ms international federation

ANNUAL HIGHLIGHTS

2025

TOGETHER WE'RE STRONGER THAN MS

A YEAR OF PROGRESS AND PURPOSE

My first year as Chief Executive of MSIF has been a year of listening and learning. I am sincerely grateful to our Chair, Mario Alberto Battaglia, as well as the Board, the Secretariat, and all our members for the warm welcome I received. It meant so much to meet many of you in person and online at the Global Networking Meetings in October.

This past year has shown what is possible when we work together. We strengthened scientific understanding, widened access to care, and built deeper connections across our global network. Our shared voice helped drive progress around the world, from new data on childhood and progressive MS to joint global action on diagnosis, essential medicines, and medical imaging.

We saw advocacy wins, growing organisational strength, shared learning, and a World MS Day that reached further than ever before. Our fundraising community stretched far, generating vital support for both national and global work.

There is still much to do in 2026. I look forward to continuing this work with you, building on what we have achieved, and carrying the global MS cause forward together.

Lydia Makaroff
CEO

AIM I

Improved scientific understanding to prevent, treat and stop MS

MSIF rallies the global community to advance research into preventing, treating and stopping MS. We work to increase the meaningful participation of people affected by MS throughout the research and development process. Learn more about the international action MSIF has taken with MS organisations this year, to support the MS research environment.

Estimating the global prevalence of pediatric MS

The Atlas of MS has collected pediatric MS data since 2013. In 2025, contributed to a new analysis in the Journal of Neurology, Neurosurgery & Psychiatry, which estimates that over 31,000 children and adolescents live with MS worldwide – around 1.49 cases per 100,000 children.

The study highlights that pediatric MS is rare but likely underdiagnosed, especially in lower-resource settings where access to MS specialists and diagnostic tools is limited.

> *Understanding the global prevalence of pediatric MS is critical for improving early diagnosis and treatment. This research emphasises the need for international collaboration to ensure children and adolescents everywhere have access to the care they need.*
>
> **Professor Brenda Banwell, Chair of MSIF's International Medical and Scientific Board.**

People with MS publish their perspective on the use of AI and patient data

Members of the of the Global Patient Reported Outcomes for MS (PROMS) initiative, including people with MS, co-wrote a paper describing the potential healthcare benefits from using AI in MS research and the clinic.

> *The PROMS Initiative will help ensure that people with MS have space to raise ethical questions in relation to the growing use of AI as it applies to large, patient-reported datasets. We will work closely with other members of this multi-stakeholder initiative to consider the impact of any recommendations on all aspects of the life of a person with MS.*
> **Helga Weiland, co-author, South Africa.**

The global reach of the International Progressive MS Alliance

The International Progressive MS Alliance is a global partnership of MS organisations, scientists, people with MS, philanthropies and industry partners working to speed the development of effective treatments for progressive multiple sclerosis. The 19 MS organisations contributing to the Alliance are listed on the website.

In 2025, the Alliance unveiled the MS Clinical and Imaging Data Resource (CIDR).

Developed with McGill University and industry partners Biogen, Novartis, Roche and Sanofi, CIDR includes 72,000 MRI scans and data from 200,000 clinical visits from 13,500 people with MS. This resource will accelerate understanding of MS progression and speed up clinical trials for progressive MS.

Building on the previous years, the International Progressive MS Alliance organised three live webcasts. Over 760 people from 56 countries registered to watch the webcasts in 2025.

Supporting the global implementation of the updated McDonald diagnostic criteria

In 2025, MSIF and its member organisations played a central role in translating the updated McDonald diagnostic criteria into clear, public-facing content for people with MS and non-specialist health professionals.

The updated criteria refine how MRI, clinical evidence and biomarkers are used together to enable earlier and more confident diagnosis of MS, including in people with less typical presentations.

At the Global Networking Meetings in London, MSIF members shared practical solutions to enabling earlier MS diagnosis across different health systems, and discussed what they planned to do to support the dissemination and implementation of the updated McDonald criteria. Through this work, MSIF has positioned itself as a bridge between diagnostic science and national MS organisations, supporting earlier diagnosis as a foundation for timely treatment and better outcomes.

The MS movement in action at ECTRIMS

In September, MSIF joined 9,500 participants at ECTRIMS in Barcelona, the world's largest MS conference.

MSIF kicked off the week with a networking event for members including Österreichische Multiple Sklerose Gesellschaft (Austria), Associação Brasileira de Esclerose Múltipla (Brazil), Multiple Sclerosis New Zealand and Esclerosis Múltiple Uruguay (Uruguay). Later in the week, we partnered with the National MS Society (USA) to launch a new networking group, enabling MS organisations to share innovative approaches to rehabilitation, psychological support and digital services.

The Atlas of MS featured prominently, with Professor Andrew Solomon presenting new data on access to diagnostic tests from 122 countries.

This year, the Patient Community Day was supported by 41 organisations, including MSIF and many of its members including MS Australia, the MS Society (UK), MS Ireland, MS Canada, the National MS Society (USA), Associazione Italiana Sclerosi Multipla (Italy), Esclerosis Múltiple España (Spain), Polskie Towarzystwo Stwardnienia Rozsianego (Poland), the Deutsche Multiple Sklerose Gesellschaft (Germany), France Sclérose en Plaques (France), Stichting MS Research (Netherlands), Multiple Sclerosis New Zealand, and Multiple Sclerosis South Africa.

The event included a panel of people with lived experience, who were invited to talk about the importance of patient engagement in MS research. **Eduard Pletea, President of Asociația Pacienților cu Afecțiuni Neurodegenerative (Romania)**, delivered a powerful message:

> *Research about us should never be done without us… Invite us in from the very beginning.*

Professor Ludwig Kappos wins the MS Charcot Award

Professor Ludwig Kappos, internationally renowned neurologist and one of the most influential figures in modern MS research, was the recipient of the 2025 MSIF Charcot Award.
This prestigious award, for a lifetime of exceptional achievement in MS research, honours Professor Kappos' decades-long leadership, which has helped redefine the landscape of MS diagnosis, treatment, and patient care globally. Upon receiving the award **Professor Kappos said**

> *I feel extremely grateful and honoured – well knowing that this award is deserved by my colleagues in the team here in Basel and the many excellent clinicians, scientists and dear friends with whom I had the privilege to work in international projects.*


The Charcot Award
Professor Ludwig Kappos
ms

AIM 2

Greater access to effective healthcare, information and support

Improving access to MS healthcare, information and support is a key goal for MSIF and our members across the globe. MSIF brings organisations together to share resources and improve access to clear and trustworthy information. We support national and international advocacy to improve early access to effective, safe and affordable DMTs for people with MS around the world. Together we advocate for improved access to early diagnosis, treatment and care. Learn more about MSIF's work towards this strategic aim this year.

MSIF at the United Nations High-Level Meeting

In September, Paola Zaratin, Director of Scientific Research at Associazione Italiana Sclerosi Multipla (Italy), represented MSIF at side meetings during the United Nations High-Level Meeting on non-communicable diseases in New York.

Her engagement with key stakeholders supported MSIF's advocacy to ensure neurological conditions are included in the 2025 UN Political Declaration on Non-Communicable Diseases, and that MS remains visible on the global health agenda.

The final declaration, adopted during the UN High Level Meeting, makes reference to brain health and neurological conditions – a significant achievement for the neurological community, including MS.

Advocating for MS at the World Health Assembly

In May 2025, MSIF's Head of Communications, Campaigns and Advocacy, Abdel Ibrahim, attended the World Health Assembly (WHA) in Geneva, the decision-making body of the World Health Organization (WHO).

MSIF participated to ensure MS and other neurological conditions are recognised, prioritised and better resourced. Inclusion in the 2025 Political Declaration on Noncommunicable Diseases (NCDs) would create a global mandate for governments to improve care, diagnosis and support.

MSIF issued joint statements with the Non-Communicable Disease Alliance and the International Alliance of Patients' Organisations, and acted as a neurological coalition convenor as well as a voice for MS. MSIF led a statement, supported by seven international NGOs, urging WHO Member States to include neurological conditions in the 2025 UN High-Level Meeting declaration. Abdel Ibrahim delivered the statement at the UN Palais.

A major outcome was the adoption of a resolution to strengthen medical imaging capacity – explicitly mentioning MS. This is a critical step towards improving access to diagnostic tools such as MRI worldwide. MSIF also co-signed statements with the International Society of Radiology and the World Federation of Nuclear Medicine and Biology, in support of this resolution.

New recommendations support advocacy for improved access to MS treatments

MSIF and our collaborators have been working hard to publish the rigorous evidence and decision-making behind the WHO Essential Medicines List (EML) application, ensuring that all recommendations are made available for national level advocacy. The first paper was published in the Multiple Sclerosis Journal at the start of 2025, describing which DMTs for MS should be available, at a minimum, in low-resource settings. The second paper published in Multiple Sclerosis and Related Disorders focused on the use of rituximab in low-resource settings. Rituximab is the most widely used off-label treatment for MS globally and was one of the MS treatments that was added to the WHO EML in 2023.

From global listing to local impact: Improving access to MS treatments

The inclusion of MS treatments on the WHO Essential Medicines List in 2023 is already driving real-world change. Access to MS treatments in Nepal was previously very limited, but thanks to the MS Society of Nepal's advocacy, rituximab is now subsidised under the national insurance scheme. In Abu Dhabi, United Arab Emirates (UAE), the Department of Health used guidelines developed by the National MS Society UAE to develop its own MS Management Guidelines, including a policy on the off-label use of rituximab.

> *These new guidelines help address some of the access challenges people with MS have faced in the past, particularly around insurance approvals. They're a step toward ensuring broader availability of high-efficacy, cost-effective treatments.*
>
> **Yasmin Mitwally, Research and Advocacy Manager, NMSS UAE**

MSIF's global wellness resource

MSIF launched the **Wellness practices and complementary therapies for MS** guide in 2025. This resource provides balanced, evidence-based information on wellness practices and complementary therapies.

MSIF members are making this guide accessible to more people. Thanks to efforts of Associação Brasileira de Esclerose Múltipla (Brazil), Stichting MS Research (Netherlands), Vlaamse MS Liga (Belgium), Ligue Nationale Belge de la Sclérose en Plaques (Belgium), and Esclerosis Múltiple Uruguay (Uruguay), the guide is now available in Dutch, French, Portuguese, Spanish and Arabic.

Translations are also underway in Czech, Danish, and Macedonian. Many organisations have added the guide to their website, helping it to reach more people with MS and healthcare professionals.

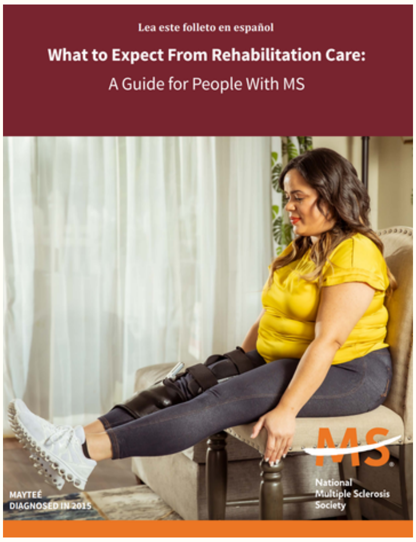
Wellness practices and complementary therapies in MS

Download our new guide now!

Rehabilitation care booklet

MSIF worked with our member in the USA, the National MS Society, to share their comprehensive booklet **'What to Expect From Rehabilitation Care: A Guide for People With MS'.**

The guide is currently available in English and Spanish, and translation in Hindi & Marathi is underway by the MS Society of India.



Lea este folleto en español

What to Expect From Rehabilitation Care:

A Guide for People With MS

MAYTEÉ
DIAGNOSED IN 2015

National
Multiple Sclerosis
Society

AIM 3

A stronger, broader, global MS movement

Building a stronger, broader global MS movement is at the heart of our work. We bring MS organisations together to build solidarity and engagement in the MSIF movement, strengthen MS organisations to address challenges faced by people affected by MS, and grow and deepen collaborations to better address global MS challenges. Learn more about MSIF's work towards this strategic aim this year.

MSIF CEO's engagement across the movement

Over the past twelve months, MSIF's CEO, Lydia Makaraoff, dedicated significant time to engaging with and listening to our members. She held 29 one-on-one meetings (both online and face-to-face) with MSIF member organisations, where members shared their challenges, successes, and aspirations.

Lydia also visited members in Italy, Belgium, Ireland, the UK, the Netherlands, Australia, and New Zealand, and met many more during the Progressive MS Alliance, ECTRIMS, and MSIF's Global Networking Meetings in Philadelphia, Barcelona, and London respectively.

During her visits, Lydia spoke with people coordinating services for thousands of individuals affected by MS with minimal staff, and with others just starting out in countries where MS remains misunderstood.

Lydia reflects on her engagement with members and the wider movement:

> *Each conversation has made me stop and reflect on what kind of support from MSIF makes a difference, and how MSIF can show up in a way that matches what people really need.*

MSIF welcomes new members from Honduras and Argentina

This October, during MSIF's Global Networking Meetings in London, the MSIF Board welcomed two new Associate members from Latin America, the Honduran Fundacion de Esclerosis Múltiple Amor (MS Love Foundation – FEMA) and the Asociación de Lucha Contra la Esclerosis Múltiple (Association for the Fight Against MS – ALCEM) in Argentina, bringing the total number of MSIF members to 49.

Suyapa Mejia De Lupi, FEMA President, shared what membership means to them:

> *Being part of MSIF represents an invaluable achievement for FEMA and a new chapter in our commitment to people living with MS in Honduras. For us, being part of this great global network means being able to learn, share experiences, and join forces with leaders who inspire real change. It is an opportunity to grow, raise awareness of our work, and actively contribute to the international MS movement.*

MSIF visits MS organisations in Namibia and South Africa

This year, MSIF undertook in-depth research to better understand the MS landscape in Namibia, Nigeria, Kenya, South Africa, and Zambia. Desk-based research and analysis was carried out and online interviews held with health professionals and MS organisation leaders.

As part of the research, MSIF staff visited MS organisations in Namibia and South Africa. From TV interviews to focus groups and hospital visits, the trip underscored the urgent need for greater MS awareness, improved access, and equity in care.

The visit highlighted the extraordinary impact of MS Namibia and MS South Africa, whose small volunteer teams achieve remarkable results despite limited resources.

The trip also revealed clear opportunities for growth and collaboration with the global MSIF movement.

These findings have helped shape MSIF's initial multi-year work in Africa which aims to strengthen partnerships with and amongst African organisations; equip MS organisations' staff and volunteers with tools and skills to strengthen their organisations in the areas of governance, communications and fundraising and increase the visibility and amplify the voice of MS communities in the wider Africa region within the global MSIF movement.

In the longer-term there are opportunities to link up with ongoing engagement in the Middle East and North Africa (MENA) region and member outreach in Africa - advancing our aim of a stronger, broader global MS movement.

Connecting with MS communities in Honduras and Guatemala

As Fundación Esclerosis Múltiple Amor (Honduras) was applying to become an MSIF Associate member, we took the opportunity to visit them, and Asociación Guatemalteca de Esclerosis Multiple in Guatemala, to connect with local leaders and gain insight into MS care in Central America.

The visit revealed the challenges faced by MS communities, and highlighted the resilience and the transformative power of community-led action, despite scarce resources, demonstrated by the MS organisations. These insights will inform MSIF's ongoing work to strengthen MS organisations in Latin America and deepen the collaboration between local and global partners.

Latin America's "Learn, practice, share" 2024 -2026 Programme

This multi-faceted programme ran throughout 2025 beginning with the "Learn" component. Through online training modules 72 people from 26 MS organisations from 17 countries were equipped with knowledge, tools and resources in data collection and analysis; improving financial management and strengthening financial sustainability and staff/volunteer management.

In terms of volunteer management, participants learnt how to design a volunteering programme and had the opportunity to learn from the Multiple Sclerosis Society of India (MSSI). Having the MSSI participate increased the appetite for cross-region collaboration and brought new ideas to tackle similar challenges.

The “Practice” component, consisting of small grants, was launched in August 2025 to support projects working to address the barriers to early diagnosis, incorporating and demonstrating skills acquired from the “Learn” component.

India multi-year organisational strengthening partnership

MSIF continued its structured partnership with the MS Society of India (MSSI), focusing on building the skills and knowledge of staff and volunteers, improving communication and learning exchange amongst its Chapters and strengthening its fundraising processes and core organisational processes.

With MSIF’s support the MSSI has developed and approved key policies and standardised project implementation and monitoring. The National Office has been able to identify and work with Chapters that need additional support in specific areas such as fundraising and local advocacy work.

The MSSI has organised online workshops and training sessions to educate and empower people with MS and Chapter volunteers alike with topics including communication skills, supporting people to apply for disability ID cards and the importance of support groups.

The National Youth Wing has grown in its role, leading campaigns and organising workshops. It is now a formally recognised body within the MSSI with members becoming more involved in national-level decision-making.

To ensure the sustainability of their advocacy work and Chapter network support, the MSSI has diversified its income streams.

The partnership also includes a staged transition plan to encourage long-term sustainability once direct MSIF support finishes in early 2026.

Leadership and project management training in MENA

To support MS organisations serving the MS community in the region, MSIF co-designed a Leadership and Strategic Project Management Training course with the American University in Cairo (AUC). The 13-week program brought MS organisation leaders together to strengthen skills in developing, managing, and evaluating projects focused on improving access to treatment and to prepare them for applying for furture project grants.

Participants from Syria, Yemen, Morocco, Tunisia, Sudan, Iraq, Algeria, and Egypt included MS organisation presidents, volunteer coordinators, healthcare professionals, and people living with MS. Beyond the syllabus, the course built confidence as well as practical skills:

> “*This training helped me turn my ideas into a fundable proposal”* **said a participant from Syria**.
>
> **Another from Algeria shared:** *“Now I feel I can lead a project confidently”*

The course also encouraged cross-border exchange and collaboration, with participants continuing to share challenges and project ideas after completion. Small grants were launched in June 2025, encouraging practical application of the skills gained through the AUC training.

MSIF also regularly convened organisations including a regional MENA MS exchange, facilitated in partnership with the National MS Society –UAE, during which they shared their regional resource hub.

World MS Day 2025 united the global MS community with creativity and purpose

The second year of the My MS Diagnosis campaign was increadible. World MS Day was marked in 156 countries (up from 124 in 2024), with 96% of MSIF members taking part.

MS organisations engaged decision-makers at the highest levels. The Polskie Towarzystwo Stwardnienia Rozsianego (Poland) brought World MS Day to the Polish Parliament, holding a dialogue with lawmakers about MS diagnosis and care. MS Australia hosted a special event at Government House, where the Governor-General welcomed guests and delivered the opening address. In Egypt, the Ministry of Health partnered with MS Care Egypt for a public awareness event, and Puerto Rico's Community Organization of MS & Cancer mobilised mayors, hospitals and agencies in a nationwide show of support. MS Ireland hosted a briefing for over 40 parliamentarians about MS diagnosis and access.

Campaigns made headlines globally. Argentina aired a live radio broadcast; and Spain amplified its message through national media. Training and awareness were key themes, with Nepal hosting a national MS conference. Communities also celebrated creatively, from Seoul's cultural performances to Namibia's 5K run and Iran's cycling event.

This year MSIF collaborated with the Menzies Institute for Medical Research to develop a free online course, MS Diagnosis and Symptoms with support from MS Australia and MS Plus. The course attracted 1,591 participants from 116 countries. This engagement represents a meaningful step towards addressing gaps in early diagnosis of MS.

You can read the 2025 Campaign Highlights article here

The May 50K: Leave your limits behind

It was another successful year for the May 50K fundraising campaign with South Africa piloting the campaign.

Together with our member organisations, the campaign raised £905,500, a 3% increase on 2024. Over 10,000 participants from more than 50 countries took part in the fitness and fundraising challenge to walk, roll, or run 50 kilometres during May. Funds raised were shared between MSIF and participating member organisations to support both global and national MS programmes.

> *The May 50K played a significant role in my recovery. Through the challenge, I managed to integrate consistent movement into my daily routine again. Step by step, this helped me regain stability — physically and mentally. Thanks to that foundation, I was even able to complete my first ultramarch in September: 50 km in 12 hours. A year ago, I would never have believed that possible" —* ***Pamela (The May 50K 2025 participant, Germany)***

Cycle for MS: Conquer the Tour

In 2025, 19 riders from 6 countries took on some of the most iconic Tour mountains—Col du Tourmalet, Col du Soulor, Col d'Aspin, and Superbagnères, while raising funds for MS. Together, the cyclists raised £108,000 to advance the MS cause and created lasting memories.

> *An unforgettable experience—everything was so well-organized that I could fully focus on riding, resting, and enjoying the beautiful climbs. The support and camaraderie among riders created a powerful sense of unity and purpose. It was truly moving to be part of a group so dedicated to making a difference for the MS community —* ***Hermine (2025 rider)***

Expert groups in action

The newly formed People with and Affected by MS, CEO, and Fundraising Expert Groups began to meet in 2025. The Groups ensure that member organisations can share peer learnings as well as have a direct role in shaping MSIF's strategy, priorities, and programmes.

Representatives from 29 MSIF member organisations took part this year, reflecting their strong commitment to a connected global movement. Discussions covered wellness practices and complementary therapies, global advocacy and gaming-related fundraising.

The People with and Affected by MS Expert Group places lived experience at the centre of MSIF's work. The meetings focused on patient reported outcomes, digital tools, and wellness and complementary therapies.

The CEO Expert Group brings together the leaders of all MSIF member organisations. It met to examine why global advocacy matters at national level, and to explore the barriers and enablers to early MS diagnosis across health systems.

The Fundraising Expert Group links fundraising leads and CEOs to strengthen income across the movement. The group held practical sessions on the use of AI and gaming in fundraising, as well as engaging the next generation of volunteers. Members were also invited to co-design MSIF's next global shared-revenue fundraising campaign through a short series of focused virtual workshops.

The International Medical and Scientific Expert Group provides MSIF's scientific leadership. In 2025, the group selected the Charcot Award recipient, reviewed the Global Prevention Initiative led by MS Australia and MS Canada, prepared for the 2026 McDonald Fellowships selection round, and set future priorities on diagnostic tests, criteria development and global research collaboration.

The global MSIF movement gathered in London

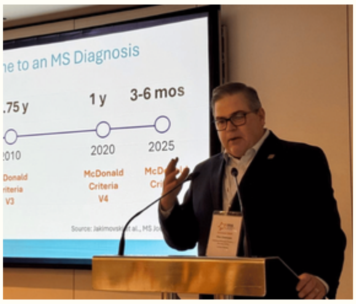
In October, MSIF held its 2025 Global Networking Meetings in London, bringing together more than 80 delegates from 31 countries, both in person and online.

Over three days, participants shared progress, explored key areas of MSIF's work and set strategic priorities for 2026 and beyond. Sessions and discussions were structured around MSIF's three strategic aims.

The MSIF Board formally approved the 2026 budget and operational plan, recognised outgoing trustees, welcomed incoming members, and reaffirmed governance continuity.

Representatives from Lebanon, Germany, India, Greece, Canada, and Uruguay shared what made the event meaningful, from impactful sessions to lessons they will carry forward.

Watch the video series here.

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