







# **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 and care they deserve.

Around the world, people living with MS often face long, frustrating journeys before receiving a diagnosis. <u>83% of countries</u> worldwide experience issues that prevent an early diagnosis of MS.

"There is no reliable MS prevalence data in India. While there has been some increase in level of awareness, advancements in diagnostic tools there is a huge delay in diagnosis resulting in delayed medical intervention that impacts quality of life. Delay in receiving Unique Disability Identity Card UDID leaves PwMS without access to government schemes and benefits. At MSSI our call to action has been to establish the National Registry of MS, provide financial risk cover to afford treatment and expedite the process of issuance of UDID cards to deserving PwMS" – Renuka Malaker (Hon) National Treasurer- Multiple Sclerosis Society of India

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>Multiple Sclerosis Society of</u> <u>India</u> is joining forces with <u>the MS International Federation</u> (MSIF) and more than <u>2.8</u> <u>million</u> people living with MS worldwide to advocate for change.

'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</u> <u>Health and Substance Use Department</u> adds:





'WHO supports the MS community's 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.'

#### Visit <u>www.worldmsday.org</u> to learn more and get involved.

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#### Notes to editors:

For more information, spokespeople, case studies and detail of local events happening in your region please contact:

#### **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.

#### Data Source: Atlas of MS: Clinical management of multiple sclerosis around the world.

#### Materials and events:

- 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 <u>here.</u>
- 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: <u>https://iris.who.int/bitstream/handle/10665/371495/9789240076624eng.pdf?sequence=1</u>
- 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: <a href="https://www.msbrainhealth.org/">https://www.msbrainhealth.org/</a>
- 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: <u>https://www.msif.org/wp-content/uploads/2021/04/Atlas-3rd-Edition-clinicalmanagement-report-EN.pdf</u>
- 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: <u>https://www.msif.org/wpcontent/uploads/2020/10/Atlas-3rd-Edition-Epidemiology-report-EN-updated-30-9-20.pdf</u>

## 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: <u>https://www.msif.org/</u>.

## 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: <u>https://worldmsday.org/tools/</u>

## 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: Multiple Sclerosis Society of India

Multiple Sclerosis Society of India (MSSI) is a registered non-profit organization that was established in 1985, to work with persons with Multiple Sclerosis (MS), caregivers and their family at large. MSSI has 9 chapters (Bangalore, Chennai, Delhi, Hyderabad, Indore, Kolkata, Mumbai, Pune & Thiruvananthapuram) with 3000 registered Persons with Multiple Sclerosis as their members. We operate at 2 levels. At the centre, MSSI advocates for better and inclusive policy for Persons with MS (PwMS) and their family. At the Regional Level we provide services <u>https://www.mssocietyindia.org/services/</u> to our registered members and their families which include. Our policy intervention through campaigns have been and are very well received both nationally & internationally. All the campaigns were followed up with recommendation to the government and relevant ministries that included MoH&FW, MoF, MoSJ&E & ICMR.

To know more, visit Ms Society India website: <u>https://www.mssocietyindia.org/</u>

# 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: <u>https://www.msif.org/</u>