MS news

Spring / Summer 2025

Issue 114

10

Life with an assistance dog

10

World MS Day

17

National Volunteering Week #NVWIreland

MS Volunteers

MS Information Line

0818 233 233

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

CHY No: 05365
CRA: 20007867
CRN: 296573
RCN: 20007867

MSIreland
THE MULTIPLE SCLEROSIS SOCIETY OF IRELAND

CONTENTS

Multiple Sclerosis Ireland, 80 Northumberland Rd, Dublin 4.
www.ms-society.ie | 01 678 1600 info@ms-society.ie | Info Line: 0818 233 233

EDITOR & EDITORIAL
Aoife Kirwan - aoifek@ms-society.ie

ADVERTISING
Fundraising - fundraising@ms-society.ie Tel - 01 6781600

CONNECT WITH US

Find us on Facebook twitter YouTube

www.ms-society.ie

Dear Friends,

Welcome to the Summer edition of *MS News*.
This issue brings together a wide range of stories, updates, and reflections from across the MS Ireland network. From national campaigns to local branch activities, we hope the content offers something meaningful for everyone connected to the MS community.

To mark World MS Day this year, we launched a six-week cinema campaign aimed at raising public understanding of MS. We also introduced *Living with MS*, a podcast series sharing real-life experiences of people living with the condition. We also held a briefing in Leinster House, where members of the Oireachtas heard first-hand accounts of how MS affects daily life. Regional events were held up and down the country and 'Dip for a Diagnosis' saw people take a plunge to help raise funds and awareness. You can read about our World MS Day activities on **page 10**.

You'll also find personal contributions in this edition. One writer offers a frank and thoughtful piece about intimacy and MS **(page 18)**. We also hear from Edel Carey on **page 8** who tells us about her assistance dog, Nala. These articles help to show the varied realities of living with MS, and the different ways people navigate those changes. As always, we thank our contributors for sharing their stories.

Elsewhere, we report on the results of the recent *Impact of MS Symptoms Survey* and the EMSP Conference in Prague. Both highlight important areas for development in research and care, including diagnosis, treatment access and representation in clinical trials. You can find out more about these on **pages 6 and 16**.

We also acknowledge the contributions of our volunteers, whose time and involvement shape many of our day-to-day services. A new *Volunteering Handbook* has been developed in response to feedback, offering practical guidance and support for new and returning volunteers. Read more about this on **page 17**.

Fundraising continues to play a vital role in our work. From skydives and Camino treks to golf events and marathons, supporters have raised impressive sums over recent months. See **page 22** for more. We're very grateful for all the imaginative and generous efforts described in these pages.

Finally, our Community News section on **page 20** features activities from branches including South Dublin and Limerick, where events and initiatives have been underway.

Thank you for reading this edition. We hope you find it informative and worthwhile.

If you have any feedback on this edition, or would like to contribute to future editions of MS News, please contact the editor, Aoife Kirwan – aoifek@ms-society.ie

Warm regards,

Ava Battles

Ava Battles
Chief Executive, *MS Ireland*

Multiple Sclerosis Ireland,
80 Northumberland Road, Dublin 4

T: (01) 678 1600 | MS Info Line: 0818 233 233
E: info@ms-society.ie | www.ms-society.ie
CHY No: 05365CRA: 20007867 | CRN: 296573
RCN: 20007867

Ministerial Engagement Highlights Cross-Departmental Commitment to Neuro-Rehabilitation

On Tuesday, 27 May, NAI representatives, including MS Ireland's Advocacy and Research Officer, Alison Cotter, met for the second time with Minister of State for Disability, Hildegarde Naughton T.D., for a discussion on advancing the implementation of community neuro-rehabilitation services. The Minister expressed strong support for prioritising neuro-rehabilitation and recognised the critical role of NAI member organisations in delivering community-based supports. Key issues raised included:

- The urgent need to complete the national rollout of community neuro-rehabilitation teams
- Increased access to inpatient neuro-rehabilitation beds
- Establishment of multidisciplinary rehabilitation services in all Health Regions

This meeting builds on a previous engagement with Minister Naughton earlier this year, where NAI highlighted the importance of collaborative approaches between statutory healthcare services and community-based organisations. The Minister acknowledged the positive impact of these partnerships and committed to ongoing dialogue.

Earlier in 2024, NAI also had the opportunity to meet with Minister for Health, Jennifer Carroll MacNeill T.D. for a valuable exchange on the future of neurological care in Ireland. The discussion focused on enhancing healthcare responsiveness and accessibility for people living with neurological conditions. Both parties recognised that collaboration will be key in delivering long-term, practical improvements.

MS Ireland, as NAI members, welcome the continued commitment from both Ministers and we look forward to working together on evidence-informed, person-centred initiatives to support the neurological community.

Collaborating for Change: MS Ireland's Engagement with DFI in 2025

MS Ireland has been actively engaging with the Disability Federation of Ireland (DFI) throughout 2025 to support stronger rights-based approaches, community engagement, and practical implementation of the UN Convention on the Rights of Persons with Disabilities (UN CRPD).

Driving Local Change: UNCRPD in Action

Earlier this year, MS Ireland attended the DFI-hosted launch of new research by Dr. Charles O'Mahony and Dr. Mary Keogh on implementing the UNCRPD at a local level. The event brought together local authority officers, public bodies, policy experts, researchers and advocates to share insights and experiences.

The research underlines the importance of local action in delivering meaningful change and ensuring the rights of people with disabilities are upheld in every community. The event sparked valuable conversations around barriers, opportunities and next steps.

Launch of the Self-Advocacy Toolkit

MS Ireland also welcomed the launch of DFI's Self-Advocacy Toolkit, a resource developed with and for people with lived experience. The toolkit aims to equip individuals and communities with the tools they need to influence and shape decision-making, while also supporting organisations to embed inclusive and participatory practices in their work.

The resource is a timely and practical contribution to strengthening the voice of people with disabilities across sectors.

Regional Engagement in Tuam

MS Ireland joined fellow DFI member organisations at a regional meeting in Tuam. The event, organised by DFI's Elaine Teague, brought together representatives from across the West and North West to share updates, strengthen collaboration, and explore innovative approaches to advocacy and service delivery.
Thanks to Tony Canavan, Regional Executive Officer for the West and North West, and Aoife O'Donoghue for leading a valuable and energising session.
These engagements reflect MS Ireland's ongoing commitment to collaborative advocacy and systems change—centred on the lived experience of people with MS and grounded in human rights.

AIMS Symposium

The All-Ireland Multiple Sclerosis (AIMS) Research Network held its 2025 symposium at Maynooth University on June 6th. The event brought together researchers, clinicians, policymakers and people with MS, covering topics like cannabis impacts, biomarkers and clinical trials. A panel of people living with MS, chaired by MS Ireland's Alison Cotter, shared their invaluable insights and experiences. The day also included engaging poster sessions and discussions on public and patient involvement (PPI) in MS research. The event underscored the importance of collaboration and the voices of people with MS in shaping future research.

Change to the Information Service email

We're pleased to announce a dedicated email for MS Ireland's Information Service: msinformationservice@ms-society.ie. General enquiries can still be sent to info@ms-society.ie. By using the dedicated email, your important queries will be dealt with faster, as they will no longer be mixed with general emails. This helps us to streamline our service and provide the best support possible.

Over 40 Oireachtas Members Attend MS Ireland's World MS Day Briefing

On 28 May, MS Ireland hosted a well-attended World MS Day Briefing and Panel Discussion in Leinster House, welcoming over 40 Oireachtas members. The event, hosted by Deputy Colm Burke, served as a powerful platform to raise awareness of the lived experience of MS and present two key funding proposals ahead of Budget 2026.

The session featured personal testimonies from people living with MS and insights from service providers, illustrating the urgent need for greater investment in community-based supports.

MS Ireland's Budget 2026 proposals include:

- €1 million to expand specialist physiotherapy services nationally, enabling 9 senior physiotherapists to support over 1,400 people with neurological conditions
- €72,997.56 to fund a Community Worker post in Sligo-Leitrim, the only region without this critical support

Research shows that this physiotherapy model can reduce healthcare service use by over 43%, reduce A&E visits by a third, and improve quality of life across multiple indicators.

MS Ireland extends sincere thanks to all Oireachtas members who attended, and especially to Deputy Colm Burke for hosting. Their presence signals strong political will to support evidence-based investments in neurological care.

'I Have MS' Cards

We are delighted to share that we have updated our 'I have MS' cards, a discreet communication tool for people living with MS. These cards help individuals easily inform others that they may need assistance or access to a toilet. Designed to promote understanding and ease of interaction, the cards are available upon request through MS Ireland. This simple tool helps people living with MS communicate their needs with dignity and reduce misunderstandings in various social situations.

To request a card contact your local MS Ireland office.

Ageing and MS Course

The University of Tasmania's Menzies Institute for Medical Research has launched a free online course titled *Ageing Well with MS*. Designed by the MS Research Flagship in collaboration with the MS community, this course delves into the concept of ageing and how it intersects with multiple sclerosis. Participants will explore practical physical, mental and emotional strategies to support healthy ageing and future planning. Delivered across three self-paced modules (1.5-2 hours each), the course features insights from clinical professionals, researchers and individuals living with MS. A completion certificate is available. Find out more here: ms.mooc.utas.edu.au/i/ageingIE.

MS Ireland's 2025 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 the MS Care Centre, 65 Bushy Park Road, Rathgar, Dublin 6, D06 CV90 or to alicem@ms-society.ie. **The closing date for receipt of nomination forms is Friday, 10th October 2025**.

The annual national awards for 2025 will be presented at the National Conference.

MS in the Workplace

We now offer MS Awareness in the Workplace training for companies. This is an interactive and experiential training session that can be tailored to any group size. If your company would be interested, please contact melaniec@ms-society.ie

Impact of Multiple Sclerosis Symptoms Survey Launch

The *IMSS (Impact of Multiple Sclerosis Symptoms)* is a Europe-wide initiative led by the European Multiple Sclerosis Platform (EMSP), alongside its member patient organisations, aiming to give people living with MS a voice in shaping policies and healthcare services.

The survey captures a wide variety of information aimed at helping to understand the impact of MS symptoms. The survey was launched on the 10th of May 2023 and was open until the end of August 2023. In total, 17,151 people living with MS, from across 22 European countries responded to the survey.

The results of this survey were recently launched at the EMSP Annual Conference 2025, which took place in Prague in May. While it was a Europe-wide project, individual fact sheets for each participating country shared local insight. ***So, what did it tell us about Ireland?***

Characteristics of participants

- **Respondents:** 266 individuals from Ireland participated.
- **Gender Distribution:** 82% were female and 18% male.
- **Type of MS:**
    - 78% have *Relapsing-Remitting MS (RRMS).*
    - 11% live with *Secondary Progressive MS (SPMS).*
    - 7% have *Primary Progressive MS (PPMS).*
    - 5% of respondents were unsure of their type of MS.

Diagnosis

- Over 54% experienced their first symptoms between ages 18-35 years.
- The average age of symptom onset was 30.3 while the average age of diagnosis was 34.5, meaning the average delay in diagnosis was 3.8 years.

Symptoms

As reported by people with MS in Ireland,

- The *most* reported symptoms were **fatigue, cognitive impairment, sensory problems, sleep disturbances,** and **spasticity/ muscle spasms.**
- The *least* reported symptoms were **trouble swallowing, speech difficulties, tremors, hearing problems,** and **arm and hand problems.**
- 100% of respondents experienced at least one symptom.
- The symptoms that were affecting the daily lives of people with MS the most were **fatigue, sleep disturbances, mobility impairment, bladder control problems,** and **anxiety.**
- The symptoms reported to be the *most well managed* included **mobility impairment, trouble swallowing** and **bowel control problems.**
- The symptoms reported to be *least well managed* were **sexual problems, fatigue** and **cognitive impairment.**

Care

- On average, respondents had 4.2 healthcare professionals involved in their care.
- The healthcare providers who were shown to be most involved in people with MS's care were neurologists, GP's and MS nurses.
- 76% of respondents said they do not need caregivers, while 13% felt they need caregivers but unfortunately do not have them and 12% reported they have caregivers.
- Of those who have caregivers, 94% of caregivers are their family, partner or friend and only 10% of caregivers were paid professionals.
- The average number of hours per week that caregivers supported people with MS for is 46.7 hours/week.

Treatment and Medication

- On average, respondents reported a 1.3 year gap between diagnosis and starting on a disease modifying therapy (DMT).
- 90% of respondents have used DMT's.
- 77% currently use DMT's.
- In relation to care of symptoms, 80% of respondents that they access care/treatment for their symptoms.
- People with MS reported using 5.3 treatments or care on average for their symptoms.
- The most used treatments were: **prescription medication, personal life modifications, physical activity,** and **physical therapy.**
- Where people did not access care/treatment for their symptoms, the top reasons were:
    - Having no need.
    - Treatment was not offered to them.
    - They cannot afford the treatment.

Employment and Work

- **Employment Status:**
    - A total of 30% of respondents reported not working due to MS.
    - 44% of respondents were working full-time.
    - 16% report that they are working part-time.

Quality of Life

- The majority of those who responded had no or slight problems affecting their overall quality of life while 5.3% reported experiencing moderate or severe problems affecting their quality of life. This does not negate that many symptoms affect the quality of life of people with MS immensely.

What's next?

Over the coming months, MS Ireland plans to:

- Use the findings to guide conversations with healthcare professionals and policymakers about how services can better support symptom management.
- Share the data with multidisciplinary care teams, especially where gaps in symptom management are evident.
- Support awareness campaigns that highlight less visible symptoms like cognitive difficulties, fatigue, and bladder control issues.
- • Continue gathering feedback from our community on how this data reflects their experiences, and where more research or action is needed.

To read more about the Irish results of the IMSS Survey, scan the QR code or visit

https://emsp.org/wp-content/uploads/2022/12/Ireland_IMSS-Country-Sheet.pdf

Wagging Tails and Open Doors: Life with an Assistance Dog

My name is Edel Carey and I'm from Tipperary. I've recently become a County Champion for Irish Dogs for the Disabled to help promote their wonderful work. In October 2022, I received the incredible gift of an Assistance Dog, Nala, and she has transformed my life ever since!

Nala is my 5-year-old "partner in crime" a beautiful, clever and loyal black Labrador. I was diagnosed with MS thirty years ago when I was in my twenties and between then and now, I have developed some difficulty with my balance and mobility. I walk with crutches and use a power wheelchair when I'm out and about.

I'm 54 now and honestly, I never thought about having an assistance dog until a friend suggested it. At first, I was nervous about the commitment, especially because I was starting a new job that required a lot of travel. But all those worries disappeared as soon as Nala came into my life. Nala is not only my picker-upper, door-opener and door closer - she's a loyal companion who loves nothing more than jumping up to the sound of something hitting the floor. She loves her tasks because she knows there's a treat waiting for her!

On a practical level, Nala has been a game changer for me. If I'm on my crutches and drop something, my balance is too poor to bend down safely but Nala is always there to rescue me. She picks up my phone, purse, shoes, keys, or even a sock. She once picked up a receipt for me in a shop! She'll grab anything that's not too awkward. She doesn't like metal, so I've attached a long rubber keyring to my crutches. As anyone who uses crutches or sticks knows, they're constantly falling to the floor!

Another way Nala helps is by nudging doors open when I'm on my crutches or in my power chair - and even more so by pulling doors shut behind me, since reaching back to close a door is hard for me. I attach a long piece of string to the door that Nala can grab and pull behind her, which is particularly useful for my patio door, as it opens outward.

On a wellbeing note, dogs need attention, love, exercise, and companionship. Nala motivates me to get up in the morning when I feel like staying in bed. She gets me outdoors, even when I don't feel like going for a walk (or roll!). After a long day's work, the couch calls to me, but getting outside with Nala has been amazing for my energy, mood, and overall mental wellbeing. It's a blessing I hadn't really considered when I got her, but she helps keep my mood upbeat and I quickly reached the stage where I couldn't imagine life without her.

I work as a Schools Liaison Officer with the Irish Wheelchair Association and Nala is always ready and waiting for a school visit or a day in the office. She's usually in the car before me, tail wagging with excitement. She loves meeting people and is incredibly sociable, sitting under my desk at work and popping up to say hello to anyone who stops by. She has an amazing welcome for everyone! Nala is also great with my mother, who has mobility issues as well and she replicates her skills with the same love and loyalty.

Nala's favourite things in life are food, treats, walks, zoomies on the lawn and curling up at my feet when we wind down for the night. She's the first thing I see in the morning when she nudges me to get up, melting my heart with her big brown eyes. She truly is the best thing that has happened to me in a long time.

If anyone with MS is considering applying for an assistance dog, I would be more than happy to recommend Irish Dogs for the Disabled and to share my experience. These dogs are highly trained, loved and matched to an applicant's unique needs and personality.

Dogs for the Disabled
Creating Change

Summerlea House, Togher, Cork T12 E264
Telephone +353 21 431 6627
Email info@dogsfordisabled.ie
www.dogsfordisabled.ie

Dogs for the Disabled is a pioneering charity established in 2007 and based in Cork City. We train specially bred dogs to assist disabled adults and children to help them achieve greater independence in their lives. We're driven by our wish for a better world… a world where our partners are not limited by their physical disability but are active members of society.

Disability can often lead to isolation, loss of confidence and feelings of low self-esteem. Not only that, but for many people living with a disability and being unable to do even a simple task like picking up the post or a dropped phone can leave them feeling depressed and dependent.

So since 2007, we have ethically bred and trained Labradors, Golden Retrievers and Standard Poodles to assist with practical, everyday tasks to help a person with a disability to live life to the full, breaking down barriers to the outside world and helping to improve confidence and lower stress levels.

Our Task Assistance Dogs are partnered with both adult and child wheelchair users eg. spinal cord injury, Multiple Sclerosis, Muscular Dystrophy, Cerebral Palsy, Spina Bifida etc. These special dogs are able to help with a range of everyday practical tasks including:

- Opening and closing doors
- Bark to raise the alarm in an emergency
- Retrieve items like a mobile phone, crutch etc
- Pick up dropped articles like keys, bag etc
- Help a person undress eg remove jacket, socks, gloves etc
- Empty washing machine
- Fetch the post
- Switch lights on and off
- Press a pedestrian crossing button

Over the last 18 years we have placed over 400 dogs and currently have over 190 active partnerships all over Ireland. Our dogs generally qualify at 2 years of age and retire at age 10.

We receive no government funding but year on year, through voluntary contributions and philanthropic support, we continue to grow and to create more powerful partnerships.

Each of our life-changing dogs costs €15,000 to produce and we have a very strict policy that no money exchanges hands for our dogs. This ensures we retain legal ownership of each dog throughout their lifetime to guarantee their welfare and care and, most importantly, to ensure that beneficiaries receive their dog based on NEED and not their ability to pay.

We also train Stability Assistance Dogs, Parkinson's Assistance Dogs and work with hospitals and community facilities, where our dogs who do not graduate as Assistance Dogs are trained as Therapy Dogs and Canine Assisted Intervention (CAI) Facility Dogs for patients and service users.

2025 will see Dogs for the Disabled enter into an exciting new phase of expansion to meet the 4-fold increase in demand for our dogs over the last 12-18 months.

We have just purchased a property to create our new permanent National Training Centre and Head Office on the outskirts of Cork City.

The property, on 11 acres, is derelict and requires complete renovation - it is estimated to cost €2 million to complete.

We will be launching our fundraising campaign this month at:

https://dogsfordisabled.ie/

If you are interested in applying for one of our life-changing dogs, just go online to:

https://dogsfordisabled.ie/apply

For further information;
Cathy Matthews
Media & Communications
087 7716355
media@dogsfordisabled.ie
www.dogsfordisabled.ie

Scan to Donate

Registered Charity No. 20067069
Revenue CHY 17821

World MS Day 30th May 2025

worldMSday
30 MAY

On May 30th, World MS Day 2025, MS Ireland led an nationwide effort to bring MS to the forefront of public awareness. From cinema screens to Leinster House, from personal stories to community action, MS Ireland's activities highlighted the diverse experiences of the MS community living in Ireland.

Cinema Campaign

A major highlight of World MS Day 2025 was the launch of a groundbreaking cinema campaign designed to reach audiences across Ireland. Over six weeks, starting on May 30th, viewers can watch a powerful 40-second advertisement which displays images of people living with MS as well as some which help to highlight MS Ireland services.

> "We are thrilled to launch this campaign"

said Aoife Kirwan, MS Ireland's Information Officer who led on this project.

> "It is an opportunity for us to help raise awareness of MS amongst the general population in an engaging and innovative way. To have the ad run in over 80 cinemas across the country for this six week period offers us an opportunity to reach the general public at a level that is unprecidented for our organisation."

The initiative was made possible through the generous sponsorship of Novartis Ireland, who kindly funded the campaign without any input into the content or design. Our sincere thanks to all who participated in this campaign.

The "Living with MS" Podcast

On World MS Day, MS Ireland launched "Living with MS", a podcast series. Often referred to as a "snowflake illness" because no two people experience it the same way, MS presents unique challenges to each person affected by it. This podcast delved into that reality by sharing episodes that capture individual journeys, highlighting the many ways MS impacts lives.

The first episode, featuring Shirley Keane O'Brien, was released on World MS Day itself. Through candid conversations, the series aims to explore each guest's personal path.

By sharing these stories, the podcast can help to enhance understanding of MS and foster a sense of community and support for listeners navigating their own experiences with the condition.

World MS Day Briefing at Leinster House

On May 28th, MS Ireland hosted a powerful World MS Day Briefing and Panel Discussion in the AV Room of Leinster House. The event, hosted by Deputy Colm Burke, drew the attendance of over 40 members of the Oireachtas, demonstrating a strong commitment to understanding and addressing the challenges faced by people with MS in Ireland.

The briefing featured a moving testimony from Louise Power, who courageously shared the realities of her condition and the impact the diagnosis has had on her life.

> “World MS Day is a reminder of the importance of listening to the MS community,”

said Alison Cotter, Advocacy Officer at MS Ireland.

> “The attendance of over 40 Oireachtas members showed a genuine commitment to understanding and addressing the challenges faced by people with MS.”

MS Ireland extended heartfelt thanks to Deputy Colm Burke for hosting the event and to all the Oireachtas members who joined. Their presence and engagement sent a clear signal that the voices of the MS community are being heard.

Regional Events & Iconic Illuminations

Beyond these projects, World MS Day 2025 was marked by a rich tapestry of Regional events and community-led activities. Local events throughout the country brought people together, from informative webinars and poster-making sessions to social gatherings that celebrated the MS community. Iconic buildings and heritage sites across Ireland were illuminated in MS Ireland’s signature colours, a striking visual symbol of unity and recognition that lit up the night sky in towns and cities nationwide.

These collective efforts reflected a great sense of community and solidarity on World MS Day.

Dip for Diagnosis

People across Ireland took part in “Dip for Diagnosis,” a nationwide initiative that invited the public to take a quick dip in the sea, a lake, a pool, or even a cold shower, to represent the over 10,000 people living with MS in Ireland. Whether it was a group sea swim at dawn, a solo river plunge or a refreshing cold shower at home, participants took the plunge to raise funds and awareness to support the MS community.

Mater Hospital marks World MS Day

On May 30th, Mater Hospital staff held an MS Awareness Day to mark World MS Day. They shared information about multiple sclerosis and the work of MS Ireland, engaging with the hospital community to raise awareness and promote understanding of this condition.

Looking Forward: Carrying the Momentum Beyond World MS Day

As World MS Day 2025 came to a close, the momentum generated by these initiatives continued to ripple outward. The conversations sparked, the stories shared, and the solidarity demonstrated have all served as reminders that while MS is unique to each individual, a supportive and informed community can make all the difference.

Multiple Sclerosis Society of Ireland

Pre-Budget Submission 2026

Summary of key asks for Budget 2026

- Sustainable funding for national physiotherapy services for people with Multiple Sclerosis, and other neurological conditions totalling €1 million per annum.
- Establishing a Community Worker Post for Sligo-Leitrim totalling €72,997.56 per annum.

Sustainable funding for national physiotherapy services for people with Multiple Sclerosis, and other neurological conditions

MS Ireland is seeking funding from the 2026 National Service Plan for a programme to directly employ 9 senior physiotherapists nationally to enable 1,458 people living with Multiple Sclerosis and other neurological conditions to receive group physiotherapy programmes and to deliver 3,726 individual appointments per annum. The funding of this programme would provide much needed specialist services at a local level providing an egress point from the Community Neuro Rehab Teams (CNRT) in the post rehab phase, and providing a service for those who do not meet the criteria for CNRT referral or who can't access primary care services. The programme will cost **€1 million per annum** to run nationally and will support the HSE in reducing the burden on primary care waiting lists, avoid A&E and OPD pinch points and prevent disability and comorbidities.

Extensive research has shown the effectiveness of this service in reducing symptom severity, disability, falls and healthcare utilisation.

MS Ireland has consistently demonstrated the organisational capacity to run these programmes on budget, on time and exceeding output and outcomes targets and has the appropriate clinical and organisational governance systems in place. This specialist physiotherapy team will leverage the extensive experience, knowledge, systems and governance that are already in place and ready to expand.

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

Reduction in usage of healthcare services of participants 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).*

Delaying and reducing disability due to MS could reduce costs to the Irish health system annually by up to €19m.

Establishing a Community Worker Post for Sligo-Leitrim

MS Ireland is seeking an additional investment of **€72,997.56** in 2025 to fund a Community Worker post in Sligo-Leitrim, ensuring the provision of casework services to people with Multiple Sclerosis (PwMS) in the region.

At present, MS Ireland currently provides a Community Work service in all counties in the Republic of Ireland, except for Sligo and Leitrim. The absence of a dedicated worker in Sligo-Leitrim leaves PwMS in the region without structured, ongoing support.

The Community Worker Will Provide:

Comprehensive casework support for PwMS and their families, from diagnosis through disease progression.

Improved access to early intervention services, which are proven to yield better outcomes for PwMS.

Reduced pressure on Case Managers, Occupational Therapists, and Social Workers by taking on tasks more suited to a Community Worker.

Stronger collaboration with HSE and statutory services, in line with Sláintecare's vision of integrated, accessible, locally delivered services.

Enhanced visibility and impact of MS Ireland's services in the Northwest Region.

The Community Worker will provide tailored support in symptom management, employment, housing, education, and emotional well-being, as well as advocacy and referrals to essential services. They will ensure PwMS and their families receive holistic, goal-oriented support.

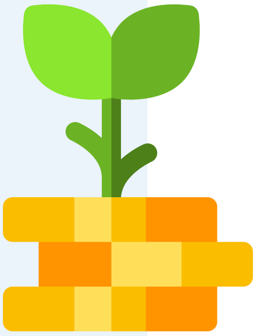
Impact of the Community Worker Role:

- Direct casework and referrals for PwMS in Sligo-Leitrim
- Support for PwMS and their families through advocacy, education, and practical assistance
- Reduction in pressure on other healthcare professionals
- Integration with HSE services to ensure a coordinated approach

This investment aligns with Sláintecare's objective of providing the right care in the right place at the right time. The estimated cost for this post, including salary and overheads, is **€72,997.56** per annum.

By funding this additional post, MS Ireland will ensure that PwMS in Sligo-Leitrim receive the same level of care as those in Donegal, significantly improving their quality of life and health outcomes.

MS Ireland echoes the asks of the Neurological Alliance of Ireland (NAI), the Disability Federation of Ireland (DFI), and Family Carers Ireland in advocating for increased support for neurological conditions in Ireland.



Charity Number: 05365 | CRA Number: 20007867

The Nuts and Bolts of it ...
We Need Your Help to Renew

MS Ireland would like to tell you about Renew MS Ireland - an important project that will allow us to expand and improve the services we provide to people living with Multiple Sclerosis across the country.

At MS Ireland, we are committed to ensuring that everyone living with MS has access to the care, resources, and community they need. However, to meet the growing demand for specialised support, we need your help.
Renew MS Ireland will allow us to build and renovate essential spaces, including:

A modernised MS Care Centre in Dublin

Large-scale renovations and refits are necessary to enhance our ability to provide high-quality care and support to the MS community nationwide. Since the late 1980s, the 12-bed respite facility has been a cornerstone of our services, offering respite and rehabilitation for thousands of people living with MS and other neurological conditions across Ireland.

A new Resource Centre in Limerick

Serving Limerick and the Midwest region, featuring a fully accessible gym, physiotherapy-led exercise sessions, and symptom management programmes.

Yes, I want to help Renew MS Ireland! Here's my gift of:

☐ **€35** may go towards upgrading our nurse call access system in the MS Care Centre

☐ **€65** may fund crucial renovations in our MS Care Centre, such as the upgrade to double-glazed windows, for enhanced comfort and well-being of our respite users

☐ **€125** may fund the installation of a fully equipped accessible gym in our new Limerick Resource Hub

☐ **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 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: 65-67 Bushy Park Road,
Dublin 6, D06 CV90
Email: fundraising@ms-society.ie

Registered Charity No. 20007867 | Charity Number: CHY 5365

Your support can make a tangible difference.

By making a general donation or sponsoring a specific item, ranging from physiotherapy equipment to accessible fittings, you will be directly contributing to life-enhancing services for people living with MS.


Rehab Treadmill


Aerobics / Physio Room


Nursecall Access


Kitchen

You can find out more about this initiative or make a donation today at **www.renewmsireland.ie**

Every donation brings us closer to making these essential services a reality.

Whether you can contribute €10, €50, or €500, your generosity will have a direct impact on improving the quality of life for people living with MS. Together, we can build a stronger, more inclusive future for the MS community in Ireland. Thank you for being a part of this journey with us.

With gratitude,

Ava Battles

Ava Battles
CEO, MS Ireland

☑ **Yes! I want to make a durable impact.**
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?

Signature: ____________________ Date: ____________

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 witin 8 weeks starting from the date in which your account is debited. Yor rights are explained in a statement you can obtain from your bank.

Creditor:
MS Ireland

Credit Identifier:
IE4ZZZ303335

Creditor Address:
65-67 Bushy Park
Road, Dublin 6,
D06 CV90

To make an instant donation call **01 678 1600** or visit **www.ms-society.ie**

Reflections on the 2025 EMSP Conference:

Collaboration, Inclusion and a Vision for the Future of MS Care

By Aoife Kirwan

The 2025 EMSP Conference in Prague brought together a diverse community of people living with MS, researchers, clinicians, and advocates. Across the sessions and poster displays, a few key themes stood out: the importance of trust and inclusion in research, the power of patient engagement, and the hope that future advances will lead to more personalised, equitable, and holistic MS care.

One of the most impactful sessions focused on fostering community, diversity, and inclusivity in research. It was a powerful reminder that trust in research, particularly among Black and other underrepresented communities, has been damaged in the past and that earning it back requires openness, honesty and concrete policies to reduce harm. Community engagement cannot be tokenistic. It must be built from the ground up, in partnership with grassroots organisations and shaped by the lived experiences of people living with MS.

Andrea Sennett spoke about how under-representation of Black and minority ethnic communities in MS research has led to data that doesn't fully reflect the realities of living with MS in those communities. She noted that in Jamaica, only 6% of participants in disease-modifying therapy trials, and 9% in neurorehabilitation, were non-white. It's a stark reminder that the data driving clinical decisions and policy can be incomplete and that inclusive research isn't just about fairness; it's about producing accurate, relevant, and actionable evidence.

A talk by Natalie Busari explored her MS diagnosis, adjusting to life with this new reality and the UK-based organisation she founded. "The Nerve of My Multiple Sclerosis" aims to build a supportive community of black individuals living with MS, combatting cultural stigmas by normalising difficult conversations about MS within the black community.

Professor Eva Havrdova presented on the topic of prevention in MS. The research she discussed spanned decades and outlined some practical strategies that act as powerful tools in preventing MS progression. These included smoking cessation, vitamin D supplementation and regular exercise.

Sessions also explored how to remove barriers in research, like offering translation services and culturally sensitive approaches to recruitment and highlighted the role of patient involvement (PPI) in making research and care more responsive. A key point was that inclusion and engagement should not be seen as optional or supplementary. They are fundamental to good research and better outcomes.

In another engaging session, speakers including Anne Helme, Juan Acosta and Pascal Rufi shared their visions for the future of MS prevention and management. From more accurate and prompt diagnosis to the promise of treatments that address both inflammation and neurodegeneration, the outlook was cautiously optimistic! AI and digital biomarkers were discussed as potential tools to bridge the gap between lived experience and clinical measures like MRI, offering new ways to track disease progression and tailor care.

One powerful takeaway was the need for information. Accessible, up-to-date information that empowers people living with MS to have meaningful conversations with their healthcare providers. As Anne put it, knowledge is a foundation for self-advocacy and better outcomes.

The poster displays also offered a rich glimpse into the lived experiences of people with MS and the challenges they face. Studies showed that older people with MS are often less active than their healthy peers and that innovative approaches like tele-rehabilitation or even traditional dance can offer real benefits. Posters explored everything from sleep disorders and sexual dysfunction to the hidden financial and emotional costs of MS. Across all of these, there was a shared understanding that care must be shaped by the full range of patient experiences because MS does not respect borders or barriers.

As I reflect on the conference, I am struck by the depth and honesty of these conversations. They highlight both the challenges we face and the opportunities we have to create a more inclusive, equitable, and person-centred approach to MS care. And while technology and science continue to advance, it is the trust, collaboration and respect that we build along the way that will make the greatest difference.

Celebrating Our Volunteers during National Volunteering Week (19-25th May)

At MS Ireland, volunteers are more than just supporters — they're the heart and soul of what we do. Whether it's lending a hand at local events, providing a listening ear, organising fundraisers, or helping run our branches, our volunteers are at the centre of everything we stand for: community, compassion, and connection.

Every day, across the country, volunteers are quietly making a big difference in the lives of people living with MS. The work of our 27 branches, in the Care Centre, on committees with the fundraising team and across our services. Their kindness, energy, and commitment shape the services we offer and the sense of community we're so proud of.

In 2024 we commissioned a survey with our volunteers. This was supported by the All Ireland MS Research Network, Maynooth University, conducted by Linda McDonald and supervised by Assistant Professor of Psychology, Dr. Rebecca Maguire. The results revealed that most of our volunteers are over 35, with 65% living with MS themselves. Volunteers, many of whom have served for over a decade, contribute in diverse roles such as fundraising, branch activities, and advocacy. The primary motivation was to "help others," with high levels of satisfaction reported, especially in relation to values, learning, and social connection. Most felt their work positively impacts people with MS—especially through fundraising, peer support, and community events. While experiences were largely positive, volunteers highlighted areas for improvement, including stronger support, better communication between branches and head office, and greater recognition of their efforts. Encouragingly, the majority plan to continue volunteering into the future.

In response to feedback from the survey a brand-new Volunteering Handbook has been devised. This is a practical and welcoming guide designed for both new and long-time volunteers. It includes everything from expectations of volunteers, to safeguarding, health and safety and how people can go about making an application to volunteer. It's part of our ongoing commitment to make volunteering with MS Ireland as positive and supported an experience as possible.

To capture just a slice of what volunteering in MS Ireland looks like in real life, we recently recorded a special episode about volunteering for our MS Ireland podcast channel. In it, a few of our amazing volunteers shared what inspired them to get involved, their motivation, the challenges along the way, and deep personal rewards they experience. Hearing their stories was a reminder of the impact volunteers have and the reward they derive from their involvement. If you haven't had a chance to tune in, it's well worth a listen!

A sincere thank you to everyone who gives their time to MS Ireland. Your support helps us do more for the MS community every day. Whether you're offering a helping hand, sharing your expertise, or simply showing up — your contribution matters, and we truly value it.

Intimacy and MS

The names in this article have been changed to protect the writer's anonymity as she opens up about something incredibly private and deeply personal. At 27, Caroline courageously shares her experience of navigating sexual challenges after being diagnosed with MS. Her story offers an honest, vulnerable glimpse into the impact of MS on intimacy and how it shapes her self-image and relationship. In sharing her experience, Caroline hopes that others living with MS who may be facing similar challenges, might feel a little less alone.

My memory of the day I was diagnosed is patchy. I remember aspects of it in minute detail while I struggle with some of the parts I probably should remember. I had gone to my optician for what I thought was a routine appointment. I have worn glasses since I was in primary school so thought nothing of the visit, even though I had noticed a deterioration in my left eye. My optician recommended I be seen by a specialist and long story short, after some investigations, I was told I had MS.

My jaw was on the floor and my heart was broken in pieces. People my age don't get MS, do they? I was 24 with my whole life ahead of me. This diagnosis was not part of my plans. I told my family and my close friends about the diagnosis and moved forward, trying to keep life as normal as I could.

I succeeded with that, most of the time! I have not had many symptoms since my diagnosis. I do get fatigue but otherwise I am doing okay.

I met my boyfriend about 2 months after my diagnosis. It was a weird time for me. At first, I didn't tell him about my MS because I thought he would lose interest. I needed to understand him better as a person before sharing this with him and soon enough, I did. He was so supportive and said it didn't matter to him. He has been amazing about it all. We moved in together about 3 months ago. We had hoped to do it sooner but the Irish rental market is nuts and we didn't want to move in together into one of our family homes.

Getting our own place was such a great step and we are still so delighted to have our lovely home together. There is just one thing that is getting in the way and that is my recently acquired lack of sex drive. Fatigue is a huge part of my MS and some days I just want to collapse on the couch and not move at all. Although my boyfriend is really supportive, I feel like I am letting him down. I know that feeling is all me and he couldn't be better about it all, I am the one judging myself.

It's like I'm stuck in this loop of no desire because I'm stressed, and then stressed because I have no desire. The truth is, I feel ashamed. I feel like I'm supposed to be in my prime. Everyone thinks that when you're young and in love, moving in together just unlocks this perfect, passionate phase. But here I am, feeling too tired and too… well, unsexy.

I have tried to talk to my friends about it but they don't really get it. They all think moving in together means constant fireworks and can't really understand why I'm struggling. I know I'm not alone but it still feels like it sometimes. It's not a topic I want to bring up with my family either because… well, it's a bit awkward!

I am linked in with support and therapy and this has been good. I do feel I am making progress but I just feel that this topic is under discussed. I hope that with support from my boyfriend, doctor and therapist, things will be on the up soon.

While I am not brave enough to share my identity, I am proud that I am brave enough to share my experience. I think that maybe many other people with MS go through this too but we just don't talk about it. But at least now, if you're reading this and you have issues like mine, you know that it's not just you.

Understanding Generic, Biosimilar and Hybrid Medicines

For people living with MS in Ireland, medicines are often an important part of managing the condition. In recent years, there has been a gradual increase in the use of generic, biosimilar, and hybrid medicines across the health service. But what do these terms actually mean, and what should you expect if your treatment is switched to one of these alternatives?

What Are These Medicines?

Generic Medicines

A generic medicine is a version of a branded drug that has the same active ingredient, which means that the part that treats MS works in the same way and is just as effective. These medicines are approved by the Health Products Regulatory Authority (HPRA) once they meet the same safety, quality and effectiveness standards as the original. So while it might have a different brand name or the look of the packaging or drug may be different, the way they work in the body is the same.

Biosimilar Medicine

Biosimilars are used for more complex medicines made from living cells, like some MS treatments. A biosimilar is a “highly similar” version of an existing biological medicine (called a reference drug). Because they are made using natural processes, exact copies are not possible. These medicines have large, 3D structures and can vary slightly, even between batches of the original brand. In fact, a biosimilar is about as close to its reference product as one batch of an antibiotic is to another and both are equally effective and safe. Biosimilars go through strict testing to prove they work in the same way as the original. They are approved by either the HPRA or the European Medicines Agency (EMA) after detailed review.

Hybrid Medicines

A hybrid medicine is based on an existing drug but includes a small change — for example, it might come in a different strength or form, such as a tablet instead of an injection. These changes mean extra checks are needed, but they can sometimes offer more convenient options for people depending on their individual needs.

What Should You Expect If You Switch?

If your healthcare team recommends switching your treatment to a generic, biosimilar, or hybrid medicine, you might notice a few practical differences:

Effectiveness: The new medicine should work in the same way and be just as effective.
Appearance: It might look different, such as a change in colour, shape, or packaging but this does not affect how it works.

How It’s Taken: The device or method used to take the medicine (like an auto-injector) might be different, and instructions could vary slightly.

Support Services: Some medicines come with extra supports, like patient support programmes or home delivery. These may change or no longer be available with the new medicine. If you’re unsure what to expect, ask your healthcare provider.

Your Healthcare Team: You should be informed and supported throughout any change in your treatment. Don’t hesitate to raise any concerns with your neurologist, MS nurse, GP or pharmacist.

What is the benefit?

Generic, biosimilar and hybrid medicines often cost less than original branded versions. This helps reduce pressure on the health service. In Ireland, it’s estimated that using these alternatives has saved over €1.6 billion since 2013. These savings could be reinvested into other areas of healthcare to improve services.

Being asked to switch to a different version of a medicine can naturally raise questions or concerns. It can be reassuring to know that these medicines go through thorough checks for safety, quality, and effectiveness. If your treatment is changing, remember that your healthcare team is there to support you and you should ask them any questions you might need to. Open conversations can help ensure the transition is as smooth, comfortable and well informed as possible.

If you have any concerns or unexpected side effects or new neurological symptoms after a transition to a new drug, your MS team should be contacted immediately.

For more information, visit www.hpra.ie

South Dublin Branch

Branch Person of the Year Aislinn O'Moore Cunningham with flowers, pictured with outgoing Secretary Clíona.

Volunteer of the Year Goolam Bhamjee pictured next to his wife Anne and Mary McKeon.

Special Persons Joe and Breda Flood. Breda is a Branch Committee member. They are pictured with outgoing Chair Gerry Quinlan.

Our incoming Chair is Brian Blake, Secretary Laura Strong, Treasurer Mary McKeon.

We have a full programme of events planned for this year, details on our Facebook page, with a major gala concert proposed for October. **Watch this space!**

Limerick Branch

Noreen O'Shea (our assistant Treasurer) ably representing our MS Limerick Branch at the launch of the **Annual 7 Bridges Walk**.

Noreen O'Shea proud as punch after finishing the **7 Bridges Walk in Limerick City**.
Funds raised will go to the Limerick Branch.

Tipperary North Branch

The Tipperary North Branch had great fun at their recent coffee morning.

26th Annual General Meeting

(65th AGM since MS Ireland's foundation)

Date for the AGM – 27th September 2025 at 2.00 p.m.

Dear Member,

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 Saturday, 27th September 2025 at 2.00 p.m. Venue to be announced nearer the date.

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 the:

MS Care Centre,
65 Bushy Park Road,
Rathgar, Dublin 6

before 2.00 p.m. on 25th September 2025.

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 22nd August 2025.

UPCOMING EVENTS

Dublin City Marathon

If you have a place in the Dublin City Marathon and you would like to join Team MS Ireland – please contact melaniec@ms-society.ie for a fundraising pack.

Abseil

We have an exciting new location in the Burren to Abseil as well as Dalkey Quarry – if you are interested in either of these please contact melaniec@ms-society.ie

Skydive

If you are interested in doing a skydive to support MS Ireland, 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.

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

THANK YOU

We had an amazing group of runners in the Dublin Marathon who raised over €60,000! This is one of our most successful events of the year – if you have a place and would like to fundraise please contact melaniec@ms-society.ie

MS Ireland Receives €2,500 from Inspirational Fundraisers

We were thrilled to receive a generous €2,500 donation from Ciaran Delaney and Annette O'Neill, who completed a 100km fundraising walk last July. The cheque was presented to Caitriona Hughes at Round Tower GAA Club, Clondalkin.

Ciaran's personal connection to MS inspired this initiative. Caitriona said, "We're incredibly grateful to Ciaran, Annette, and their supporters for raising vital funds and awareness."

Photo credit: Tommy Keogh

Exceptional Fundraisers

Our exceptional fundraiser are: Derek Grogan who, with his partner, Emer, walked the Camino and raised over €9,000;

Anne Marie Harrington walked the Camino and organised an event raising over €9,000;
Sean Keane – who with his team cycled from Dublin to Crossmolina over a weekend and raised €8,500.

Other amazing support came from: Specific gym.

Louise and Michelle Cannon, who raised €14,000.

The Irish Villains who raised €11,000

Mick Fogarty, The Flanagan sisters who raised €10,000. Catherine Hayes, Leonie Patterson and the Wednesday Hot Shots.

Corporate Partners

Huge thanks to our **Charity Partner of the Year** Aurivo - Homeland Stores – who ran a variety of different events and joined in some MS Ireland events to raise a whopping €40,000.

The Access Foundation kindly sponsored our very successful Miesta Fiesta event – if you know of an organisation who would like to sponsor this event in the future please contact melaniec@ms-society.ie

ACCA – held their annual Christmas event in aid of MS Ireland – this was a spectacular event at the intercontinental. The raffle and auction raised over €15,000

Windward management – charity golf day and walk – this event raised over €40,000

UNLEASH THE UNREAL

2025

NOVEMBER

MS Readathon Ireland

READ STORIES. CHANGE LIVES.

REGISTER NOW AT MSREADATHON.IE

Scan here for
more info and
to register

MSIreland
THE MULTIPLE SCLEROSIS SOCIETY OF IRELAND
RCN: 20007867