

World MS Day Special Edition



e-Newsletter

Tēnā Koutou Katoa. A warm hello to you all,

Welcome to our May 2025 Edition of MS Voice. It's hard to believe we're almost halfway through 2025! Time is flying by as we continue our mission to educate, campaign, and advocate for everyone impacted by MS, ensuring they can live well and access the support they need.

Today, 30th May, we're celebrating <u>World MS Day</u>. You can learn more about this year's campaign in the articles below. Before you dive in, we have some incredible news to share: **MSNZ has been allocated \$72,000** from the recent <u>Bangers to Bluff fundraiser</u>, thanks to the generous support of the <u>Rotary Club of Half Moon Bay</u>. We're so grateful for this amazing contribution, which will help us continue advocating for first-world treatment, resources, and services for people with MS in New Zealand.

The needs of those impacted by MS remain at the heart of everything we do, but we can't do it without you. Please explore the articles below and share your thoughts and feedback. You can reach us on social media, email us at <u>info@msnz.org.nz</u>, or call us on **0800 675 463**.

MSNZ News and Updates

Critical Neurology Shortages Put MS Patients at Risk

Today, on World MS Day, **MSNZ is sounding the alarm** on a worsening shortage of neurologists across the country, as new research reveals a 67% rise in MS diagnoses over the past 16 years.

With over 5000 New Zealanders now living with the condition, MSNZ is urgently calling for greater investment in specialist care to ensure timely diagnosis, treatment, and ongoing support. Read our <u>press release</u> to learn about the findings and what needs to change.



P R E S S R E L E A S E

A Promising Breakthrough for Progressive MS

A newly published study shows that Tolebrutinib, an oral BTK-inhibitor, may slow disability progression in non-relapsing secondary progressive MS. This marks a major step forward in treating MS progression, where few options currently exist.

Learn more about what this could mean for the MS community in New Zealand and how you can help shape the path to access by reading the article on our website, then let us know what funding of this treatment would mean to you.

New Research Sheds Light on MS Prevalence and Gaps in Diagnosis Across Actearoa

A new study led by COMPASS Research Centre and supported by Multiple Sclerosis New Zealand and partners, has used the Integrated Data Infrastructure (IDI) to estimate the prevalence of MS in Aotearoa New Zealand. The findings highlight rising prevalence, significant ethnic disparities, and potential barriers to diagnosis. Read more about the study's methodology, key findings, and how this data will inform future advocacy and support efforts.

World MS Day - 30th May

We're joining the global My MS Diagnosis campaign to advocate for early and accurate diagnosis for everyone living with MS. The campaign shines a light on the barriers people face in getting diagnosed, from lack of awareness to limited access to specialists.

WMSD is a day of solidarity, collective action, and hope. We're calling for better MS training for healthcare professionals, more research, and advances in diagnostic tools. Together, we can build informed, supportive communities and systems that help people get the answers they need, faster.

Every five minutes, someone, somewhere in the world is diagnosed with MS. This animation shares their voices and experiences - highlighting why early diagnosis matters, and the challenges faced along the way.

Regular Kiwi Kid to Facing the Unknown: Angus's Journey to Diagnosis

Angus grew up your regular Kiwi kid enjoying lots of outdoors activities like rugby, hockey, diving and hunting. He became an active police officer, then unexplained symptoms began to surface. What followed was a long road to an MS diagnosis, marked by uncertainty, stress, and major life changes. In this powerful and honest account, Angus shares his journey, from confusion and fear to clarity, resilience, and a new way of living well with MS.

Explore these MS Diagnosis Animations on YouTube. As we approach World MS Day, we're providing informative articles and resources, including animations that explain the diagnostic tests for MS. We invite you to share your diagnosis story with us: what tests you underwent, how long it took, and any challenges you encountered. Delve deeper into the diagnostic processes and click the images below. Feel free to email your story to info@msnz.org.nz

The MS International Federation have joined forces with Menzies to create a WMSD special edition of their Understanding MS Course. It's free, and available online until 15th June. The course will increase your knowledge of MS symptoms, how MS is diagnosed and the impact of an MS diagnosis. You will also learn about the global barriers to early MS diagnosis and explore solutions.

Testing for MS

Neurological Exam

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Testing for MS Evoked Potentials Test

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Testing for MS Magnetic Resonance Imaging worldMSday

Testing for MS

Lumbar Puncture

worldMSday

Everyone's journey to an MS diagnosis is different, and yours could help someone else feel less alone. That's why we've shared these <u>Diagnosis</u> <u>Posters</u>: a simple way to share when your symptoms started, time to diagnosis, and what barriers you faced along the way.

We've been asking our social media community to share their posters, and the response has been powerful. Each one offers a snapshot of real-life experiences that can inspire, inform, and connect others. <u>Download your poster</u>. Your story matters. Let's raise awareness, together.



Join MSIF's World MS Day webcast *Improving MS Diagnosis Globally* as they explore global solutions with real case studies. The webcast unpacks key findings from the *Brain Health – Time Matters* report and how these can be applied to improve MS diagnosis. Hear from an international panel featuring people with MS, experts in neurology and MS research, and MS organisations leading innovative diagnosis work.

This one-hour webcast is open to everyone; people living with MS, advocates, healthcare professionals, and anyone passionate about improving MS care.

Register to attend, and you will receive a copy of the recording after.



Many of our <u>Regional Societies</u> are coming together in creative and meaningful ways to raise awareness this WMSD and celebrate the MS community. Here's a snapshot of some of the fantastic events happening around the country:

Northland MS Society is painting the town red! Members will be donning red scarves, shoes, even lipstick Seminar and morning teated and raise funds MS Hawkes Bay is hosting a Wellness Seminar and morning tea MS and Parkinsons Canterbury offer a special session on brain health and exercises MS Taranaki is taking it outdoors with a fun-filled day at the cycle park and MS Otago is sweetening the day with a Dessert Evening! A delicious way to mark the occasion and share time together

Supporting MSNZ

Pedal for a Purpose: Your Ride. Their Future.

Ride for MS is your chance to cycle through Cambodia while making a real difference for over 5,000 New Zealanders living with multiple sclerosis. Every kilometre you ride and every dollar you raise helps provide vital healthcare, life-changing treatments, and essential support. This is more than just a cycling trip, it's a powerful way to fuel better services, advocacy, and outcomes for the MS community across Aotearoa.

Curious to know more? <u>Read the highlights</u> from our recent Q&A session to find out what's involved, how you'll be supported, and why your involvement matters.

Register for Just \$1: Sign up now using code **MS-RIDE25** and save \$389. Whether you're riding for a loved one or for the future of MS care in New Zealand, this is your moment to ride with purpose. Join us and help create lasting change.

Information for You



Wellness Practices and Complementary Therapies

Symptom management is an important component of living well with MS. Wellness practices or complementary therapies, can often reduce life-limiting symptoms such as pain, fatigue, muscle stiffness and tightening. Certain therapies might help people feel more in control of their MS or make them feel better overall, reducing stress and helping with relaxation. Whilst some practices may provide relief for some MS symptoms, others may be ineffective or even harmful. Read on to discover more about wellness practices and complementary therapies.

Maintaining a Sexual Relationship Whilst Living with MS

Physical intimacy is an important part of life for many people, including those with MS. Being intimate with your partner can be a great way to build your relationship outside of your care needs, as well as boosting confidence and overall wellbeing. But MS can cause difficulties with loss of libido and muscle tone. Read on to discover three tips for improving your sexual relationship when living with multiple sclerosis.

Research Opportunities for Young Adults with Autoimmune Disease

PhD candidate Nikki Singh is exploring how autoimmune conditions impact identity in young adults. Her research goes beyond biology to understand the real-life experiences and social challenges behind a diagnosis. Keen to learn more or take part? <u>Read more on our website</u>.

Giveaway Alert! 🔶

This month, MS New Zealand and Allied Medical are giving away a **Relax & Read Pack** – the perfect duo for book lovers and keen puzzlers!

The prize includes a **Whitcoulls voucher** so you can choose your next great read, plus a **handy reading stand** to hold your book, magazine, or tablet at the perfect angle for hands-free comfort.

Whether you're curling up with a novel or tackling a crossword, this giveaway is all about making reading more enjoyable and accessible.

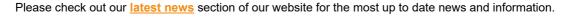
Enter now for your chance to win!

Congratulations to our April winner, Carey Simpson. We hope you are enjoying your Cozy Comfort Pack ●

Our Sincere Thanks

MSNZ would like to show our appreciation to the amazing support received from the Rotary Club of Half Moon Bay for the 2025 Bangers to Bluff Car Rally.

To each and every one of our sponsors and everyone that made a donation, we THANK YOU!













Noho ora mai. Stay well and look after yourself.



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