

ms. voice

A stylized illustration of a megaphone in teal and orange, enclosed within a circular orange border. Three curved lines to the right of the megaphone represent sound waves.

Newsletter

February 2024

Kia ora,

Welcome to the February edition of MS Voice, your ultimate hub for the latest updates and inspiring stories from MS New Zealand.

In this edition, we pay tribute to the legacy of Dr. Riccardo Saccardi. We update you on our submissions to Pharmac for funding, invite you to dive into Graham's incredible cycling challenge during Bangers to Bluff and discover how our new Superhero activity book is making waves this Children's Day, complete with a thrilling colouring competition offering a chance to win a \$50 prezzie card and we proudly introduce new resources designed to empower and educate.

Plus, mark your calendars for the Michael Ford Memorial Charity Golf Tournament hosted by MS Waikato this April, honouring a beloved figure and supporting those affected by MS.

A heartfelt thank you to our sponsors for their invaluable support during Bangers to Bluff. Together, we're making a difference in the lives of those impacted by MS.

Join us in celebrating the resilience and strength of the MS community. Explore, engage, and be part of the conversation.

MS Announcements and Events

[In Memorium - Dr Riccardo Saccardi](#)

We are deeply saddened to hear Dr Riccardo Saccardi passed away on Monday 19th February in Italy after a battle with cancer. At Multiple Sclerosis NZ we owe a huge debt to Dr Saccardi, whose visit in 2017 was the turning point for many in their knowledge, understanding and attitudes towards aHSCT.

Dr Saccardi continued to provide advice and support to MSNZ over the years following his visit, regarding the progress internationally with aHSCT along with guidance during the Covid Pandemic.



[Read More](#)

About Us

Multiple Sclerosis New Zealand (MSNZ) is a non-profit organisation, established in 1967. We are striving towards our vision of being the national leader for service excellence for people impacted by multiple sclerosis (MS). To achieve this, we are on a mission to coordinate and lead the advances in best practice MS care, national leadership, advocacy, information, education and awareness.

We promote internationally recognised MS Brain Health principles and recommendations for living well with MS. We encourage resiliency, self-management, and preventative services.

Positive attitudes and lifestyle modifications, which we encourage, can have a profound effect on symptoms management and maximising opportunities for long term health and brain health outcomes.

To access our evidence-based information head to our website or reach out to us.



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ms
Multiple Sclerosis
New Zealand
www.msanz.org.nz

What is Multiple Sclerosis



What is Multiple Sclerosis - Our NEW Resources

Last month we introduced you to our new Living Well with MS resource, which we hope you are enjoying. This month, we're highlighting our 'What is Multiple Sclerosis' leaflet. We would love to know what you think, so please take a read and let us know.

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

[Read More](#)

Graham's Bangers to Bluff Challenge

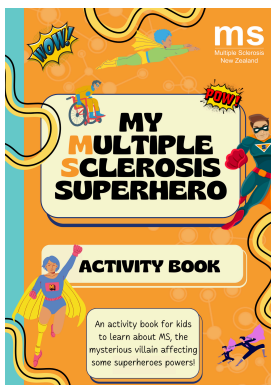
In his quest to let the nation know about Bangers to Bluff, Graham, the President of MS Taranaki has been interviewed by the papers and radio. You can read the article on Stuff [here](#). As in previous years, Graham will take to the road in the early hours, ahead of the bangers, to see how far he can cycle before being caught.

We would love your support during this rally, whether that is in the form of a donation, cheering the teams on as they cycle and drive through your region, or coming on board as a sponsor. If you can support us, please, get in touch.

At the end of the rally, Graham's bike and all the cars are auctioned off, so if you are in the market for a road bike or a new (old) car, watch this space!



[Read More](#)



Calling All Superheroes!

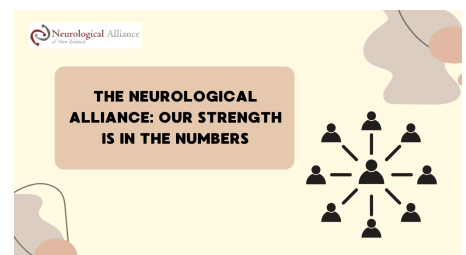
Join us in celebrating this year's Children's Day on 3rd March. We have crafted an interactive and fun way to educate children about MS in our new 'Multiple Sclerosis Superhero Activity Book'. Children can learn about signal pathways by doing the maze or discover the names of symptoms in the wordsearch.

To make it super fun, we are launching a colouring-in competition where the lucky winner will receive a \$50 prezzie card. So encourage your tamariki to get creative, take a picture and submit their creations to us.

[Read More](#)

The Neurological Alliance: Our Strength is in the Numbers

In 2023, the members of the Neurological Alliance, which includes MSNZ, came together to develop a briefing for the incoming Minister of Health to highlight common issues our organisations and the people we support face. Read more about the issues we have raised with the government below.



We hope to meet with the Minister this year to be able to discuss the issues further.



[Funding Sativex for MS Spasticity](#)

In December 2023, Pharmac proposed to decline funding for inactive applications, this included an application to fund Sativex for MS spasticity.

MSNZ has written to the Pharmac Board to ask that this application remain live and we be permitted to present more evidence regarding the patient's need. Sativex is currently unfunded and costs approximately \$300 per month. Should our request be accepted, MSNZ will be looking for stories from people with MS to highlight the burden that non-funded Sativex places on those diagnosed and their whānau. You are welcome to send your personal story to info@msnz.org.nz.

[Read More](#)

[Call for Pharmac to Widen Criteria for Shingrix Funding](#)

Pharmac announced it was looking to extend funded access to Shingrix, the new vaccination for shingles, to immunocompromised people over 18 years old. However, the proposal listed specific treatments and conditions eligible.

Together, MSNZ and Drs Jennifer Pereira, Deborah Mason and Zoe Dyer wrote on behalf of the MS patient and clinical communities to call on Pharmac to widen their proposed criteria to include people with MS, particularly those on immunosuppressive therapies.

Call for Pharmac
to Widen Proposed
Criteria for
Shingrix Funding



[Read More](#)

Amplify Your Voice



[Carers Need Respite and Care](#) 🗣️

Together with over 50 other national not-for-profits, we are backing the Carers Alliance campaign, calling on a formal place in Government to help carers access respite, and get financial recognition for their work and legislative recognition for wellbeing protection.

Please show your support by [signing the petition](#), sharing your carer's story and demand better services and support for family carers. We can supply you with hard copies to collect signatures manually, please email info@msnz.org.nz

[Sign the Petition](#)

Our Fabulous Fundraisers

Walking in Their Shadows 🚶

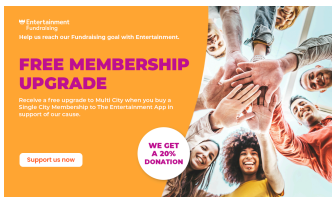
Help us to help them! Colleen and Sean are walking 1000km in Spain to raise awareness and funds for Multiple Sclerosis in New Zealand.

"Two sixty-something kiwis are attempting to walk 1000km carrying everything we need on our backs. We are starting the Via de la Plata Camino in Seville, southern Spain, on 9 March 2024 and are hoping to reach Santiago de Compostela, northwest Spain, towards the end of April."



Support Colleen & Sean

Support Us



Free Membership Upgrade

We're fundraising with Entertainment and right now you can bag a free membership upgrade saving you up to \$110 when you purchase in support of our cause!

Experience unbeatable value across Australia and New Zealand with this epic offer! A Multi City membership gives you thousands of exclusive discounts in 20 cities and right now you can unlock access for as little as \$69.99.

Want to know the best part? Your purchase directly supports us as **20% of the proceeds** will be donated directly to our cause to help us reach our Fundraising goal.

Get ready to give, get and share with a membership to The Entertainment App.

Purchase Savings

🎉 Let's Get Your Registry Party Started!

Ever thought about giving back your special event for good?

What if your birthday could raise funds to provide information resources? What if your wedding could raise funds for access to education for local community advisors? Or if your farewell could raise funds to advocate for those with MS to have access to the treatments and services that they deserve?

Create a Good Registry today here to get the party started with your go-to solution for spreading joy to causes you care about.



Giving Back



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.

[Read More](#)

Looking after you

[Staying Safe Online](#)

Whether you are new to being online, or are more experienced, it can be tricky to navigate all the information and emerging technology safely. Find out how you can stay safe online with the resources and tips from Netsafe, below.



[Learn More](#)



[Understanding MS is a Free Online Course with Positive Impacts!](#)

Understanding MS is an award-winning online course that aims to improve understanding and awareness of MS. More than 40,000 people from 170+ countries have enrolled in this free course to date!

You can participate at your own pace — including logging in at any time of the day (or night) that suits you — and the next course opens on 11th March.

[Enrol Now](#)

[Show Your Ability](#)

New Zealand's premier annual disability equipment show is back. With various dates and locations around the country to choose from, free entry and free parking, it is the ideal opportunity to see what's new in the world of disability and care equipment.



[Learn More](#)

Regional MS Society News



The Michael Ford Memorial Charity Gold Tournament

Join **MS Waikato** for the annual Michael Ford Memorial Golf Tournament at Ngahinepouri Golf Course on April 12th. In memory of Michael, who battled MS, this event supports those affected by MS and Huntington's Disease.

MS Waikato are seeking individuals or businesses to join as sponsors and/or players for a day of fun and fundraising. There are many levels of sponsorship available. To learn more and register, follow the link below.

[Learn More](#)

Get Involved

Oceans of Hope Challenge 2024

Are you ready for a life-changing sailing adventure? Oceans of Hope's aim is to help you gain self-confidence and a renewed sense of empowerment.

The camaraderie of sailing a boat with people who have similar experiences creates an environment where people can comfortably share their hopes and fears. The Oceans of Hope experience is a catalyst for creating lasting friendships and a sense of community.



[Learn More](#)

In the Spotlight

MSNZ would like to show our appreciation to the amazing sponsors of this years Bangers to Bluff Car Rally.

Thank you!



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.



P.S. Please check our our [Latest News](#) section on our website for the most up to date information.



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