





News Release

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FOR IMMEDIATE RELEASE

The right diagnosis changes lives: a global call for early, accurate MS diagnosis

The multiple sclerosis community faces barriers preventing early diagnosis in almost every country across the world. Now, the global MS movement is rallying together to improve early and accurate diagnosis, so people with MS can get the answers an

d care they deserve.

Around the world, people living with MS often face long, frustrating journeys before receiving a diagnosis. 83% of countries worldwide experience issues that prevent an early diagnosis of MS. These delays prevent many from accessing the care they urgently need.

This <u>World MS Day</u> (30 May 2025), the MS community is calling for global action to improve the early and accurate diagnosis of multiple sclerosis (MS). <u>The MS International Federation</u> (MSIF) and more than <u>2.8 million</u> people living with MS worldwide are pushing for change with the My MS Diagnosis campaign.

'Too many people with MS face delays in diagnosis because of low MS awareness and limited access to specialist services. This campaign shines a light on those barriers and calls for urgent action to ensure that every person with MS can access the right diagnosis and care' said Lydia Makaroff, CEO of the MS International Federation (MSIF).

When MS is identified early, people can begin disease-modifying treatments that help delay progression, reduce future disability, and improve their quality of life. A timely diagnosis also gives individuals more clarity to make informed decisions and adapt their lifestyle to manage MS.

Dr Tarun Dua, Unit Head at the World Health Organization (WHO), <u>Mental Health, Brain Health and Substance Use Department</u> adds:

'WHO supports MSIF efforts to raise awareness and reduce barriers to MS diagnosis globally. This aligns with WHO's Intersectoral Global Action Plan for Epilepsy and Other Neurological Disorders, which aims to improve the lives of people living with neurological conditions like MS with effective, timely and responsive diagnosis, treatment and care.'







Three journeys, one message: The right diagnosis matters

Kanya, Indonesia

It took ten years for Kanya from Indonesia to finally be diagnosed with MS. A decade of mysterious symptoms, misdiagnosis, social stigma and emotional turmoil. When she was diagnosed, Kanya finally got the answers she was looking for.

'When I heard that I had MS, on the one hand I was scared, but on the other hand, I also felt very relieved, because all the burdens caused by the uncertainty of my disease seemed to suddenly all be lifted from my shoulders. After years of getting the wrong treatment due to misdiagnosis, I was finally able to get the right treatment for my disease.'

Bernhard, Austria

Bernhard from Austria speaks from experience about the long and often uncertain journey to diagnosis. His journey was delayed when his general practitioner did not recognise the early signs of MS or refer him to a neurologist.

'The hurdles on the way to a correct diagnosis are numerous and often discouraging. In my case, the delay began with a general practitioner who didn't take the symptoms seriously enough to refer me to a neurologist. Once I was finally able to see a competent and compassionate neurologist, things progressed quickly. But even then, the waiting period for tests and results was full of uncertainty and fear — an emotional strain that affects everyday life.'

Jessica, South Africa

As a university student, Jessica began experiencing unexplained symptoms—extreme fatigue and sensory loss on her left side. She was misdiagnosed a number of times before finally receiving an MS diagnosis. The main barrier she faced was low MS awareness amongst healthcare professionals, which delayed her access to care and treatment.

'The main challenge to diagnosis was a seeming unawareness of the general practitioners. It wasn't a lack of access to funds or access to the MRI, it was a lack of the doctors asking for it.'

A Global Call to Action







MSIF and its global network of MS organisations are calling on governments, healthcare providers, and communities to:

- Increase awareness of MS symptoms among the public and health professionals
- Improve access to specialist neurology services and diagnostic tools such as MRI scanners
- Establish national MS guidelines in alignment with international guidelines for diagnostic criteria and treatment

Visit www.worldmsday.org to learn more and get involved.

Media enquiries and interviews available: worldmsday@msif.org

Notes to editors:

Global MS Diagnosis Facts

- Every 5 minutes, someone, somewhere in the world is diagnosed with MS.
- There are more than 2.8 million people living with MS around the world.
- There are at least twice as many females (69%) with MS as there are males (31%).
- MS affects children as well as adults, with at least 30,000 people under 18 living with MS.
- Barriers to diagnosing MS early exist in the majority of countries (83%), but they are more common in lower-income nations.
- The biggest global barrier is a lack of awareness about MS symptoms—both among the public (68% of countries) and healthcare professionals (59%). While lack of awareness is a common issue everywhere, lower-income countries also face challenges like a shortage of trained healthcare professionals and limited access to affordable diagnostic tests and equipment.

Materials and events:

- The new My MS Diagnosis poster maker explore the poster gallery sharing real MS diagnosis journeys <u>here.</u>
- The My MS Diagnosis campaign film can be viewed here
- More personal diagnosis stories of those living with MS around the globe are available, along with imagery here.
- See the global MS community in action on the World MS Day map here







Data sources:

- WHO's 'Intersectoral Global Action Plan for Epilepsy and Other Neurological
 Disorders'. The vision of the global plan sets out a world in which: brain health is
 valued, promoted and protected across the life course; neurological disorders are
 prevented, diagnosed and treated, and premature mortality and morbidity are
 avoided; and people affected by neurological disorders and their carers fulfil their
 potential with equal rights, opportunities, respect and autonomy. For more
 information: https://iris.who.int/bitstream/handle/10665/371495/9789240076624-eng.pdf?sequence=1
- The 'Brain Health time matters' report highlights the critical importance of timely diagnosis in MS, NMOSD, and MOGAD. It calls for greater MS awareness among healthcare professionals and better access to specialist neurology care. The report also recommends aligning national treatment guidelines with international standards, emphasising early diagnosis and access to effective therapies. For more information, see Section 3 (pp. 21–29) for more and full recommendations on p. 40: https://www.msbrainhealth.org/
- The 'Atlas of MS: Clinical management of multiple sclerosis around the world' shows
 the number of countries where people with MS face barriers in accessing diagnosis,
 treatments, care and rehabilitation. For example, the Atlas shows that Barriers to
 diagnosing MS early exist in the majority of countries (83%) and the biggest global
 barrier is a lack of awareness about MS symptoms. For more information:
 https://www.msif.org/wp-content/uploads/2021/04/Atlas-3rd-Edition-clinical-management-report-EN.pdf
- The 'Atlas of MS: Mapping multiple sclerosis around the world key epidemiology findings'. The findings show that there are more than 2.8 million people living with MS around the world. For more information: https://www.msif.org/wp-content/uploads/2020/10/Atlas-3rd-Edition-Epidemiology-report-EN-updated-30-9-20.pdf

About multiple sclerosis (MS)

Multiple sclerosis (MS) is one of the most common neurological conditions and causes of disability in young adults.

There are more than 2.8 million people with MS worldwide. It is likely that many more remain undiagnosed and many lives are affected indirectly, through caring for someone with MS. Most people with MS are diagnosed between the ages of 25 and 31, with around twice as many women diagnosed as men.







The cause of MS is not yet known and as yet there is no cure, though there are treatments available that can help some forms of MS and there are many options to improve and manage the symptoms.

There's no set pattern to the severity of someone's MS, the course it takes and the symptoms they experience. Every person is different. Symptoms can include blurred vision, weak limbs, tingling sensations, unsteadiness, memory problems and fatigue.

For some people, MS is characterised by periods of relapse and remission (meaning it gets better for a while but then can attack from time to time), while for others it has a progressive pattern (meaning that it gets steadily worse with time) or a mix of both. Some people may feel and seem healthy for many years following diagnosis, while others may experience severe disability very quickly.

MS makes life unpredictable for everyone. To find out more about MS, get in touch with an MS organization near you, or visit the MS International Federation website: https://www.msif.org/.

About World MS Day

World MS Day is an international awareness day for everyone affected by multiple sclerosis. It is a day of global solidarity, collective action and hope.

World MS Day is officially marked on 30 May. Events and campaigns take place throughout the month of May and early June. It brings together the global MS community to share stories, raise awareness and campaign with and for everyone affected by MS.

In 2009, the MS International Federation (MSIF) and its members initiated the first World MS Day. Together we have reached thousands of people around the world, focusing on a range of campaign themes. Last year World MS Day was marked across 124 countries – and this year the momentum continues. Across the globe, communities are coming together to advocate for better access to diagnosis.

MSIF provides a toolkit of free resources to help everyone to take part in World MS Day. These tools are available in English, Spanish, Arabic for anyone to use. For more information, please visit the World MS Day website: https://worldmsday.org/tools/

About the My MS Diagnosis campaign

The theme for World MS Day 2024-2026 is diagnosis. The name of the campaign is My MS Diagnosis and the tagline: navigating MS together.

The My MS Diagnosis campaign advocates for early and accurate diagnosis for everyone living with MS. It highlights the global barriers to diagnosing MS, raising awareness by







sharing real stories and data. We are calling for better MS training for healthcare professionals, new research, and clinical advancements in MS diagnosis. Together we are building informed, caring communities and systems that support people diagnosed with MS. For more information, please visit the World MS Day website:

https://worldmsday.org/about/

About the MS International Federation (MSIF)

The MS International Federation (MSIF) is the world's only global network of MS organisations, people affected by MS, volunteers and staff from around the world. The MSIF movement is made up of 47 MS organisations with links to many others around the world.

MSIF and its members work together to boost scientific progress to prevent, treat and stop MS. We strive for a world where everyone living with MS can access early diagnosis, treatment and care. MSIF collaborates with organisations in countries where there is limited provision for people with MS, providing information, resources and support. Together we grow the global movement to place MS higher on the global health agenda, and to tackle the challenges for everyone affected by MS.

MSIF's mission is to bring the world together with urgency to improve the quality of life and wellbeing of everybody affected by MS. Together we're stronger than MS.

To find out more, visit the MS International Federation website: https://www.msif.org/