

# MS *news*

Spring / Summer 2024

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# MS Information Line

**0818 233 233**

Open Monday-Friday from 9:30am-5pm (excluding public holidays)

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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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## CONNECT WITH US



www.ms-society.ie

Dear Friends,

Welcome to the latest edition of MS News.

In this issue, we are proud to introduce a comprehensive mental health resource aimed at providing support and guidance to those navigating the complex landscape of living with multiple sclerosis. Mental well-being is an integral aspect of managing MS, and we are committed to offering resources that address this crucial aspect of the condition. You will find this resource on **page 10**.



As we approach World MS Day, marked annually on May 30th, we are reminded of the global community's strength and resilience in facing the challenges posed by MS. This year, the theme is 'diagnosis'. Our team have been incredibly busy preparing activities to mark the day. You can read more about it on **page 24**.

In this edition, we are pleased to feature articles by individuals living with MS, sharing their unique perspectives and experiences. Niamh recounts the recent gathering of the EMSP Young Persons Network in Dublin, highlighting the importance of community and solidarity among young people living with MS. You can read Niamh's piece on **page 18**. On **page 17** Paul shares his personal story as an urban cowboy living with MS. Additionally, Katie shares a poignant poem reflecting on the experience of being diagnosed at a young age. Katie's poem can be found on **page 12**.

Furthermore, we bring you updates on fundraising initiatives and information on our recent Annual General Meeting (AGM) and conference. Your support and engagement are invaluable as we work towards our shared goal of enhancing the lives of those affected by MS.

I encourage you to immerse yourself in the stories, resources, and updates featured in this edition of MS News.

Warm regards,

**Ava Battles**  
Chief Executive  
MS Ireland

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## NEWS COMPILATION

## My MS My Needs



In 2023, MS Ireland revisited and expanded upon a survey first conducted in 2016 to understand the evolving needs of individuals with Multiple Sclerosis (MS). The My MS My Needs survey results have significantly influenced MS Ireland's services, shaping their planning and advocacy efforts. By capturing real-world experiences, the survey guided strategic initiatives and policies to address gaps in service provision.

The collected data provided an evidence-based foundation for MS Ireland's advocacy, empowering them to champion the rights of the MS community effectively. The survey underscored our organisation's commitment to providing comprehensive support based on the nuanced understanding gained from individuals with MS.

The success of this initiative relied on the active participation of the MS community. Our sincere thanks to all who took part in the survey. The My MS My Needs Report launch will take place on May 29th at an AV Room briefing in Leinster House

## World MS Day 2023

World MS Day 2023 bustled with activities and events, celebrating the community. To help raise awareness, MS Ireland conducted a portrait photography campaign at St Stephen's Green Shopping Centre. Passers-by were asked if, without context, they could name what condition linked the people portrayed in 6 photographs. Our aim was to highlight that MS has many faces and that you cannot always tell that someone is living with the condition. Fact Sheets were distributed to increase understanding of MS. The MS community were invited to join the campaign by sharing portraits online.

Television and radio featured MS stories, alongside regional events showcasing diversity. Local events like the annual World MS Day coffee morning and a Community Radio Kilkenny City takeover furthered awareness. The 'Light Up for MS' initiative symbolised unity as buildings from across Ireland lit up in red to show their support of the MS community.

A briefing in Leinster House was attended by over 30 Oireachtas members, including Minister Anne Rabbitte, it signified a notable political engagement for MS Ireland. During the briefing, MS Ireland amplified the voices of the MS community and outlined pre-budget requests for 2024.

To find out about our World MS Day 2024 plans, see **page 24**.



## EMSP 2023



In 2023, MS Ireland's Information and Advocacy Departments represented the organisation at the EMSP Annual Conference in Helsinki, centred on 'Social Policy: A Better Life for People with MS.' Co-hosted by Neuroliitto, the four-day event provided a platform for European MS organisations to collaborate, exchanging insights and addressing key issues.

Day one commenced with a warm welcome from EMSP President Herbert Hemmes and Helena Ylikyla-Leiva, CEO of Neuroliitto. Discussions focused on pivotal social policy themes such as employment and social inclusion, featuring speakers like Professor Elisabeth Celius Gulowsen and MS Ireland's Aoife Kirwan.

Day two included an inspiring session with Chris Wright, a professional basketball player living with MS. Conversations covered palliative care, long-term care, and system reforms, acknowledging pandemic challenges.

The event concluded with reflections from Interim CEO Jana Hlaváčová, highlighting the importance of addressing social systems affecting the MS community.

## National Conference 2023

MS Ireland's National Conference took place on Saturday, 16th September at The Radisson Hotel, Athlone. The event catered to individuals living with MS and their loved ones, offering pertinent information. Attendees delved into topics such as Silent Progression in MS with Dr. Hugh Kearney, explored the Mental Health Toolbox for MS with Dee Hennessey, gained insights into Benefits and Financial Awareness from Deborah Dwyer, and learned about MRI's role in measuring the immeasurable in MS with Dr. Brendan Kelly. It was an invaluable opportunity for education and support, empowering both individuals and their community in navigating life with MS. Videos are available on MS Ireland's YouTube channel or scanning this QR code.



## Care Centre Business Case



In September 2023, MS Ireland unveiled the MS Respite Centre Business Case with Senator Tom Clonan, aiming to secure €627,000 for extended operations to 350 days yearly. This expansion would add 1,248 bed

nights, supporting those affected by MS. It marks a significant stride in MS Ireland's mission, addressing evolving community needs. The initiative underscores the commitment to enhancing quality of life for MS-affected individuals, fostering a more inclusive, compassionate environment.

## MS Ireland Launches 'MS and Finances' Resource with Bank of Ireland Support

MS Ireland have recently launched 'MS and Finances', a new website resource, thanks to the Bank of Ireland Begin Together Fund. Tailored for those affected by multiple sclerosis, it offers comprehensive financial guidance. Expert-reviewed content ensures relevance and depth, covering State supports, mortgages, pensions, insurance, transport, education, and beyond. Empowering individuals and families, it equips them to navigate financial challenges with confidence. The resource is available on our website or scanning the QR code.



## Podcast Season 2



MS Ireland was thrilled to launch the second season of 'MS Explored – the Podcast' in partnership with Novartis Ireland. The latest instalment comprises four insightful episodes delving into pivotal topics such as consultations with neurologists post-diagnosis, managing MS-induced fatigue, and treatment breakthroughs. Hosted by MS Ireland's Information Officer, Aoife Kirwan, the series features discussions with specialists, consultant neurologists, as well as Andy Walsh, who lives with MS, offering authentic perspectives on living with MS. You can listen wherever you access podcasts, by visiting our website or by scanning the QR code.



## Sativex Access Programme

In a remarkable development, Sativex, an anti-spasticity medication, is now accessible for those with moderate-to-severe MS-related spasticity unresponsive to other treatments. Sativex was made available for reimbursement in early 2023, subject to a managed access programme. The managed access programme was announced in October. MS Ireland championed this cause tirelessly. Ava Battles, Chief Executive of MS Ireland expressed her enthusiasm for 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."

## Reflective Video Series

MS Ireland has launched an insightful video series, generously supported by Viatrix, exploring the transformative developments in the MS landscape over the past thirty years. This collaborative project features experts, professionals, and individuals with first-hand MS experience. Through insightful interviews, it celebrates the positive changes witnessed in research and treatment. Whether living with MS, supporting someone who does, or advocating for MS Ireland, this series offers valuable insights for all. The videos that have been released so far are available on MS Ireland's YouTube channel or by scanning the QR code.



## Brain Awareness Week

To mark Brain Awareness Week, MS Ireland hosted a Research Roundup Webinar.

### Key Topics Covered included:



- **Stigma in MS**
- **Anxiety in MS**
- **Supporting Psychological Wellbeing with Connected Health Technology**
- **Communication for People with Progressive Motor Conditions**
- **Evaluation of Inflammation in the Peripheral MS Retina**
- **Research Update from St. James's Hospital Physiotherapy Department**
- **Cognitive Reserve in MS**

The discussions were dynamic and insightful, fostering collaborative knowledge exchange and exploration.

You can watch back on our website or by scanning the QR code.



## Dean Medal

In December 2023, the esteemed Dean Medal was awarded to Dr. Brendan Kelly, highlighting his remarkable contributions to MS research. Although absent, Professor Ronan Killeen graciously accepted the award on his behalf. The Dean Medal symbolises our commitment to MS research, honouring Dr. Kelly's efforts in integrating transformer models into an AI change detection project. Our sincere appreciation to Professor Ronan Killeen for representing him. This recognition underscores our dedication to celebrating excellence in MS research through innovative approaches.



## Oceans of Hope

MS Ireland in conjunction with Oceans of Hope Challenge hosted the first 'Introduction to Sailing' day for people living with MS, in Dun Laoghaire in April.

This project was being spearheaded by Kerry man, Stephen Fitzpatrick who sailed with Oceans of Hope on their Athens Challenge in Greece last year.

Stephen says the experience spending time at sea transformed his life. He now plans to run sailing days around the coast for people with MS.

The sailing day was a great success with Robert Munns CEO of Oceans of Hope Challenge coming over for the first event in Ireland. Oceans of Hope Challenge hold a number of sailing events for people with MS around the world, initially in Turkey and Croatia. More information can be obtained at <https://oceansofhope.co.uk/>





## Sunflower Lanyards


For those living with MS, the challenges of everyday life can often be unseen by others. Tasks that others may take for granted - like shopping, travelling, or even just being in public spaces - can present unique obstacles. However, a small yet powerful initiative, the Hidden Disabilities Sunflower lanyard can make a significant and positive difference.

The Hidden Disabilities Sunflower lanyard scheme originated in the UK and has gained traction globally, including in Ireland. The concept is simple yet profoundly impactful. Those who wear the sunflower lanyard discreetly indicate that they have a hidden disability, such as MS, that may not be immediately apparent to others. The lanyard acts as a signal, prompting awareness and understanding from those around them.

So, what does wearing the Hidden Disabilities Sunflower lanyard mean for someone with MS? Firstly, it's about visibility - though not necessarily in the way one might think. Rather than drawing attention to a disability, the lanyard quietly communicates that the wearer may require a bit of patience, understanding, or assistance. This subtle cue can be invaluable in public settings, where stress and anxiety about potential misunderstandings can often arise.

For someone navigating the aisles of a supermarket, for instance, wearing the sunflower lanyard can signal to staff that they might need extra time or support. Similarly, when travelling, wearing the lanyard can prompt staff to offer assistance, acknowledging the unseen challenges faced by those with MS.

The lanyard scheme has been embraced by various organisations across Ireland, including major retailers, shopping centres, transport providers, and cultural institutions.

It's important to remember that wearing the sunflower lanyard is a personal choice, and it's entirely up to you whether you decide to use it. For many, it can offer a sense of empowerment - a small yet meaningful tool in navigating the world with greater ease and confidence. If you have MS and are considering using the Hidden Disabilities Sunflower lanyard, obtaining one is straightforward. Many participating organisations provide them free of charge upon request. Simply ask at customer service desks or check online for local availability. You can find a map with participating stores by scanning this QR code: 

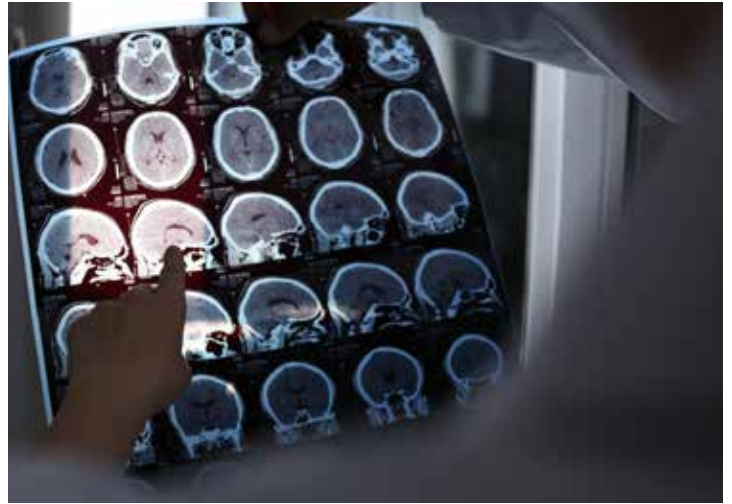
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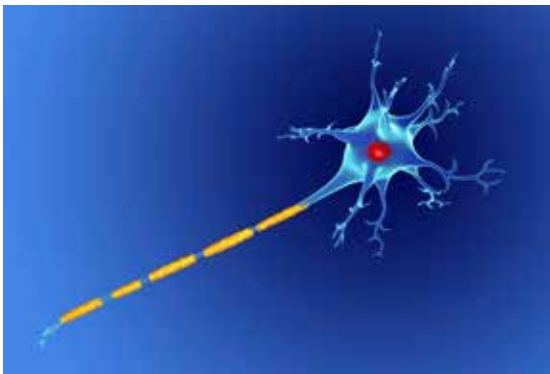


## Progression Without Relapse: Understanding PIRA in Multiple Sclerosis

MS is recognised as a chronic disease affecting the central nervous system, impacting millions worldwide. Secondary progressive MS (SPMS) poses a particular challenge, where symptoms worsen gradually over time without clear relapses. In recent years, the concept of Progression Independent of Relapse Activity (PIRA) has gained attention, shedding light on this aspect of the disease.



PIRA refers to MS progression occurring without the typical relapse activity seen in the earlier stages. This means symptoms worsen over time, even when acute relapses or flare-ups aren't evident. This presents a unique challenge for doctors and researchers, as traditional measures like relapse frequency or new MRI findings may not accurately reflect disability progression.



The reasons behind PIRA in MS are complex and not fully understood. Irreversible damage to the central nervous system, including demyelination and nerve cell loss, is a key factor. This damage accumulates over time, worsening disability independently of acute inflammation. Other factors like age, disease duration, genetics, and other health conditions may also contribute to PIRA.

PIRA in MS has significant clinical implications. Unlike relapsing MS, where treatment aims to suppress acute inflammation, managing PIRA requires a broader approach. This involves slowing disability progression and improving quality of life through various means, including medication, symptom management, rehabilitation, and holistic care.

Research into PIRA is ongoing, focusing on understanding its mechanisms, identifying predictive markers, and developing targeted therapies. Advanced imaging techniques, such as MRI and optical coherence tomography (OCT), show promise in detecting subtle changes in the nervous system preceding clinical disability in PIRA.

PIRA is a critical aspect of MS progression, demanding attention and tailored interventions. Understanding its mechanisms and developing effective management strategies can improve outcomes for those with SPMS. Continued research and collaboration are vital to advancing our understanding of PIRA and enhancing outcomes for individuals facing this challenge in MS.

# MENTAL HEALTH RESOURCES



Living with MS often means navigating a host of challenges, both physical and emotional. Among these, maintaining good mental health is paramount. Anxiety, depression, and social isolation can frequently accompany the physical symptoms of MS, making it crucial to address mental health needs alongside medical treatment. Fortunately, in Ireland, there is a wealth of resources available to support individuals managing MS and mental health concerns.

### **MS Ireland:**

MS Ireland's Community Worker Service can help link you in with mental health services. Contact details for the Community Workers are available using this QR code.



### **General Practitioners (GPs):**

Your GP is often the first port of call for mental health support. While discussing mental health concerns might seem daunting, GPs are equipped to provide guidance and refer you to specialist services if necessary.

### **Helplines:**

**Pieta House** provide support to people who are experiencing thoughts of suicide, those who engage in self-harm, and those bereaved by suicide. They can be contacted 24 hours a day by phone on 1800 247 247.

**They also offer a text service – Text HELP to 51444 (standard message rates apply)**

**Samaritans** also provide free support and are available 24 hours a day on freephone 116 123

**Text About It** is a free, anonymous messaging service which is operational 24/7. To engage with this text HELLO to 50808.

**Emergency Services** can be contacted by calling 999. You can also present to your local A&E if you are feeling in immediate risk.

## Additional Resources:

A multitude of organisations and resources further support mental health and wellbeing in Ireland. To find out more, visit our MS and Mental Health Resource by scanning here:



### MS and Wellness

MS Ireland offers a comprehensive resource to aid individuals, families, and caregivers in managing the challenges of MS. This resource includes videos addressing anxiety and tools to support positive mental wellbeing. It can be accessed here:



**Recovery College** provides a valuable resource for individuals seeking to improve their mental well-being. Through educational courses and workshops, participants can acquire skills and build confidence to navigate life challenges. These courses offer opportunities to relax, destress, and empower individuals to live their best lives. Find out more about it here:



**Digital Cognitive Behavioural Therapy (CBT)** is available to help manage mental health and wellbeing. The HSE and SilverCloud® provide internet-based CBT for people aged 18+ in programmes that run for up to 8 weeks. This is accessible 24 hours per day.

You need a referral from your GP, Primary Care psychology, The National Counselling Service, Community Mental Health Teams or Jigsaw to access this service.

Living with MS can be challenging, but it's essential to remember that support is available. Engaging with the resources and services outlined above, can help people to prioritise their mental health and enhance their overall quality of life. Whether seeking immediate assistance during a crisis or exploring long-term coping strategies, know that you are not alone on your journey towards mental wellness while managing MS.

*Remember, taking care of your mental health is not a sign of weakness but rather a testament to your resilience and strength in facing life's challenges.*



# 'Jealousy'

## By Katie Murphy

I'm so jealous of people diagnosed with MS older than me.  
Whenever I hear someone say they were 30 or older when they were diagnosed,  
a pinch of jealousy enters my body.



Although no one wants MS.  
Why did I have to get it so young?  
Only 16.

Before I had been able to drink.  
Before I had my first love.  
Before I was even on a plane for the first time.

I'm jealous of the life they got to live.  
That I never even got.  
They grieve the life they lost.  
I grieve the life I never had.

I deal with the consequences of never being able to do  
the things other people my age get to do.

Can't travel, too exhausting.  
Can't drink, makes my symptoms worse.  
Can't plan for the future because you don't know what it contains.

Questions of what do you want to be when you grow up,  
clouded by what can I be when I grow up.  
What will I be able to do?

As I approach my 8 years anniversary.  
I'm still the youngest in the room.  
While being one of the people who has been diagnosed the longest.

When I ask you when you were diagnosed.  
I'm asking because I'm looking for that relief.  
That's assurance.  
That I'm not alone in this feeling.



## Empower with Care: A Sanctuary of Support in Our Community

Dear Friends,

My name is Janet, I manage the MS Ireland Care Centre. It is with great enthusiasm that I would like to introduce you to two of its service users, Bridget and Christina. Despite their age difference and being at different stages in their MS journey, both say their lives were profoundly impacted by their time at the Care Centre. Their stories illustrate how respite for all is at the heart of the Care Centre's mission – and how we provide a supportive environment for anyone navigating the challenges of MS and empower them to live the life of their choice to their fullest potential.

Located on Bushy Park Road, Dublin, the MS Care Centre is the only respite centre dedicated to people with MS in Ireland. Each year, it welcomes over 350 service users in its 12-room facility. In my time working there, I have witnessed countless stories of hope and resilience.



Janet, Care Centre Manager



The Care Centre offers support and community to its service users.

The Centre not only offers respite to people with MS and their families – it also fosters a deep sense of community and belonging, of solidarity and mutual understanding between individuals at different stages of a shared journey. Through a combination of specialised care, social activities, and rest, residents are supported in the management of their MS symptoms (which are sometimes invisible) while still experiencing the simple joys of a normal life.



Christina, Care Centre service user since 2023

Christina’s story is a testament to the power of tailored support and the sense of belonging that the Care Centre fosters. Diagnosed at 26, she was initially apprehensive at the idea of a respite stay – she dreaded feeling stuck in what she thought would be a nursing home for the elderly. At the same time, she couldn’t help but feel guilty for taking up the spot of someone else who might need it more than her. Despite her preconceived idea of what the Care Centre would be, Christina’s first experience during the Young Person’s Week highlighted how the facility caters to the specific needs of younger individuals with MS, offering a wide range of activities and support that resonate with their age and interests. Christina’s words, “I’ve never felt a connection like that with a group of people – I call them my people,” echo the sentiment of finding a community that understands and uplifts.

“I’ve never felt a connection like that with a group of people – I call them my people”

Bridget, having lived with MS for over 13 years, always looks forward to her next stay at the Care Centre. Her journey of coming to terms with her diagnosis was profoundly impacted by the empathetic support and friendship she found within its walls. “It was the Centre that really saved me,” Bridget shares, highlighting the essential role of the Care Centre in her path to self-acceptance and resilience. Knowing only very little about MS when she received her diagnosis, Bridget initially had to rely on the support and guidance of her immediate family to choose a treatment, oftentimes facing difficulties to access professional care. Now, surrounded by the team in the Care Centre and fellow service users who can understand her symptoms, Bridget feels truly understood and listened to.



Bridget, Care Centre service user since 2010

“It was the Centre that really saved me”

While its main purpose is to provide a haven for its service users, the Care Centre also brings relief to the families of people living with MS. Some, like Christina, live with close relatives who they can rely on for daily tasks. Others don’t receive the support they need at home or live in isolation. In both cases, the Care Centre is there to offer a helping hand.



That is the Care Centre’s core mission: to deconstruct preconceived ideas about MS and offer multi-level support tailored to individual needs, from physiotherapy and meditation to invaluable one-on-one support and community building. The Centre stands as a testament to living fully and has seen service users like Christina and Bridget find relief and newfound confidence in themselves.

“I feel like the Care Centre has given me a new lease of life. I’ve become more independent since going there - things that I never would have done, I am now doing by myself.”

- Bridget, service user



However, the Care Centre’s ability to continue providing these life-changing services depends on the generosity of donors like you. To continue to provide a high level of specialised care in a home away from home environment, your support is now more crucial than ever. By donating, you’re not just contributing to a facility but to a community that empowers people with MS to live their lives to the fullest, as Christina aptly put it: “I think it’s important for people to know that when they donate, they’re not just donating to a building, they’re donating to everything: the physio, the people that they get in to provide services for, the meditation, the yoga, the tips on how we can manage our everyday symptoms, feeling part of a community, part of a group. It really changes our lives.”



Yes! I want to help to support services every month. Here is my monthly commitment of:

€10     €21\*     €50\*     My own choice of € \_\_\_\_\_

I would like my monthly donation debited on the  1st OR  15th of each month (please select one)

\*If you are a tax payer, a gift of €21 a month or more could be worth up to an additional 45% to us at no extra cost to you.

Sepa Direct Debit Mandate

IBAN:

BIC           Your BIC number may contain eight or eleven digits.

- Is there more than one signatory needed to sign on you account?
- Is this a Republic of Ireland account?     Can the bank account accept direct debits?

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Credit Identifier:  
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Creditor Address:  
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D04 T856

Your Rights: By signing this mandate form, you authorise (A) MS Ireland to send instruction to your bank to debit your account and (B) your bank to debit your account in accordance with the instructions from MS Ireland. As part of your right, you are entitled to a refund from your bank under the terms and conditions of your agreement with your bank. A refund must be claimed within 8 weeks starting from the date in which your account is debited. Your rights are explained in a statement you can obtain from your bank.

To make an instant donation call 01 678 1600 or visit [www.ms-society.ie](http://www.ms-society.ie)

Let us come together to ensure that the MS Ireland Care Centre can remain a sanctuary of support, empowerment, and community for all those living with MS. Bridget, Christina and hundreds of other people with MS and their families across Ireland rely on your generosity to access the care and support they need. Your donation will ensure we can keep providing these life-changing services to them all year-round. To make a contribution, please complete the enclosed form and return it to us. Alternatively, you can go to [ms-society.ie/donate](https://ms-society.ie/donate) and follow the simple instructions. We thank you for your kind support. With gratitude,

**Janet**

Janet Lee Nurse Manager, MS Ireland Care Centre

“Transform lives with your donation. Together, we provide a haven of care for those navigating MS.”  
- Janet, Care Centre Manager

Donate online instantly



P.S. Don't underestimate the power of your contribution; it's the lifeline for our services.

Yes! I want to make a difference. Here's my gift of:

€35 may fund an hour of care, ensuring our residents receive the best possible care tailored to their needs

€65 may enable a comprehensive neuro physiotherapy assessment, aimed at improving or maintaining independence

€125 may contribute to the upkeep of crucial equipment, such as hoists, to ensure the safety and mobility of our residents.

My own choice:

I enclose a cheque/bank draft/postal order made payable to MS Ireland OR Please debit my:  Visa  Mastercard  Visa Debit

Card Number:

Expiry Date:   /   Security Code:

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

I would like to receive information about leaving a gift to MS Ireland in my will

If you would prefer not to receive postal communication from us, please tick this box

For further detailed information on how we store and use your information please visit [ms-society.ie/privacy](https://ms-society.ie/privacy) to see our full privacy statement. If at any time you'd like to change how we communicate with you, or you don't want to hear from us again, that's okay! Just let us know by contacting us .

Address: 80 Northumberland Road, Dublin 4, D04 T856

Email: [fundraising@ms-society.ie](mailto:fundraising@ms-society.ie)

Registered Charity No. 20007867 | Charity Number: CHY 5365



**Howdy, I'm Paul Rabbitte, an urban cowboy with the courageous heart of a gunslinger from the Wild West. My Suzuki GS1000 shaft drive was my horse. I have always been a free spirit. I lived in London in the 1980's. I've worked on a Spanish fishing trawler. In the 1990's, I turned my hand to organic farming. I inherited my father's genes and have a gift for music and mechanics. By the 2000's, I was a self-employed tiling contractor, working throughout the country.**

My world changed in 2011, when I woke up one morning, unable to feel my legs. This was just days before my 44th birthday. I went to A&E and within 5 days, I was diagnosed with relapsing-remitting MS. My medical history was examined. An isolated episode of optic neuritis that I had experienced back in 1998 was deemed to have been my first MS symptom! Despite conventional treatment options, I chose to explore low-dose Naltrexone due to concerns I had about potential side effects. (If I need to change this line it will be to "Despite conventional treatment options, I chose to explore alternative treatments due to concerns I had about potential side effects.")

While I anticipated physical challenges from MS, the toll it took on my cognitive function caught me off guard. Over the next 2 years, I tried to live my best life, challenging my body. I climbed Croagh Patrick many times. However my mood and behaviour changed. My short term memory declined. I had difficulty banking, and more than once found myself at a cash register without my wallet! My van broke down, and I was unable to fix it. I cycled everywhere after that until falls became too frequent.

In 2014, I had a major relapse. I lost all power down one side of my body. Following a serious fall at home, I was brought by ambulance to hospital. My symptoms were very severe. I couldn't sit up straight or speak clearly. I lost all bladder control and had to be catheterised. My neurologist prescribed Intravenous immunoglobulin (IV Ig) treatment for a week followed by a long-term disease-modifying treatment plan, administered



monthly via infusion. Eventually, due to cognitive impairment and the need for personal assistance, I transitioned to a residential nursing unit in October 2014.

My MS is now in secondary progressive phase. I use a wheelchair most of the time. I'm on a symptomatic treatment to improve walking now, along with various other medications to treat MS symptoms. I have keenly watched the progress of cannabis-based medications being made available to people living with MS. While progress has been made in this area, my hope is that access to treatments and medications that benefit people living with MS, will be made easier.

With the aid of the wonderful staff in my residential unit, my family and few close friends, I make the most of my life. In the words of John Wayne; **"Life is getting up one more time than you've been knocked down"**.

# EMSP YOUNG PERSONS NETWORK

## By Niamh Redmond

My community worker got in touch with me in mid January to tell me about an event that was coming up hosted by EMSP (European Multiple Sclerosis Platform) and MS Ireland. The event was called Young, Connected & Educated, as part of their YPN (Young Persons Network). I put my name forward and I was delighted to be one of the 10 chosen to attend the event. Apart from the 10 Irish people with MS, there were also 10 people with MS from different parts of Europe like Finland, Croatia, Brussels and many more.



The event took place in The Gibson Hotel in Dublin over two days. We had check in at 6pm followed by dinner. Then to finish the evening off we went into Dublin City for a bit of craic agus ceol. Despite being anxious in the run up to the event, once I arrived and met this group of strangers it felt like I was catching up with old friends.

On the Saturday we were welcomed to the event by EMSP and MS Ireland. EMSP told us about the advocacy work they do for people living with MS across Europe and the various projects they run such as MS Nurse Pro which is an e-learning course for MS nurses. And the One Million Minds campaign which is a petition that is to address the unmet needs of people with MS and other neurological disabilities. The petition can be signed now on their website. MS Ireland then spoke about their recent Young Person's Survey Report which was a survey carried out to help better understand the needs of young people aged 18-35 with MS.

We then had a group discussion about the barriers that we have faced when it comes to MS and Education. It was very interesting to hear the challenges that people in other countries face. Overall, while it seemed there are challenges facing people with accessing education, one of the biggest problems seemed to be not having the support to be able to stay in education.

We then broke up into groups to do various group tasks like discussing if there are approaches that can be taken to improve the educational experience of people with MS. Questions like "Can educational institutions help contribute to this?" were explored. We also shared our own stories of barriers we faced in education.

Finally, we had to create our own campaigns. The ideas everyone came up with were amazing with concepts encouraging people to 'Live Your Life', remember that 'You are not your MS' and consider 'How Many Spoons Do you Have?'

The entire day went by way to fast. The energy in the room was amazing.. It is so nice to be in a room full of people who you know understand the struggle of being a young person living with MS. One thing that really stood out from the day was how positive everyone was. No matter how bad things can get, we found that there is always an embarrassing story to laugh about.

*In early 2023, MS Ireland undertook a comprehensive survey aimed at delving into the experiences and needs of young adults aged 18 to 35 living with Multiple Sclerosis (MS). The survey, which 126 people responded to, sought to gauge awareness of and engagement with MS Ireland, experiences at the time of diagnosis, challenges faced, and suggestions for improvement. Here's what the survey revealed:*

# YOUNG PERSONS SURVEY REPORT

**Awareness and Signposting:** The survey indicated varying levels of awareness about MS Ireland among young people with MS, with 28.07% reporting substantial knowledge. Significantly, 50% of respondents were signposted to MS Ireland at the time of their diagnosis, but a substantial portion expressed a desire for such guidance, underlining the need for better collaboration with healthcare professionals.

**Engagement and Channels:** A majority of respondents engaged with MS Ireland within five years of diagnosis, with various channels like the website, social media, and community worker services being utilised. However, reasons for non-engagement included not perceiving MS as a priority and lack of awareness about available services.

**Representation and Catering:** Opinions were divided regarding the representation and catering to the 18-35 age group, with several feeling under-represented and under-catered for. Factors contributing to this sentiment included a perceived focus on an older age cohort and timing issues with events.

**Challenges Faced:** The survey identified numerous challenges faced by young people with MS, ranging from symptoms and access to services to barriers in work and education, public misunderstanding, and feelings of isolation.

**Key Activities and Recommendations:** Respondents suggested various activities for MS Ireland. These included social events, employment support, tailored information, and greater public awareness campaigns. Other recommendations included, public awareness campaigns, increasing representation in materials, developing tailored resources, enhancing collaboration with healthcare professionals, and expanding digital outreach efforts.

The insights gained from this survey will enable MS Ireland to refine its strategies and initiatives, ensuring that it remains responsive and supportive to the needs of young people in the MS community. [The report is available to view here:](#)



# 25th Annual General Meeting (64th 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. 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 Thursday, 5th September 2024 at 8.00pm in the Care Centre, 65 Bushy Park Road, Rathgar, Dublin 6. Members will attend online.

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 Tuesday, 3rd September 2024.

**Maurice O'Connor**  
**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 1st August 2024.**

## Call for Board Members

We are currently seeking candidates including candidates with HR and legal 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 2024, are invited to submit their application form by **5.00 p.m. on 31st May 2024**. **The closing date for Applications under Article 56 of the Constitution is Friday, 14th June 2024**



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

**MS Person of the Year – Bronagh Moran**  
Nominated by Dublin South Branch Committee



**Carer / Helper of the Year – Joe McArdle**  
Nominated by the Louth Branch



**Volunteer of the Year – Mary P. McCaffrey**  
Nominated by Lorna Callaghan, Monaghan Branch  
Pictured with Maurice O'Connor, Chair of the Board of MS Ireland



## MS Ireland's 2024 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 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, 9th August 2024.**

The annual national awards for 2024 will be presented at the National Conference.

# PHYSIOTHERAPY AND EXERCISE



**MoveSmart MS** is MS Ireland's online, nationally recruited, symptom-focused exercise program. It offers specialised, tailored, symptom-specific online exercise programmes for participants living with Multiple Sclerosis, grouped by age and stage in their MS journey.

**Active Neuro** is a specialist online exercise and symptom support programme for adults living with any neurological conditions in Dublin, the West or Mid-West.



**Getting the Balance Right** is MS Ireland's regional Exercise and Physiotherapy service. We offer online and in person exercise classes, such as physiotherapy and yoga, in all 10 regions across the country. The classes are stratified by ability so that exercises can be tailored to meet the needs of participants.

**Physio West** offers physiotherapy and physiotherapy-led individual programmes for people with MS living in the West.

Taking part in MS Ireland designed physiotherapy programmes has been shown to result in:



Reduction in usage of healthcare services by **43.1%**



A&E and inpatient services utilisation reduced by **33%** and **57.4%** reduction in bed days



Significant improvements in quality of life (**20.2%**), fatigue (**16%**) and mental health (**20%**)



Our data suggests that we can **reduce the number of people falling\***, and the number of falls they have through our programmes by **49%**

\*People with MS, Stroke and Parkinsons (PD) fall at a similar rate to the over 85's (50% in a three month period).

**TO FIND OUT MORE,  
VISIT OUR WEBSITE OR  
SCAN HERE**





# World MS Day 2024

World MS Day is observed globally on the 30th May every year. The aim of the day is to raise awareness of MS and bring together those who are living with the condition to share their stories.

## What is the theme?

The theme this year is 'diagnosis'. The time of diagnosis can be emotive and challenging for many. Whether someone is newly diagnosed with MS or have been told they have progressed to a different type of MS, concerns can arise and people can experience many feelings in relation to their diagnosis.

## What is the campaign?

We know that everyone has a different diagnosis story, as unique as a fingerprint. This year, we are inviting people living with MS to write a letter about their diagnosis. This can be directed to anyone you wish. Maybe it is to your past or future self. Perhaps you might write it to your family. It could be to healthcare providers or decision makers. These letters present an opportunity to express your thoughts and feelings. You may wish to share your concerns or hopes for the future, or explain what you want people to know about MS.

## How can I join the campaign?

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

**Step one:** Write a letter about diagnosis.

**Step two:** post it to your social media along with the hashtags #ManyStories at one of three peak times 9:30am, 1:30pm and 5pm.

**Step 3:** Tag MS Ireland in the post.

**Facebook:** Multiple Sclerosis Ireland

**Instagram:** @multiple\_sclerosis\_ireland

**X:** @MSIRELAND

## Fact Sharing Campaign

This year, MS Ireland are aiming to raise awareness and understanding of MS amongst the general public. MS Ireland has reached out to pharmacy chains across Ireland, urging them to participate in our awareness campaign. We are asking that they display facts about MS in their stores, utilising a poster available on the MS Ireland website. Additionally, they're encouraged to share this information on their social media platforms.

[The poster can be found by clicking here or scanning the QR code:](#)



## To help maximise this project, we need you!

It's time to rally our communities and spread awareness about multiple sclerosis like never before.

We're calling on you to take action and engage your local pharmacies in supporting the MS community this World MS Day.

All you have to do is encourage your local pharmacy to display a physical or digital poster filled with MS facts in-store or on their social media accounts.

Direct them to the MS Ireland website, where they can easily download and print the poster to proudly showcase their support for the MS community.



### Leinster House Briefing

MS Ireland will be holding a briefing in the AV room of Leinster House to raise awareness amongst the elected officials and to garner support of MS Ireland and the MS community in advance of an election year. This will be done through the launch of the results of the My MS My Needs survey.

### Information Event

On the evening of World MS Day we will be holding an information event to explore the topic of 'Uncertainty in MS'. With a condition like MS, uncertainty can repeatedly raise its head as people progress through their lives and face other challenges. MS can become a factor when making life decisions and the uncertainty of MS can make those challenging decisions harder. The speakers lined up to explore this topic are *Consultant Neurologist Dr Hugh Kearney, Principal Neuropsychologist Dr Sarah Casey and Jamie Crawford, a person living with MS.*

This session will be supported by Novartis. This will take place in The Alex Hotel, Dublin from 7pm on May 30th.

[Register for this event by clicking here](#) or scanning the QR code:

This meeting will be streamed on Facebook Live.



### Light-Up Campaign

Buildings across Ireland will be taking part in a 'light up' for MS. Where a physical light up is not possible, virtual lights ups will be shared from the social media accounts of the buildings.

### Dip for Diagnosis

The "Dip for Diagnosis" campaign is the fundraising element of MS Ireland's World MS Day activities, focused on enhancing awareness and raising funds for people living with MS. Participants are invited to take a dip in their preferred environment—be it the sea, a pool, or a cold shower—during the week of World MS Day.

To join, individuals should register here where they can make a donation and receive a World MS Day Dip Pack, including a distinctive swimming hat or Beanie. A real-time counter on the 'dip for diagnosis' webpage will monitor the number of logged dips. We encourage everyone to log their swim, helping us achieve our goal of 10,000 dips, each representing a person living with MS in Ireland. While MS Ireland will not organise specific dip events, we will provide a map on the Dip for Diagnosis page showing several locations where participants can gather and meet others taking part in the challenge



### Care Centre Coffee Morning

A Coffee Morning will be held from 10am on the morning of May 30th in the MS Care Centre, situated on Bushy Park Road, Dublin.

### Regional events

A range of events will be taking place across the country to mark World MS Day. For more information, visit our dedicated webpage by [clicking here](#) or scanning the QR code.



## UPCOMING EVENTS



### Women's Mini Marathon

Encourage your workplace colleagues, friends and family to enter the VHI Women's Mini Marathon on the 2nd June to support MS Ireland. Please contact [melaniec@ms-society.ie](mailto:melaniec@ms-society.ie)

### Skydive

Register via our website [www.ms-society.ie/get-involved/fundraise-us/skydive-ms-ireland](http://www.ms-society.ie/get-involved/fundraise-us/skydive-ms-ireland) or contact [melanie@ms-society.ie](mailto:melanie@ms-society.ie) for dates that suit you.

### Abseil

Join us on September 21st in Dalkey Quarry – This is a great experience for the adrenalin junkies out there. For more info contact [melaniec@ms-society.ie](mailto: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](mailto:melaniec@ms-society.ie)

### Bridge

Do you play bridge? Would you nominate MS Ireland to be a beneficiary of your charity event? Please contact [melaniec@ms-society.ie](mailto:melaniec@ms-society.ie) for more information.



## The May 50k

Walk or run 50km in May whilst fundraising for life-changing research into MS, improving access to treatments and supporting people living with MS. Wherever you live, whatever your fitness level, you can decide when and where you will complete your 50 kilometres.

Every step you take, every kilometre you clock, helps people get access to the treatment they need today and takes us closer to finding a cure for MS. You can do it by yourself, or as part of a virtual team with friends, family, or work colleagues.

You can sign up at [www.themay50k.ie](http://www.themay50k.ie) or contact [shaneb@ms-society.ie](mailto:shaneb@ms-society.ie) for more information.



## Thank you!

The UCD Agricultural Society chose MS Ireland as one of their charities of the year and raises a whopping €31,000. A huge thank you to all the students and staff involved.

**Would you put MS Ireland forward to be the beneficiary of your organisation's charity of the year programme? This kind of support is invaluable to MS Ireland.**

We were delighted to have had Corporate volunteers from a variety of companies who came to Head Office to help us by packing incentives for our 5 challenges in 2023 – this initiative was a huge success - thank you to BNY Mellon, Hayes, Google and M&G Investment for their help.

We had a variety Corporate partners who chose to support MS Ireland through different fundraising events such as pub quizzes, corporate sponsorship of events such as Hell and Back, Christmas Jumper Day and Skydives – Thank you to Viatrix, Teamwork, Nine Dots and Expleo for their support.

We ran several challenges in 2023 including Dip a Day in September, The Christmas Crunch and the Advent Challenge – all of which were very successful. Thank you to everyone who participates in our challenges as these are amazing fundraisers for MS Ireland. To join our next challenge please check out our website - [www.ms-society.ie/get-involved/fundraise-us](http://www.ms-society.ie/get-involved/fundraise-us)

Exceptional Fundraisers – Sean Bagnall was supported by Murt Cleere and Mairead Walsh when he decided to run 3 marathons in 3 days from Dublin to Galway – raising €17,800, Finlay McFayden took on another amazing challenge for MS Ireland by doing the Donegal Ultra Cycle 555 raising €21,000, along with many wonderful fundraisers who took on challenges of all sorts and raised much need funds to help us to continue providing vital services to the MS community.

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.

## MS Readathon



With over 11,300 online registrations, children, “big-kids” and schools across Ireland 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. 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](http://thebookshop.ie) who we partnered with to supply 5500 €5 book tokens and who kindly sponsored half of all tokens. A second thanks to Easons for sponsoring an amazing variety of book bundles for three schools. We raised just over €248,000 in total! 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.

# SAVE THE DATE

MS Ireland National Conference  
November 6th and 7th  
Hillgrove Hotel in Monaghan

Further details to follow from our website,  
social media and Regional Offices.