

e-Newsletter

Tēnā Koutou Katoa, a warm hello to you all,

We're thrilled to welcome you to the June edition of MS Voice, your go-to place for the latest news, updates, and real life stories from Multiple Sclerosis New Zealand. Can you believe we are almost halfway through 2024? For us here at MSNZ the year has been flying by and it doesn't seem to be slowing down anytime soon. However, this Matariki weekend we hope everyone will have some time to relax and connect with your whānau, friends and communities. If you're interested in how to find the Matariki star cluster, <u>watch this video</u>.

What's Happening at MSNZ

We are excited to be hosting, alongside MS Auckland and the NZ MS Research Trust our <u>MS Brain Health Seminar</u> on 11th July at Novotel Ellerslie. Our guest speaker, Professor Helmut Butzkueven, will share his knowledge on the importance of optimising brain health. We hope to see many of you there, but we appreciate not everyone can attend, so the event will be recorded. To receive a copy of the recording direct to you inbox, please <u>register here</u> or via the link below.

The amount raised by April's <u>Bangers to Bluff</u> car rally have blown us away! An outstanding \$120,000 was raised for charity. An incredible \$71,000 was donated to MSNZ and the regional societies involved en route. These crucial funds will help support individuals in Aotearoa affected by MS. We humbly appreciate each and every donation and send our sincere gratitude to the Rotary Club of Half Moon Bay, the rally participants and of course all of the supporters and donors. This event is a great fundraiser and vehicle for MS awareness. If you would like to be involved in 2025's event applications are now: <u>https://www.bangerstobluff.co.nz/</u> or if you'd like to come on board as a sponsor, please <u>contact us</u> - we'd love to take you on the journey with us.

The under-resourced health system has been causing delays in MS patients' <u>access to treatment</u>, particularly in the Canterbury region where staff shortages prevent patients from starting approved treatments or having neurology reviews. After MSNZ drew the media's attention to the issue, patients are now <u>starting treatment</u> or undergoing review. This issue of under-resourced neurology services is a national problem and MSNZ is working closely with our Neurological Alliance partners to highlight this issue with decision makers.

In July, MSNZ is meeting with Pharmac to urge the funding of new therapies for RRMS that could reduce the burden of lengthy infusion times. These treatments, while not necessarily suitable for everyone, could widen options for personalised treatment management and ease pressure on infusion centres. Patient voice is key in these efforts, so please keep your comments coming in. Thank you to those who have already sent us their <u>infusion barrier stories</u>. We genuinely appreciate you taking the time to let us know about the challenges you face in accessing treatment, and how the new subcutaneous options could help overcome these hurdles. If you'd still like to share your thoughts, please email your story by the 30th of June to <u>info@msnz.org.nz</u>.

Nationally, there are increasing delays in home modifications or equipment assessments through Enable. We are hearing reports from across the country that people are waiting up to 18 months for home modifications or electric wheelchairs, which impact quality of life and independence. Reports of these delays are being collected to address with Whaikaha, the funders

of Enable NZ. Furthermore, issues with Whaikaha and <u>changes to purchasing rules</u> are being monitored, as more changes are anticipated. One key problem is the lack of information about what can be funded, and work is ongoing with alliances to address this information barrier. Concerns should continue to be reported through Community Advisors of your <u>local regional</u> <u>society</u>.

Last week was <u>National Volunteer Week</u> and we wholeheartedly sent appreciation to everyone who has generously donated their time, effort, and resources by volunteering with us or the regional societies. We also expressed our heartfelt thanks to MSNZ's dedicated Committee of volunteers. We simply couldn't do all the wonderful things we do for those affected by MS in Aotearoa without this amazing group of talented and hardworking volunteers.

Share your Infusion Story with us

Time Matters in MS - Brain Health Seminar





MSNZ Resources

MS Diagnosis Wallet Card

The next item in our <u>Information Resources</u> to introduce you to is our MS Diagnosis Wallet Card. This compact resource provides an overview of assistance you may require when out and about. In addition it provides a space for you to list contact details for your MS support team which may need to be contacted in an emergency.

The card is available as part of the <u>Living Well with MS Information Packs</u> you can obtain from <u>your local regional society</u> or download from our website to print at home.



Esme Tombleson Award - Applications Open

In honour of our co-founder, we present an <u>Esme Tombleson Award</u> each year to anyone who has made a significant contribution, nationally, to MSNZ and people impacted by MS. If you know of a deserving recipient, nominate them via your regional society.



Supporting MSNZ

Without the support of amazing people like you, we wouldn't be able to do the work we do at MSNZ. Your generous contributions enable us to continue providing advocacy and information that improves the lives of families affected by multiple sclerosis.

Each year, MSNZ needs to raise over 90% of our income through kind donations, grants, bequests and business support. Every bit helps and we're incredibly thankful for any donation received. We'll send a receipt for all donations and guess what? If your donation is over \$5, you're eligible for a tax refund. Now that's a win-win!

Below are some ways you can support us this July. Click on the pictures to learn more. Thank you.



Walk, Run or Roll for MS!

The video of the staff, kids, family and whānau at Learning Curves Montessori Lincoln taking part in their walk, run or roll for MS event recently brought tears to our eyes! We are deeply touched by their support for 'their Bruce' and our advocacy work for the MS community. Their efforts help us support local regional societies and ensure everyone has access to the best information.

Their fundraising will go a long way in helping people like Bruce. Watch their heart warming short <u>video</u> on their Facebook page.



Fancy Giving a Little to MSNZ?

Why not use <u>Givealittle</u>, 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.



School Holidays Sorted!

Keep the kids entertained these school holidays with unbeatable fun and value! Get up to 50% off kid-friendly restaurants, thrilling activities, exciting outings, travel adventures, and so much more! All with a 12-month Entertainment Membership starting at just \$69.99!

Don't let boredom strike! Jump on this incredible offer and keep the kids entertained all holiday long while saving big and supporting our Fundraising cause.



A Regular Helping Hand

Regular donations make a big difference to our work, enabling us to plan more effectively for the future, achieve our goals and commitments to supporting New Zealanders living with MS. To become a regular donor donate <u>online</u> or contact your bank for support.



Explore Ways to Donate Here

In the Spotlight

To our wonderful volunteer Committee members, your knowledge and support are both greatly appreciated. We genuinely value each and every one of you.

The team photo below shows MSNZ National Manager, Amanda Rose, holding our MS Brain Health Team Award. In the photo, from left to right: Committee members Prue, Jeff and Neil. Staff members Louise, Amanda and Emily. Committee members Jan, Graham and Jan. Committee members missing from this photo include Ingrid, Jenny and Johnny, and staff member Vereana. Thank you, all.







Please check out our latest news section of our website for the most up to date news and information.

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: <u>info@msnz.org.nz</u>

Your continued support helps us to achieve so much for those impacted by MS.

Noho ora mai. Stay well and look after yourself.



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