

ms. voice



Newsletter

November 2021

Welcome to our November 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.org.nz

MS Announcements and Events

Hi, I really wanted to get in touch and say a huge thank you 🙏. I have just received the information from the Nelson Marlborough DHB that I am now eligible to apply for Pharmac funded disease modifying therapy again, two years after I had to stop because I couldn't do the walk required. I am so grateful for Your lobbying for this change to happen, I don't have enough words 🥰 but your hard work is so appreciated 🙏

We still need your support!

MSNZ needs your support to continue helping New Zealanders like Nicki, gain access to treatments earlier to improve longer-term brain health outcomes.

Any donation, no matter the size, will help us make those with Multiple Sclerosis continue to feel supported and connected.

If you can support us on a regular basis this will make an even bigger difference to our work, allowing us to plan more effectively for the future, achieving our goals and commitments to supporting those living with MS in NZ.

[Please Donate](#)

ECTRIMS 2021



ECTRIMS Conference 2021 - Review

The 37th Congress of the European Committee for Treatment and Research in MS (ECTRIMS) was held online recently. The scientific programme comprised of well-known session formats such as Scientific Sessions, Hot Topics and Meet the Experts, as well as live discussions between the international faculty and participants at the end of each session. Southern DHB Neurologist Dr. John Mottershead has provided an excellent review of some of the hot topics.

Highlights in this review include:

- MRI activity vs relapses as markers of disease activity in SPMS
- Real-world experience with ocrelizumab in patients with PPMS
- Humoral immune response to SARS-CoV-2 vaccines in patients with MS.

[Read More](#)



Acklin tacklin' Araroa

Blake Acklin has a bucket-list adventure in his sights — walking the 3000km Te Araroa Trail the length of New Zealand. The epic tramping trail, which stretches from Cape Reinga to Bluff, is not only a personal challenge for Mr Acklin, it is a chance to raise awareness and funds for a cause dear to his heart — multiple sclerosis.

[Support Blake](#)



Andrew: Passionate poet and crafter

Andrew Hodson was diagnosed with Secondary Progressive MS (SPMS) in 2008.

"I probably had it for 20 years before that. A mixture of symptoms appeared then went away, including numb legs plus pins and needles. The initial diagnosis was very confronting, and I shed many tears."

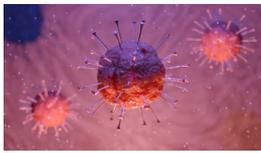
Read Andrew's story to see how he has learnt to really enjoy life by shifting his focus to poetry and other creative activities.

[Read Andrew's story](#)

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

[Please donate](#)

Covid updates

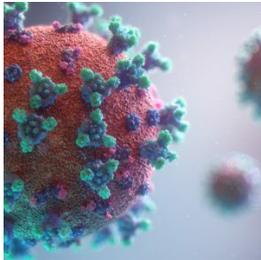


3rd Primary Dose of COVID-19 Vaccination - do you need it?

On the 19th of October 2021, the Ministry of Health announced 3rd primary dose vaccinations for those who are severely immunocompromised. This announcement was based on recommendations by the COVID-19 Vaccine Technical Advisory Group (CV TAG) who continuously review evidence and provides advice to the Programme.

We have prepared the following information with advice from our specialist advisors to assist people with MS to understand the recommendations and their eligibility.

[Read more](#)



General Covid Update

With information being published almost daily it can be hard to keep up to date with the latest information.

We have been collating the information throughout the pandemic, and have added new links to our website to assist you in staying informed.

[Read more](#)

Get Involved



O-Hand trial for Primary Progressive MS

About 15% of people with MS are diagnosed with Primary Progressive Multiple Sclerosis (PPMS) which is characterised by a slow onset and steadily worsening symptoms.

O-Hand, or Oratorio-Hand, is a clinical trial involving 1000 adults with PPMS globally and Multiple Sclerosis NZ is excited to see 4 trial sites taking part in NZ based out of Waikato, Wellington, Christchurch and Dunedin DHBs.

[Read more](#)

GLOBAL WEBCAST
TUESDAY, 9 NOVEMBER
**FATIGUE
IN PROGRESSIVE MS**
Current Treatment and the
Hope of Research

[Register Today](#)

INTERNATIONAL
PROGRESSIVE MS ALLIANCE
More than hope. Progress.

Fatigue in Progressive MS - Webcast

Fatigue is one of the most common, troubling symptoms experienced by people with progressive MS. For many people, it is the symptom that affects them most.

During this 30-minute global webcast an international panel of MS experts will answer questions submitted by people affected by MS from throughout the world.

[Read more](#)



[Let's all sign the petition](#)

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](#)



[Oceans of Hope Challenge](#)

Oceans of Hope Challenge NZ are teaming up with Sailability Nelson to challenge you to have a sail in a fully accessible Hansa boat. These are dinghy size boats that are designed on the principals of Universal Design so everyone can enjoy sailing regardless of age and ability.

Whether you have sailed before or not, this is an opportunity not to be missed!

[Read more](#)

Multiple Sclerosis in the news



[HSCT treatment in Mexico](#)

Nicola Chapman Haste was diagnosed with MS over 10 years ago and decided to have a treatment called HSCT in Mexico.

In her interview with Sky News, she describes the process and her prognosis, stating "I won't have to take drugs for life."

[Watch interview here](#)



[NZ Disability system changes ahead](#)

The Ministry of Health announced on Friday 29th October, upcoming changes to the Disability System in NZ.

The changes have been described as transformational and achieve lasting change.

[Read more](#)



[Introducing Selma Blair - documentary](#)

Actress Selma Blair gives an intimate, raw look at her life as she adapts to living with multiple sclerosis.

After revealing her diagnosis on social media, Selma becomes a platform for disability and takes steps to slow the disease's progression with HSCT.

[Read more](#)

Support Us



[Gift to us through The Good Registry](#)

We are a proud partner of [The Good Registry](#), a website where you can ask for and receive charity donations instead of physical gifts.

The Good Registry has two good ways to share the joy of giving:

[Give Good Gift Cards](#). These are online vouchers that recipients can exchange for donations to the charities they choose. There are 65 charities to choose from, including us.

[Set up a Good Registry](#) for a special event such as a birthday or Christmas. Your friends and family can donate to your favourite charity and leave celebratory messages on your registry page.

Instead of your business giving the regular corporate gifts this year, why not consider giving a gift with meaning and make a donation instead?

You can support us anywhere, anytime through The Good Registry – a gift giving choice that's good for our people and the planet.

		
Give simply	Help good causes	Reduce waste
10,000 people and businesses have given with our charity gift cards and gift registries - no stress, no guesswork, no gaffes!	We've raised \$600,000 with charity donation gifts - for birthdays, weddings, corporate gifts and more	We've replaced 17,500 gifts - adding up to tons less waste in production, packaging, wrapping and transportation

[Gift Good Gifts](#)



[WIN 6 MONTHS OF GROCERIES + FARMERS eGIFT CARDS!](#)

One of the best things about the Entertainment Membership, apart from supporting us, is that you have thousands of offers from some of the best restaurants, cafes, activities and shopping that our cities have to offer.

Just for supporting MSNZ, anybody who purchases a Membership before November 17 will go in the draw to win \$5,000 worth of groceries from Countdown! You will also receive a FREE Gift With Purchase: \$40 Farmers eGift Card when you buy a multi-city app, and \$20 Farmers eGift Card when you buy a single city app.

Thanks for your continued support!

[Support MSNZ](#)

Looking after yourself

[Top 11 tips for cyber security](#)



Cyber security attacks are becoming more and more common over time, so it's important to know what you can do to protect your information online.

While there's no bulletproof way to prevent an attack, there are a lot of things you can do that will help to lessen the risk.

Photo by [FLYD](#) on [Unsplash](#)

[Read more](#)

[Let's talk podcasts](#)



Some say it's the golden age of podcasts. Everyday millions of us stream our favourite episodes whilst commuting, exercising and getting through household chores. Podcast listeners, you'll be delighted to know there is plenty of MS content to discover.

Here, MSIF list six recommendations for podcasts around the world.

Photo by [Mohammad Metri](#) on [Unsplash](#)

[Read more](#)

[How to manage fatigue for better work, rest and play](#)



Fatigue is one of the most common symptoms of MS, occurring in approximately 80% of cases. It can interfere with participation in all aspects of life, particularly a person's ability to work.

The good news is that you can take steps to lessen its impact on your daily function and participation in work. Having a good understanding of your fatigue – what causes it; how it works; what strategies work for you to



manage and lessen it is a good place to start.

Article attributed to MS Australia.

Photo by [Luis Villasmil](#) on [Unsplash](#)

[Read more](#)

With kind regards and best wishes,

ms.
Multiple Sclerosis
New Zealand

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



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