



Newsletter

October 2021

Welcome to our October edition of MS Voice. Here, we bring you the latest news from MSNZ and what we have been working on, tips to live well with MS and much more.

We love to share real life stories, if you would like to share your MS story with the MS Community, please get in touch: info@msnz.co.nz

MS Announcements and Events



[Progression in MS Webinar Recording](#)

The New Zealand Multiple Sclerosis Research Trust's recording of Progression in MS is now available.

Learn more about progression in MS and the advances being made in research from Professor Tomas Kalincik. Dr Julia Morahan provides an update from the International MS Progressive Alliance.

[Watch recording here](#)

MS Awareness Week Update



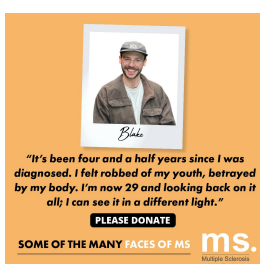
[Thank you](#)

For the second year running, our national awareness campaign was severely impacted by Covid-19 lockdowns. As a result, we extended the weeks campaign to the month of September. In these hard times, our hearts are warmed by the generosity shown during this time and we are tremendously grateful for your support and belief in our work.

There is still time to give a donation to help MSNZ or your local Regional Society continue to support people with MS in your community. Thank you.

[Donate here](#)

We would like to take this opportunity to share with you some of the Faces of MS that shared their MS journey.



[Blake: I wouldn't say I'm glad I've got MS. But if you asked me to give it and everything it's taught me up, I'm not sure I would](#)

I woke up needing to use the toilet. Rubbing my eyes and blinking furiously, I tried to focus my vision. "Damn, I need more sleep" I remember thinking as I crawled back into bed. I was living in Berlin at the time but had returned to Dresden for the weekend. The night before, we had celebrated my partner's birthday and when I woke with my vision blurred and reaping the early signs of a hangover, I was sure I just needed more sleep.

It wasn't until we got up a few hours later and sat down for breakfast that I said to Anna "I think there's something wrong. I can't see."

[Read Blake's story](#)



Hiking 3000km along Te Araroa to raise Multiple Sclerosis awareness!

Blake is raising funds for MSNZ and MS Otago by doing the 3000km Te Araroa Trail. Why? Because as Blake says "If you google MS you'll find that for every story of hope, there are 100 more stories of despair. This isn't a fair representation of the MS community! I wish I had known that as I scrolled through endless stories showing nothing but wheelchairs and disability. Hopefully, through sharing this journey, we can highlight a story of hope especially for those newly diagnosed and their loved ones."

Any funds you can spare would help provide those in our community with the support necessary to help them through their MS journey. Thank you so much for your support!

[Support Blake](#)



Lieza: I don't want MS to control my life, so I am controlling it

A big thank you to NZ Herald for publishing a fantastic article highlighting how MS has impacted Lieza and the changes she has made to make a difference to her life. "I do sometimes think, 'why me'? But having MS has made me appreciate little things in life a lot more, like when I can do things without getting too tired. I am in awe of my body and what it can do."

[Read Lieza's story](#)



Jeremy: Anyone diagnosed with Multiple Sclerosis is in for a rough ride

"No matter how 'grim' it may sound, or appear, you simply can't dwell on that or indulge that line of thinking. It can take you to a very dark place....I know, I've been there and I don't intend to go back."

[Read Jeremy's story](#)



Golriz Ghahraman MP

The whole process of getting an official diagnosis took Golriz six months, and then another couple of months to get access to treatment. "They want you to have two attacks before you qualify, just to make sure you're really, really good and MS-ed."

[Read Golriz's story](#)

There are many others like Blake, Lieza, Jeremy and Golriz, please give whatever you can this year to help us support people with MS, ensuring they live their best lives.

[Please donate](#)

Covid updates



COVID-19 vaccination guidance for persons with Multiple Sclerosis (MS)

The current number one health priority around the world is rapid and efficient roll out of an effective vaccine to contain the COVID-19 pandemic. More than 200 million people have been infected and over 4.5 million have died worldwide.

Evidence shows that a person with multiple sclerosis (PwMS) is no more likely to develop COVID-19 or its complications, including if on treatment (with the possible exception of those on ocrelizumab who may be at very slightly increased risk). Those with secondary progressive MS and higher levels of disability may be at increased risk of complications from COVID-19.

[Read more](#)



[Covid brochures from the Ministry of Health](#)

We have updated our website with some recently released resources from the MoH, including:

- [An easy read guide to the Covid vaccine](#)
- [Booking a covid vaccine and what you need to know](#)
- [Safety and side effects sheet](#)

[Read more](#)



[St John's Health Shuttle](#)

The St John's Health Shuttle is a kōhanga-based community service that transports people to health-related visits, and then brings them home again.

The service is staffed by trained St John's volunteers. It helps people get to their GP, dentist, specialist, or day surgery appointments.

Some shuttle vehicles are fitted with hoists to help passengers who have restricted mobility.

[Read more](#)

Support Us

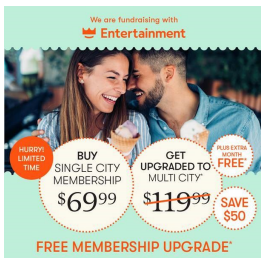
[Give a little time](#)

MSNZ, and all the Regional Societies that we support, would not function without the hard work and support of our volunteers.

Volunteering opportunities may involve collecting at Street Appeals, helping at or organising events or supporting the office staff with daily tasks.



[Support us](#)



[Still haven't purchased your new Entertainment membership?](#)

Good news: buy now until the 13th October and receive a FREE upgrade to a multi city version; unlocking every city in New Zealand, Australia and Bali for 13 months from the date you activate. *That's a saving of \$50!*

The memberships have thousands of local and regional offers for the best restaurants, cafes, takeaway, activity and retail outlets. And 20% of all sales go directly to our fundraising. Purchase below today.

[Support MSNZ](#)

Multiple Sclerosis in the news



[Kiwis with MS 'light years' behind Aussie patients](#)

A new trans-Tasman study has highlighted alarming health inequities between New Zealand patients living with multiple sclerosis (MS) and their Australian counterparts — adding fuel to the ongoing fight for Pharmac to "do the right thing" and increase access to drug treatments here.

The results prove that patients here are far worse off, disabled sooner and suffering from a poorer quality of life.

"It is research like this that drives Multiple Sclerosis NZ to improve outcomes for New Zealanders with MS. We are committed to advocating for changes that improve access to services and treatments that help people live well with MS."

[Read more](#)

Looking after each other



Keep S'myelin!

When you're talking about multiple sclerosis, children don't usually come up in the conversation. After all, most people who have this progressive neurological disease are diagnosed between the ages of 20 and 50. But MS can and does strike in childhood. In fact, as many as 10% of MS patients first have symptoms before age 16.

There are many amazing resources available to help us understand how a child or teenager may feel when they are diagnosed with MS. We have added some to our website for you to review.

[Read more](#)



All aboard the Meal Train

Supporting friends and loved ones by cooking food is not a new thing, but organising it through a website with a catchy name is. That's where Meal Train comes in.

You can set up a Meal Train page for someone you care about, by heading to their website: <https://bit.ly/2Y4YrsK>

[Read more](#)



How is Email affecting your mental health?

There are a few different ways email might be affecting your mental health. The pressure to stay connected to work at all hours of the day is the most common email-related stressor.

Email is a wonderfully helpful communication tool. So much so that it's become integral to the business world. Unfortunately, however, it's become so important that employees often feel pressured to check email out of work hours. This is called "always-on" culture, and it's painfully common.

[Read more](#)

Get Involved



Make aHSCT available in NZ for MS

Overseas, Autologous Haemopoietic Stem cell Treatment (aHSCT) is having a profound effect on the lives of many people, particularly those with highly active Multiple Sclerosis. Some with more advanced MS are also seeing their progression halted. aHSCT is not intended to reverse the damage done, but it can restart the immune response and halt further progression.

Please sign this petition to call on the Government to make aHSCT available for MS patients.

[Read more and sign the petition here](#)



Youth Parliamentarian

Once every parliamentary term a Youth Parliament is held. Each MP gets to choose a young person to represent them over a six month period from March to August 2022 with a short stint in Parliament itself.

Nominees need to be 16 to 18 years of age (inclusive) on 12 November 2021 and looking for ways to become active in their community or region.

[Read more](#)

With kind regards and best wishes,

ms.

P.S. Please check our our [Latest News](#) section on our website for updated guidelines and information.



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