

World MS Day Special Edition



e-Newsletter

May 2024

Tena koutou, Hello to you all,

Welcome to the May edition of MS Voice, your source for the latest updates, information and inspiring stories from Multiple Sclerosis New Zealand.

World MS Day is an international awareness day for everyone affected by multiple sclerosis. It is officially marked on 30th May every year to bring the global MS community together to share stories, raise awareness and campaign for change •

The 2024 'My MS Diagnosis' campaign advocates for early and accurate diagnosis for everyone living with MS. It highlights the global barriers to diagnosing MS, raises 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 those diagnosed. Read more below.

We're getting closer to reaching our goal of raising \$20,000 from <u>Bangers to Bluff</u> last month. These vital funds will support people impacted by MS, so please <u>donate</u>, if you can. Thank you ## \$\varphi\$ \$\text{\lambda}\$

MS Announcements and Events



Are you on an Infusion Treatment?

We would like to understand more about patient experiences with infusion treatments. It is reported that people are managing their condition well due to DMTs and adopting healthier lifestyles. However, there are several new treatments on the horizon or alternative subcutaneous versions of current DMTs that are currently sitting on Pharmac's Options for Investments list.

We want to know, how your treatment is working for you, what barriers you face to accessing your treatment, and how would these new options overcome the barriers.

Time Matters in MS: Brain Health Seminar

Time matters in MS. But what does that mean and why is Brain Health important? Join us to hear more from one of the world's leading MS experts, Professor Helmut Butzkueven, about the importance of being proactive in protecting and preserving Brain Health.

Thursday 11th July, 6.30pm, Novotel Ellerslie, Auckland. Tickets \$10 + booking fee. Spaces are limited. Event will be recorded and published after.



Read More



Preparing For Your Neurologist Appointment

We recently introduced you to our new <u>Living Well with MS</u> resources. This month, we're highlighting our 'Preparing For Your Neurologist Appointment' information sheet. This sheet provides an overview on what to expect from your appointment, and an area to list questions to discuss with your neurologist. There is also space to write notes during your appointment, so you don't forget what's been discussed.

Hard copies are available via your <u>local regional society</u>, so make contact with your community advisor, or download the PDF's from our <u>website</u>.

Read More

Ocrelizumab for Primary Progressive MS in Canterbury

MSNZ has been advised that clinical specialists at Canterbury Waitaha have been instructed to commence patients with PPMS through assessment and treatment minimising further delay. We are extremely pleased at this positive outcome for people in the Canterbury Regions with the most progressive form of MS.



Read More



World MS Day - Diagnosis Stories!

Everyone has a diagnosis story, but just like everyone's MS is unique to them, so is their journey to diagnosis.

We spoke with Michael, Nikki, Rachel and Zazi to learn what their journey to diagnosis was like. Some were less complicated and quicker than others, but each was fraught with emotion and turmoil.



World MS Day - Diagnosis Animation

Every five minutes someone, somewhere in the world is diagnosed with MS. This animation is about navigating an MS diagnosis. It explores the challenges people face in search of answers and why the right diagnosis matters so much. The animation features the real voices of people living with MS across the globe. Listen to Jonathan, Rayan, Leonardo, Kanya and Jessica share their diagnosis stories.



Watch Animation

Support Us



Mother's Day Special

Support our Fundraising efforts and receive a bonus \$20 eGift Card and access to over 10,000 exclusive offers in 20 cities across Australia and New Zealand.

Hurry! This limited time offer ends 1:59pm NZST, Monday 3rd June 2024. Thank you for your on-going support!

*Subject to Terms and Conditions.

Purchase Savings

Donate Directly with Payroll Giving \$

Did you know that you can donate to us directly from your pay and automatically receive a tax credit of 33.33 cents for every dollar donated?

Payroll giving is a voluntary scheme where your employer passes on donations to chosen charities and reduces your PAYE with a tax credit for payroll donations.

With all donations you are entitled to a tax credit, with payroll giving this is credited to your pay at the time of donation, rather than having to wait until the end of the tax year to receive it.

Why not speak with your employer today and see if they can set this up so you can join us in making a difference to those impacted by Multiple Sclerosis.

Learn More



Fancy Fundraising for MSNZ?

Why not use Givealittle, a registered charity, that is 100% NZ owned and operated and has been supporting Kiwi's for over 14 years. A great team of dedicated people who are passionate about fundraising for the causes close to your heart.

Fundraise

Looking after you

Prepare for Winter



With the chill of winter starting to bite, health authorities are encouraging New Zealanders to prepare early for the colder months, so they stay healthy and well and avoid placing extra pressure on health services during the worst of the cold and flu season.





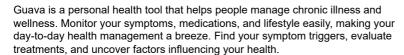
Making Sense of the System - Webinar Series

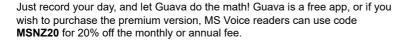
The last in the series of free webinars from <u>Flying Kites</u> in making sense of the disability system is 'Planning for the Future'.

This webinar will cover: How services change as you get older; how to plan for the future; and what things you can do now to make life easier down the track.

Learn More

An Easier Way to Manage Your Health







Learn More



Mobility Parking Permit

If you have difficulty in getting around, you may benefit from a Mobility Parking Permit. CCS Disability Action can help you with your application, so get in touch with them below.

Learn More

Stress Management and Mental Health Webinar 🛔

As part of their Living Well with MS Webinar Series, Overcoming MS facilitators, Yasmin Neves and Dr Phil Startin chat with community members Bill Morgan and Melanie Lown about their personal experience of stress management and mental health in regards to MS.



Learn More

Regional MS Society News



Living a Full Life.....Just Happen to Have MS

Suzie Delores doesn't like to muck around. There is far too much life to be lived to sit there with a woe-is-me hat on. For Suzie, it has never been about fighting MS. It's been about living, about being someone who just happens to have MS.

Read her inspiring story on page 8 in the latest edition of Multiple News from MS Auckland by clicking the link below.

Read More

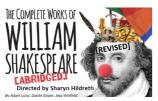
MS: A Marathon, But No Walk in The Park

With a desire to raise valuable funds, Michael trained for and entered the iconic Red Stag Rotorua Marathon to raise the profile of a debilitating disease that affects one in a thousand New Zealanders. Michael was walking for his wife, Susan, who has multiple sclerosis

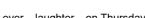
"I was very emotional at the end because my son and daughter in-law were able to bring my wife, so she could see me cross the finish line. Having family there was amazing. Several of our members from Rotorua were also on the side of the road to encourage me as I walked past."



Read More



MS Hawkes Bay - Shakespeare Play



Join MS Hawkes Bay for the best medicine ever....laughter....on Thursday 6th June for their William Shakespeare (Abridged) charity fundraiser!

Tickets are \$38pp and can be purchased by emailing info@mshawkesbay.org.nz or call 06 835 8542

Bring cash for a great raffle in Doors and bar open at 7pm. Fun starts 7.30pm

Learn More

MS Momentum - MS Otago Podcast

In this episode, Katie Burns, MS Otago's Community Connector is joined by Kirsten Dixon to discuss her recent Mastering Mountains Grant tramp and how writing her diagnosis story in her application process was a really therapeutic process for her.



You can read Kirsten's story here.

Learn More

Get Involved



Mastering Mountains Charitable Grants

Mastering Mountains wants to see people with multiple sclerosis and functional neurological disorder experience hope, connection and positive, life-long change through self-directed outdoor adventure.

For many living with these neurological disorders, a life of adventure in the outdoors can feel far from reach. That's why Mastering Mountains assists everyday people to overcome these challenges by helping them achieve their adventure dreams, experience hope and connect with community, thereby inspiring hope in others. *Applications close 31st May.*

Learn More

Oceans of Hope Challenge 2024 __

Whether you have sailed before or not, this is an opportunity not to be missed! Spaces are available for the November 2024 challenge. They will be sailing around the beautiful islands in the Hauraki Gulf, where you could find yourself sailing into Home Bay, Motutapu Island, Smokehouse Bay, Great Barrier Island and more.

Are you ready for a life changing sailing adventure? Apply today!





National Volunteer Week

This National Volunteer Week, 16 - 22 June, we'd like to acknowledge all the wonderful volunteers out there. Many of you have helped with regional society street appeals, organised and participated in events or donated your time and skills in the national and regional offices. THANK YOU!

We'd also like to acknowledge the support and mahi provided by our Committee who are all volunteers. There is so much work that goes on behind the scenes, and without them and you we would not be able to do it all.

If you're interested in volunteering with us or the regional societies, please get in touch 💚



Contact Us

In the Spotlight

MSNZ would like to show our appreciation to the amazing support in the form of grants received from the Air Rescue and Community Services.



Sharing stories offers an insight into what it's like to live with multiple sclerosis. If you would like to **share** *your* **MS story** with the MS community, please get in touch:

info@msnz.org.nz

Thank you for your continued support, it has helped us to achieve so much for those impacted by MS.

Noho ora mai. Stay well and look after yourself.



P.S. Please check our our Latest News section on our website for the most up to date information.



intended to replace medical advice. Please click here to read our full disclaimer.

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