future advocacy activities. We will be using this opportunity to launch our pre-budget asks for 2024 which you can read more about on **page 18**.





MS Explored

World MS Day Information meeting



Light up for World MS Day

MS Ireland and our supporters have been in contact with a number of heritage sites and buildings across Ireland with a request that they light up in red in a show of solidarity with the MS community this World MS Day. A number of iconic buildings in Ireland have already agreed to join in this activity, with some opting for a 'virtual light' up. With a virtual light up, the building may not be physically illuminated but they will share an image of the building lit up in red on their social media along with a post about World MS Day. Help us identify these posts and buildings by posting a photo or tagging us in the online posts.

World MS Day activities at a glance

All day

The online 'I aM Someone' campaign will be ongoing

10am – 2pm

Coffee Morning in our National MS Care Centre in Dublin

3pm – 5pm

Leinster House Briefing where we will be sharing our pre-budget asks to members of the Oireachtas

6pm

MS Explored Information event in Trinity College Dublin in collaboration with Novartis. Dr Hugh Kearney, Consultant Neurologist and Claire Dolan, Occupational Therapist from the MS Unit in St James' Hospital will speak on '30 Years of progress in MS' and 'What an Occupational Therapist wants you to know about MS'

9pm onwards

Buildings lit up Local Branches and Regional Offices may also have events happening locally. We recommend visiting our website to find out more about what is happening near you



Shhhh...secret project!

We will also be staging a public awareness stunt, details of which are strictly under wraps for the moment but we will be sharing details of this on our social media later in the day on World MS Day.

Radio takeovers

MS Ireland will be taking over the airwaves in celebration of World MS Day. We will be on Galway's Flirt FM/101.3 on May 24th from 6-8pm where we will be exploring different MS journeys with our 4 guests. To tune in you can find them on frequency 101.3FM or you can listen directly from the website at:

www.flirtfm.ie

We will also take over Community Radio Kilkenny City 88.7FM where Maurice O'Connor, MS Ireland Chairperson will be the present a World MS Day special on May 30th (time TBC). To tune in you can listen directly from the website at: **www.crkc.ie**

24th Annual General Meeting (63rd AGM since MS Ireland's foundation)

Dear Member,

In an effort to reduce costs and with the passing of our Constitution in 2016, we are now able to send AGM notices to you by email. However, we need you to consent to the furnishing of the accompanying AGM financial documentation via our website instead of by post. Please complete the below slip and return to Alice McKeon, MS Ireland, National Office, 80 Northumberland Road, Dublin 4.

We would like to thank those members who have already consented to being provided with the AGM financial documentation via our website.

In this issue of MS News, the call for motions are advertised (below). The AGM legal notice will be sent to each member by email (where we have an email address for you) or by post along with the next issue of MS News. Where we do not have a postal or email address for you, service of notice of the AGM on you will be done by posting the notice on the MS Ireland website.

The Annual General Meeting of the Multiple Sclerosis Society of Ireland, at which Board members are re-elected, is scheduled to take place on Saturday, 16th September 2023 in the Radisson Hotel, Athlone at 4.00 p.m.

The results of the vote for motions, if any, plus the Council's nomination to the board will be announced at the AGM.

The procedures for motions are listed hereunder.

Every registered member is entitled to a vote. For those unable to attend the AGM, proxy papers will be available on our website three weeks prior to the AGM and must be returned to National Office, MS Ireland, 80 Northumberland Rd, Dublin 4 before 4.00 p.m. on Thursday, 14th September 2023.

Rory Mulcahy
Company Secretary

Motions

Any member or branch may forward a motion to the Governance Committee who will decide on their acceptability for putting before the AGM.

Closing date for receipt of motions is 11th August 2023.

Call for Board Members

We are currently seeking candidates including candidates with fundraising, sales and marketing and community development experience to go on to our panel of potential Board members. Members, Branches, Council the Board and staff may propose candidates. All nominations must be proposed and seconded by members.

Nominations of retiring Board members seeking re-election must be submitted to the Nominations Committee. Other nominations may be submitted in accordance with the provisions of Article 56 of MS Ireland's Constitution and MS Ireland's Bye-Laws, nominations may also be submitted directly to the Registered Office (MS Ireland's).

National Office, 80 Northumberland Road, Dublin 4) and marked for the attention of the Company Secretary.

The Nominating Committee will review all nominations, except those submitted to the Company Secretary under Article 56, and will recommend to the Board candidates to go forward for election by the Members at the AGM.

The Nominating Committee will take into account the range of skills necessary for board membership and where possible, the geographical spread, the gender balance, the experience and the qualifications of the candidates.

All candidates must be in compliance with the requirements for Directors as set out in the Companies Act 2014, the Charities Act 2009 and MS Ireland's Constitution and will be asked to sign a declaration to that effect.

All candidates, whether proposed by the Board or nominated pursuant to Article 56, and who have signed the aforementioned declaration will be put before the Members for election at the AGM.

Further details and nomination forms are available on the website.

Applicants, wishing to apply for a position on the Board in September 2023, are invited to submit their application form by **5.00 p.m. on 31st May 2023. The closing date for Applications under Article 56 of the Constitution is Friday, 16th June 2023.**

Dear Member,

In an effort to reduce costs and with the passing of our Constitution in 2016, we are now able to send AGM notices to you by email. However, we need your consent that you will access the accompanying financial statements on a website instead of by post.

Please Tick I agree to accessing the financial statements on the website instead of by post

My email address is

Name

Address

Phone

Please return slip to Alice McKeon, MS Ireland, National Office, 80 Northumberland Road, Dublin 4



NATIONAL AWARDS

Our 2022 National Annual Awards were presented at the Annual General Meeting which was held on zoom on 17th September 2022.

These awards recognise those who through their dedication and selflessness play a significant role in the lives of others and the progress of the Society. This year we are delighted to announce the three award winners are:

MS PERSON OF THE YEAR WITH HIS AWARD
SEAMUS BURKE



CARER OF THE YEAR WITH HER AWARD
SUSAN STEPHENS



VOLUNTEER OF THE YEAR BEING PRESENTED WITH HER AWARD
CELINE O'ROURKE



MS Ireland's 2023 Annual National Awards

It is a great honour to be nominated for the national awards so we would encourage Branches, individual members and staff members to nominate members who they feel deserve recognition. The nominations for this year's Annual Awards are now open. Our Annual Awards are the Society's way of recognising the contribution many of our members make within their families, local communities and MS Ireland.

There are 3 awards and the categories are:

- MS Person of the Year**
- MS Carer/Helper of the Year**
- MS Volunteer of the Year**

Full details and Nomination forms are available on the website or from National Office, tel. **01-6781608**. We would recommend you to return your nomination forms to National Office now. The closing date for receipt of nomination forms is Friday, 11th August 2023.

The annual national awards for 2022 will be presented at the Annual General Meeting on Saturday, 16th September 2023.

Supporting someone who is newly diagnosed with MS

A diagnosis of MS can be challenging not only for those directly impacted by the condition but for their loved ones too. Many people are not sure how to best support their loved one. Here, we offer some advice on practical steps you can take to support someone who is newly diagnosis with the condition.

Let them set the pace

Some people who are newly diagnosed can take some time to adapt. This can be an overwhelming time and some people prefer to deal with the new diagnosis and all it brings a little at a time. Well-meaning loved ones may go about finding out and providing lots of information or wish to offer a listening ear for their loved one to share their feelings but the person who has been diagnosed may not be in a place where they are ready to hear the information or discuss their feelings. Others may ask for support and be ready to talk. Let them guide you in what they need in the moment.

Educate yourself

While some people who are newly diagnosed may not be in a position to discuss the diagnosis or hear information from others, you can still inform yourself. Learn about MS, the symptoms, treatment options and supports available. This will enable you to provide better support if and when your loved one needs it and if nothing else, you'll improve your understanding of the condition.

Encourage open communication

Creating an open and honest environment where your loved one knows they can discuss their feelings, concerns, fears and questions about MS can be important. That way, they can come to you if and when they need.

Offer to accompany them to medical appointments

Some people may find it useful to bring another person along to their consultations. It can help to alleviate stress, feel more supported and an extra pair of ears in medical consultations can be beneficial to some. Not everyone will want this and it is important to respect the wishes of the person who has been diagnosed, however, there is no harm in offering.

Assist with research

Offer to help your loved one to gather information. Again, this may not be for everyone but some people may find it helpful. Be sure to use credible sources and provide them with materials that will empower them to make informed decisions on whatever topic you're looking into. Don't forget that our Information Service and network of MS Ireland Community Workers can help!

Be flexible and adaptable

MS can vary greatly from one person to another and from day to day. It is important to remember that their symptoms and capabilities may fluctuate so be flexible with plans and expectations. Being patient and willing to accommodate their needs is important.

Everyone's experience with MS and needs are unique. How people deal with a diagnosis varies greatly so remember to be flexible and ensure your loved one knows that when they're ready to talk or need some support, you're there.



Always Look On the Bright Side of Life

Alison Dallywater

In each edition of MS News, we like to include the voices of people living with MS. The 'My Story' section, allows individuals within the MS community to tell us a little about their lives and views, in their own words. In this edition, Alison Dallywater shares some insight into her experience and views and offers some... unique advice!

I was diagnosed 8 years ago when I noticed that my legs wouldn't go in the direction I told them to and I couldn't walk in a straight line. After what I thought were the silliest of tests, it turned out that I also couldn't touch the tip of my nose with my index finger without missing. Additionally, my big toe kept sticking up which is called the Babinski sign which means I make holes in my socks. I find this, frankly, a bit weird.

I have always loathed exercise (unless it involved dancing or drinking) but now I am getting lots of physio. I like to think a physiotherapist is a fancy euphemism for a personal trainer like Madonna has... but free of charge! I'm proud that I've never climbed the Reek or run a marathon. Let's face it, that's just for show-offs wearing neon lycra. And nobody likes a show-off.



If I absolutely had to go to a gym, I would try to stand next to people who are not as able as me. It makes you look athletic if you join in classes attended by the very elderly, very fat or very sick. This is one way of staying positive. People say there's always someone worse off than you. Although, if you ARE the person who is actually the worst off in the world then I'm sorry, this saying doesn't apply to you.

MS sometimes causes my brain to freeze. It can be so tiring when someone is talking to you and you're unable to concentrate. I just nod and laugh heartily. Of course, this can backfire if they are telling you their budgie just died. You will be able to tell by the look of horror on their face. If this happens you need to create a diversion by falling over. They will be so surprised that they will forget all about their budgie. Tell them next time, get a proper pet. Like a cat.



I live with 3 cats. The therapeutic benefits of owning pets? – there are none. Cats are trying to kill you and are happy that you have MS. If you wake up to a dead mouse at the end of your bed, that's not a gift, it's a warning. They've seen The Godfather. Next time around get a budgie.

I loved the Covid lockdown, people think I'm a social butterfly but I'm really a hermit. Luckily, I will soon be retiring and be free as a bird. A bit like the ladies that lunch except none of my friends invite me to lunch because of the wheelchair I lug about with me. The wheelchair is great as I am essentially lazy but it means that at parties your face is only level with other people's belly buttons. I recommend a periscope.



Those of you who are unlucky enough to still have to work: remember to phone in sick as often as possible. Firstly, you need to practise. Slump your shoulders, assume a sad face and dab your eyes with your hanky. Now dial your employer. Use phrases like 'urinary tract infection' and they will stop you immediately and tell you to stay home. After hanging up, pour a glass of wine and return to Judge Judy.

The downside of giving up work is dealing with

Social Welfare. The benefit system is a bit like quantum physics and nobody in the Dept of Social Bewilderment can explain how it works, so don't ask.

I don't drive but still had to get to their offices to apply for a bus pass. The office is strategically placed in a part of town that is not serviced by a bus route. So, they expect you to get a bus to a place you can't get a bus to, so that you can get a bus pass. That's both ironic and sadistic. They then make another cup of

tea and laugh about funny that is.

Getting lifts to appointments can be tricky. Find anyone with a car, tell them about the appointment you have to try to get to this week. Use your best 'calling in sick' face. When they start with 'Sorry, I would but, but' say 'Great!' and swiftly jump into the passenger seat.

People often ask how you are. Now is your opportunity to tell them about your ailments in full and messy detail. They will, however, never ask you again.

Some people visit without warning which I hate. Just because lockdown is over, there's no need for it! When they arrive, I apologise for the mess and start to cry. They should soon be doing the washing up for you in no time. Tell them you would offer them something to eat but you have nothing. At least next time they'll bring a Battenburg or a packet of Oreos. Another good thing about MS is that it gives you the perfect excuse to say no to all the things you don't want to do. For example:

Friend: "We are having a funeral mass for my Canadian cousin, Buck, who died in 1983. Can you come?"

You: "No I am having my catheter changed, what a pity".

If relatives insist that you should live with them, turn up on their doorstep with a bag full of incontinence knickers, 3 cats and a drum kit. Make sure your cats eat their budgie. You will be home in no time.

A few years back, the town elected me Mayor. Old bylaws state that I am entitled to use the toilet of any of the houses on the street. I have only managed 3 to date. It also allows me to graze my sheep on the common land... when I get some.

I was chosen this year to be Grand Marshall of the St Patrick's day parade.

I also took part in a programme called the 'Style Counsellors' earlier this year. It can be pretty hard to look glamorous when you use a wheelchair.

When I feel gloomy I find the best way is to laugh about my various predicaments. As Eric Idle sang, **"Always look on the bright side of life."**

Pre-Budget 2024 Summary

Physiotherapy

Sustainable funding of €880,000 per annum for national physiotherapy services for people with Multiple Sclerosis and other neurological conditions

MS Ireland is seeking funding from the 2024 National Service Plan for a programme to directly employ a Senior Physiotherapist in each HSE CHO area to enable 1,458 people living with MS and other neurological conditions to receive group physiotherapy programmes and to deliver 3,726 individual appointments per annum.

This is based on evidence from our successful SlainteCare Integration Fund project and over 25 years of MS Ireland physiotherapy service provision. Our programmes have research and clinical audit evidence for their effectiveness for reducing symptom severity, improving quality of life and reducing health service utilisation. and address many of the issues associated with insufficient access to local primary care due to long waiting lists.

National MS Care Centre

An increase of €627,000 in annual investment in the National MS Care Centre to provide an additional 1,248 bed nights per year.

MS Ireland is seeking €627,000 in additional funding to see The National MS Care Centre, a 12 bedded unit which provides respite care to people living with Multiple Sclerosis and other progressive neurological conditions, open 350 days per annum, providing an additional 1,248 bed nights annually. At present, the National MS Care Centre is only open for 40 weeks per year as a result of decreases in both Statutory and fundraised income over the last number of years.

The National MS Care Centre plays a crucial role in ensuring family carers are supported and delivers a range of therapeutic services, neurological assessments and many social activities, all designed to revitalise, prevent crisis and keep people living with neurological conditions well at home.

MS Ireland echo the asks in the pre-budget submissions of Disability Federation of Ireland; Neurological Alliance of Ireland and Family Carers Ireland.

Tear out this letter, send it to the Oireachtas members in your constituency and have your voice heard.

If you have any personal details you would like to add in support of our ask, please feel free to write it in.

Dear

My name is

I am writing to you to ask you to support the Pre-Budget Submission of The Multiple Sclerosis Society of Ireland.

MS Ireland has two primary asks for Budget 2024 which include:

An ask for sustainable funding for MS Ireland to deliver a national health promoting physical activity physiotherapy services for people with Multiple Sclerosis, and other neurological conditions at a total of €880,000 per annum

Currently many people with progressive neurological conditions in Ireland have little or no access to rehabilitation services and are low priority for physiotherapy in primary care. There is a void of post-acute and post-community interventions to promote patients' health through physical activity.

MS Ireland proposes a sustainable, specialist physiotherapy service to address this need using a blend of 'online' and 'in-person' programmes which provide a pathway of care from rehabilitation to community integration. Using data from a successful SláinteCare Integration Fund project in the Mid-West, this evidence-based service will provide physiotherapist led, health promoting exercise for people with neurological conditions through a national physiotherapy service across all nine HSE CHOs.

MS Ireland have forecasted that this investment would annually deliver 1,458 participants in group programmes and 3,726 individual appointments and could be rolled out in one national development, or in phased regional stages.

An ask to increase annual statutory investment in The National MS Care Centre by €627,000

The National MS Care Centre is a 12 bedded unit which provides respite care to people living with Multiple Sclerosis and other progressive neurological conditions.

MS Ireland are requesting €627,000 additional funding which would see The National MS Care Centre open 350 days per year, providing an additional 1,248 bed nights annually. The National MS Care Centre provides Centre provides people living neurological conditions, including Multiple Sclerosis, and their caregivers a break and delivers a range of therapeutic services, neurological assessments, and social activities.

Further investment will not only support people living with neurological conditions such as Multiple Sclerosis, but will also support voluntary carers, without whom care in the home would be impossible, relieving further pressure on our health systems and hospital funding.

Please use the space below to add any additional information you may wish to share



ECTRIMS

This year, Ciara O'Meara who is a member of the MS community, supporter of MS Ireland and a healthcare professional attended the ECTRIMS (European Committee for Treatment and Research in Multiple Sclerosis) Conference. Here, she shares her highlights and thoughts.

Attendance at a conference is not something you would see on everyone's bucket list, but attending ECTRIMS has been on mine for of years. As a health care professional and researcher, ECTRIMS provided me with an opportunity to hear and meet with some of the brightest minds in health care, innovation, treatment, practice improvement and research around MS. As a person living with MS, ECTRIMS left me with a sour taste in my mouth. ECTRIMS primary focus is on presenting new and emerging treatment and research in MS and this subsequently lends itself to being a very scientific and medical focused conference. Taking a moment to look at the business end of things, there were many positives to take away:

- Introduction of Ponvory, an oral once a day medication for treatment of relapse-remitting MS.
- Increased discussion and research highlighting the importance of biomarkers in differentiating between relapsing remitting MS and progressive MS.

- Identification of the role in which lipids (cholesterol: fatty, waxy, oily compounds, stored in our body and through diet) play in MS Pathology. Lipids have been recognised as playing a central role in disease progression and involved in both inflammatory demyelination and progressive neurodegeneration.

The most interesting point I took away from this stream of the conference was around comparing outcomes of AHSTC (Autologous Hematopoietic Stem Cell Transplantation) against the use of high efficacy drugs for MS and the results were quite surprising: AHSTC should be given thought as to where it best fits along the disease continuum, rather than viewing it as a superior treatment. Results of trials with AHSTC showed that while it was substantially superior to Fingolimod for RRMS, it was only slightly superior to Natalizumab and no difference was noted with Ocrelizumab. While I can certainly appreciate the importance of this scientific focus in terms of new treatments for MS, challenges to diagnostic criteria and clinical trials moving from the bench to the bedside, my focus was on the here and now; what are we currently doing for people living with MS, how can we do it better and how can we improve outcomes and quality of life for those living with MS?

ECTRIMS presented sessions on:

- Lifestyle Factors in Disease Progression: Interesting to note from this was the identification

of the importance of pre-habilitation when it comes to exercise and not focusing on rehabilitation. Exercise should be a component of the treatment plan from initial diagnosis and not an afterthought for when mobility has been affected.

- In terms of diet, research continues to note that there is no one size fits all when it comes to diet. Evidence is limited on what is the best diet to follow and there has been no identification of what the most superior diet is.
- Quality of Life for people living with MS focused on the impact of fatigue and highlighted the absence of appropriate treatment. In a recent study of over 4000 people surveyed in the UK, 90% reported experience fatigue as a symptom of their MS, but only 31% were offered any form of fatigue management treatment. We are well aware that fatigue is one of the main debilitating symptoms of MS, yet why aren't we focusing on treating it?
- In terms of vocational rehabilitation, it was encouraging to see a multitude of research being undertaken in this area and identifying the importance of timing and context of conversations with employers around supports and accommodations to be able to continue working. These sessions highlighted the role in which health care professionals have in supporting discussions around difficulties experienced at work.
- Pregnancy & MS: these sessions focused on the importance of pre-pregnancy counselling prior to stopping contraception. Emphasis was placed on the importance of replacing high efficacy treatment with similar high efficacy treatment during pregnancy, rather than switching women from high efficacy to low efficacy treatment during pregnancy and the subsequent increased risk of relapses post pregnancy which this carries.

The recognition of the essential roles that other members of the health care team play in the treatment, management and support of those living with MS was resoundingly absent from the conference. Across a 3 day conference, only two nurse led sessions were delivered. This highlighted a disparity of role recognition across the entire MS Health Care Team, a health care team which is paramount and central to the delivery of holistic care for the individual living with MS. Ironically, the main focus of the nurse led sessions was on defining the

complex role of the MS Nurse and highlighting the direct correlation between MS Nurse Services and improved patient outcomes.

The MS Nurse Care Report Australia identified that people living with MS with no access to an MS Nurse resulted in:

- 21% reporting higher disability
- 23% higher self-reported progression
- 7% lower health related quality of life
- Higher levels of depression & anxiety
- Greater severity of symptoms

This report identified not only the benefits of the MS Nurse in improving patient care, but the significant financial health savings that were made with increased access to MS Nurses

What struck me the most about ECTRIMS was the complete absence of that vital cog within a bigger wheel – the individual living with MS. We often hear the saying 'nothing about us, without us' – well I saw no sign of us at ECTRIMS. The overwhelming pharmaceutical circus at ECTRIMS was an area that didn't sit right with me. An obnoxious amount of money must be spent on their displays. We are the ones indirectly paying for this – without us, the pharmaceutical industry's drugs have no purpose. My views is that funding for more MS nurses, funding for rehabilitation and care centres would be a better use of this money.

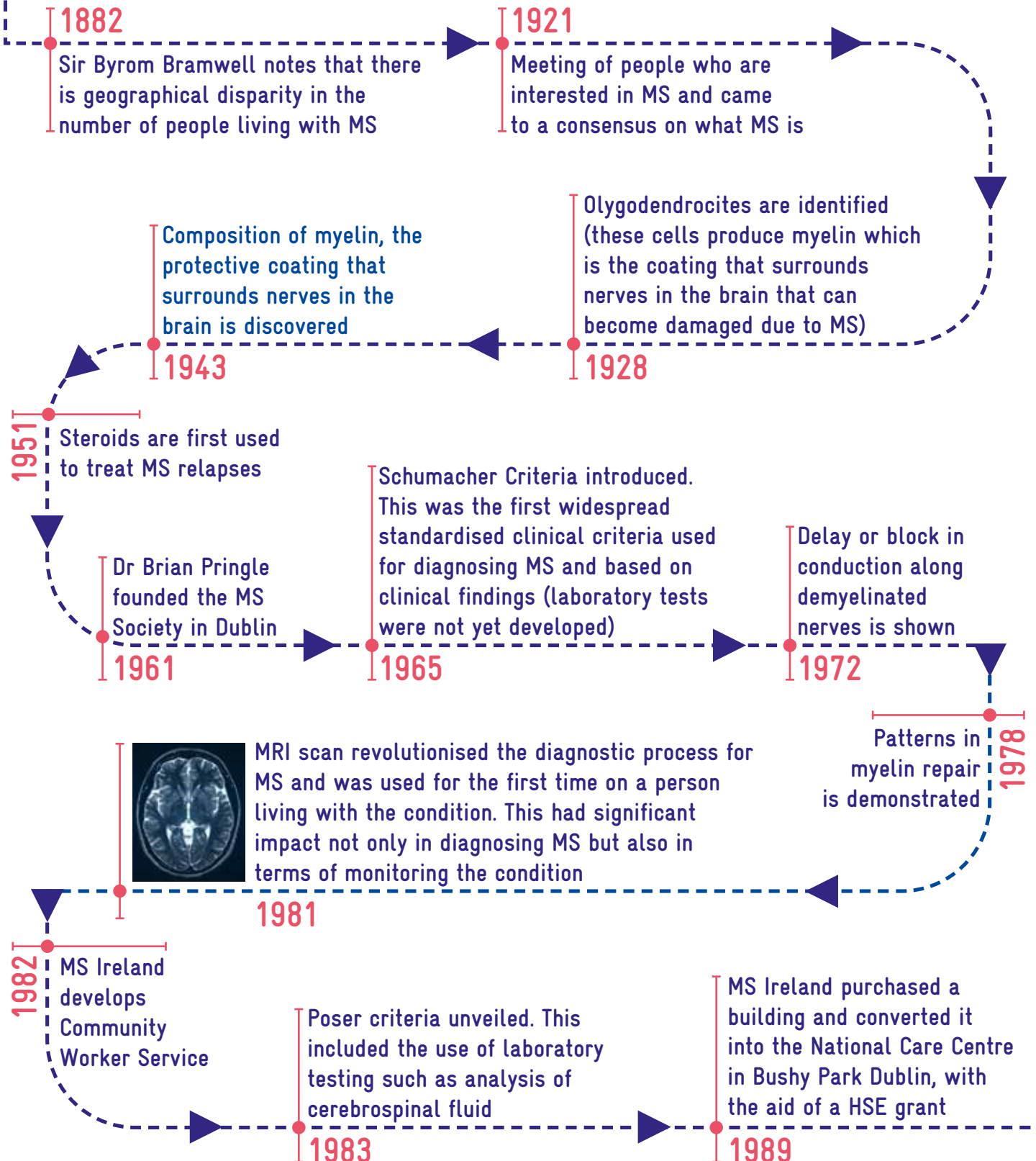
The best thing that ECTRIMS provided me with, was the opportunity to network. To meet with MS Nurse specialists and nurse consultants from around the world was amazing. To learn about how they manage their MS caseload, hear about exciting projects that are running in their country and to come away with an enthusiasm on how we can improve services and supports in Ireland. The beauty of this networking was that each and every individual had the same element of care at the forefront of their mind; the person living with MS. Being able to meet with Prof Gavin Giovanni was another highlight – to sit with him and chat about his resource the 'MS Selfie' and discuss ways in which it could be improved and altered appropriately for individuals living with MS was fantastic – again an individual where the person living with MS is the core focus.

Disclaimer: The views expressed throughout this article are solely that of the author and do not necessarily reflect the views of MS Ireland.

THE HISTORY OF MS

There are some records of individuals whose symptom sets are suggestive of multiple sclerosis but at the time, the understanding of MS and other pathologies could only be improved through

the conduction of autopsy. A small number of individuals who were had identified and written about the condition but did not name it.



➤ **1868**
Charcot named multiple sclerosis and described its characteristics. At this point it was a recognisable condition to others thanks to a series of lectures by Charcot

which explored the clinical characteristics, pathology, response to therapy and name of the disease. From here, reports from around the world began to come in as this condition could now be identified.



Jean-Martin Charcot

1993
First disease modifying therapy for MS became available

2001
McDonald Criteria was introduced (adding MRI parameters to the criteria)

First treatment licenced that can be used for both relapsing-remitting and primary progressive MS

2005
The McDonald Criteria was updated simplifying MRI evidence required

2017
Mc Donald Criteria updated. An important element of this was that oligoclonal bands (inflammation-related proteins) in the cerebrospinal fluid can be used to help meet diagnostic criteria for MS instead of having to show that damage has occurred at different points in time.



Dr Brian Pringle



National Care Centre

This small snapshot of some of the developments in MS shows the incredible progress that has happened and is ongoing. Through all of these points in time and now, numerous developments as well as a greater understanding of MS have continued. The treatment landscape continues to grow and offer clinicians and those living with MS a greater offering of treatment options. In addition to the increase in disease modifying therapies, there has been an increasing number of symptomatic therapies that help to improve quality of life. Finally, the understanding of the value, development and implementation of multidisciplinary teams has been an incredibly positive evolution in the MS space.

Keep an eye on our website in the coming months as we expand on and explore additional developments in the MS space.

MS North Dublin Branch

The North Dublin Branch are hosting a Summer Luncheon on Tuesday, July 25th from 12:30pm -3pm. The event will be held in the Rose Room in the Clayton Hotel Dublin Airport. The three course lunch will be served at 1pm followed by tea/coffee and musical entertainment by Karl Flood.

The Branch are subsidising the event and so the charging is just €10 per person.

Where transport proves difficult, please let the committee know what requirements you may have and they will try to assist where possible.

Those wishing to attend are asked to pay in advance by July 14th as numbers will need to be confirmed with the hotel.

While the hotel is not serviced by public transport, it is possible to take public transport from all over Ireland to Dublin Airport where you can take a complimentary shuttle bus from Zone 16 to the hotel. This bus departs every 25 minutes, is free of charge and will leave you at the hotel in approximately 10 minutes.

Please contact **086 403 9504** to secure your place.

Fiesta Miesta

On May 13th, MS Ireland's Dublin, Wicklow and Kildare Regions in collaboration with the North Dublin and Kildare Branches hosted 'Fiesta Miesta' an event for people living with MS. A wide range of fun activities were available on the day including an African Drum Workshop, Reiki, Sound Bath and Art Therapy. The event also had a physio clinic, OT advice and massages. It was attended by 51 people. Deputy Mark Ward opened the event, sharing a moving account of his story of living with MS with the attendees. Thanks to all involved and all who supported this wonderful event.



East Wicklow Branch

The East Wicklow Branch held their AGM this year, along with a lovely afternoon tea, in the Parkview Hotel, Newtownmountkennedy on Sunday, March 26th. On the day, the branch committee was elected and also presented two annual awards.

Branch Person of the Year was awarded to Patrice Brady Carton. Patrice did more work last year for the East Wicklow Branch and people with MS in County Wicklow than just about anyone. Not only was she branch committee secretary, but she brought to us the most innovative and successful fundraising initiative that we've ever had. At a time when flag days and supermarket collections were for obvious reasons not possible, she came up with Seeds of Hope, lovely packets of wildflower seeds with a positive and hopeful message that could be sold online when everything was closed and also sold in shops and stores when they re-opened. To date, her Seeds of Hope initiative has raised over €3,000 for the East Wicklow Branch. Branch Carer of the Year was awarded to Michael Leonard. Michael not only cares for his wife, who has MS, but he has done so much for people with MS in Wicklow by, for example, giving them lifts to coffee mornings and helping them in so many other ways. Both recipients were delighted and grateful to have won these awards.

John Mardirosian Chairperson EWB MS Ireland



Patrice Brady (left) is presented with the Branch Person of the Year award by East Wicklow Branch treasurer Jean Wilmington.



East Wicklow Branch committee member Tara Donnelly (left) presents the Branch Carer of the Year award to Michael Leonard.



Branch Chairperson John Mardirosian speaking at the AGM.

 A poster for an MS Writers Group event. It features a stack of books on the left. The text reads:

MS Writers Group
 Invite you to
 an evening of

Short Stories, Poetry
 & Live Music

Join us for a beautiful and relaxing evening of original stories, poetry & music

The Glenview Hotel,
 The Glen of the Downs
 on Tuesday 30th May
 2023 - World MS Day

7.30pm-9.30pm

Entry €5 which includes tea/coffee

All proceeds go to the MS Ireland East Wicklow Branch

We would love to see you there

Longford Branch



The Longford Branch were delighted to receive funds from local Tesco Community Fund. A cheque was presented by Paul Connell, Tesco Community Manager and Mal Blackburn, Store Manager at Longford Tesco to Ann O'Brien, Treasurer of the MS Longford Branch.

St Bridget's GAA club organised a Stephen's day football match to raise funds for MS Longford, in honour of local man, Donal Chapman (R.I.P.). Donal was a valued member of MS Longford. Family and friends gathered for cheque presentation.

Limerick Branch



Noreen O Shea, Treasurer & Clare Dollard, Secretary of the MS Limerick Branch raised funds for MS by doing the '7 Bridges of Limerick' walk in April. This activity is run by the Lions' Club. Well done to both!

MS Readathon



With over 11,000 online registrations children, schools and “big-kids” really got stuck into their books last November.

There were author visits, illustration workshops and of course our volunteer school ambassadors were out in force, chatting to children and teachers all over the country.

MS Ireland offered a hybrid Readathon this year, as we know that being fully online is not for everyone and this proved a hit with some of the newer schools who took part.

There were prizes and competitions throughout the month, with the lucky winners of our creative writing and drawing competitions winning books, Readathon swag, book tokens and one lucky pair won a brand new bike each.

22 lucky individuals won an iPad each and 60 lucky ducks won a set of wireless headphones in our draw.

Big thanks to **thebookshop.ie** who we partnered with to supply 5000 and who kindly matched the We raised just over €310,000 in total, an amazing feat in what has been a very challenging 12 months for everyone. A massive thank you as ever to all the students that take part, the parents and teachers who support and encourage them and of course the generous legions of grannies, grandads, neighbours and friends who so kindly donate each year.

UPCOMING EVENTS

Womens Mini Marathon

Encourage your workplace colleagues, friends and family to enter the VHI Women’s Mini Marathon to support MS Ireland. Please contact **melaniec@ms-society.ie**



10,000 Steps a Day in August

Join us for our August Challenge of walking 10,000 steps a day. This has been a hugely successful and fun challenge over the last few years – with hundreds of people joining our Facebook group and sharing photos of the amazing countryside that they walk in every day during august. Watch out on our social channels for the registrations in July.



Skydive

Register via our website **<https://www.ms-society.ie/get-involved/fundraise-us/skydive-ms-ireland>** or contact **melaniec@ms-society.ie** for dates that suit you.

Dublin Marathon

If you have a place for this year’s marathon and you would like to join Team MS Ireland on October 29th please contact **melaniec@ms-society.ie**

Charity Golf Day

Are you a member of a Golf Club – would you nominate MS Ireland as the charity of the year? These events are fantastic fundraisers, and we can support your event with banners, items for goodie bags etc. Please contact **melaniec@ms-society.ie**

The Lorna Mitchell Memorial Trek – Camino 2022

For 33 years the MS Trekkers have fundraised and travelled to the 4 corners of the earth, but the mainstay of the MS Ireland treks has always been the Camino de Santiago de Compostela. The Camino 2022 was named in honour of Lorna Mitchell who was the first walks co-ordinator and created the ethos of the MS Trekkers family. Many of the Camino 2022 trekkers started their walks journey with Lorna, some had walked with MS Ireland since the very first walk in the Loire Valley in 1989.

Some years there we 2 Caminos with up to 80 people trekking with MS Ireland.

We were thrilled that Lorna's husband and children were able to join the 51 MS Trekkers for part of the Camino, most importantly in Rabanal where we dedicated a plaque in Lorna's name. They also joined us as the group walked into the Cathedral Square in Santiago – which is always an emotional moment.

The 2022 Camino re-traced the steps of the 25th anniversary Camino taking in the highlights of the Camino from St. Jean Pied de Port to Sanitago. We were ably transported and looked after by our bus Driver Gustavo and Ruth – who also provided delicious and sustaining lunches each day. Our walks leaders, Lorraine and Jean, who not only lead our foreign walks but also the monthly MS Trekkers walks and organise 2 weekend walks in Ireland each year, looked after the group every step of the Camino. We appreciate their time and commitment to the MS Trekkers family – keeping the wider group of walkers together and informed of what is going on in MS Ireland.

There will be no MS Ireland Trek in 2023 but we still have the open treks to Everest Base Camp and Kilimanjaro organised by Earth's Edge – for details please contact melaniec@ms-society.ie

Thank you!

In August we had our 10,000 Steps a Day challenge with over 700 people joining our group, sending in lovely photos of where they were doing their daily walk – The Rossnowlagh Ramblers got their group of more than 30 together to do the challenge in one day. The participants raised an amazing €42,000.

Bridge

Do you play bridge? Would you nominate MS Ireland to be a beneficiary of your charity events? Please contact melaniec@ms-society.ie for more information.

Skydive

22 crazy people decided to jump out of a plane to raise money for MS Ireland in 2022! In doing so they also raised over €20,000.

Dublin Marathon. These incredible people not only ran a full marathon but also raised nearly €40,000. Thank you!

We set a Christmas challenge of doing 3,000 Crunches a day in December and our wonderful supporters joined us – even on Christmas day

- Aoife was our youngest and most enthusiastic participant! Thank you to all the participants for raising €38,000.



Thank you!

Roisin Kavanagh organised for 80 people to do a bungee jump on the pier in Moville. Many thanks to the organising team and all the participants.

Stephen Corridan one of our Physios – ran 5k every day for 3 years! All the while he was also fundraising for MS Ireland – a huge achievement.

Kate Burke and her team, **Gill, Tara** and **Johanna** organised the annual DLSP Ladies lunch in aid of MS Ireland – one of our branch members, **Anne Restan**, attended the event as the speaker. This was a hugely enjoyable and successful day.

Winward Management held their annual charity golf day and a new walking event – the Cuilcagh boardwalk trail in Fermanagh. Many thanks to the all the staff and management for their continuing support.

SAVE THE DATE

MS Ireland National Conference
September 15th & 16th
Athlone

Booking forms will be available in July from our website ,
Regional Offices and will be circulated in the AGM pack.