

ms. voice



Newsletter

July 2021

Welcome to our July 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



New Clinical Trial for those with PPMS

About 10% of people with MS are diagnosed with Primary Progressive Multiple Sclerosis (PPMS). While more common forms of MS involve a relapse-remit pattern (unpredictable attacks followed by periods of disease inactivity), PPMS 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.

The main purpose of this study is to test the effects of ocrelizumab (OCREVUS®) on upper limb function (hands, arms and shoulders) in people with PPMS, including those with more advanced disability.

[Read more](#)

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Could you be our next Independent Committee Member?

Multiple Sclerosis New Zealand's (MSNZ) National Executive Committee are currently seeking interest from people with particular skills in either Fundraising, Corporate Sponsorship and Marketing, or Health and/or Government Advocacy.

MSNZ's purpose is to deliver advocacy, information, awareness and education so people living with MS can independently live their best lives. We do this by collaborating with member organisations to provide a voice for people with Multiple Sclerosis, their families and carers through leadership, advocacy, communication, and national and international collaboration.

If you have the passion, time, skills and dedication to help us achieve these goals get in touch!

[Read more](#)

[Community Support Worker training overview](#)



Multiple Sclerosis NZ (MSNZ) was proud to once again host the annual meeting for 23 MS Community Support Workers from across the country.

With our 2020 training disrupted by the pandemic, and after a year in which many of our Regional Societies fundraising efforts had been hard hit, we were pleased to secure enough funds to cover 100% of the meeting, travel and accommodation costs of our attendees. We thank Roche, Biogen, Merck and Novartis for their support of this event.

MSNZ aims to deliver advocacy, information, awareness, education so people living with MS can independently live their best lives. This year's meeting was held over 3 days in May and promoted evidence-based concepts of optimal self-management practices, providing education to Community Support Workers to assist their local clients in developing self-management skills, to enable them to live their lives as independently as possible.

Gillian Fry, Manager and Lead Community Advisor for MS Wellington, describes below the impact of this important educational meeting.

[Read more](#)

[Street Appeals - Can you help?](#)



Multiple Sclerosis Regional Societies across New Zealand will soon be holding their annual street appeals to raise the vital funds they need to support people impacted by MS in your community.

Why not volunteer your time by helping them to help those with MS in your community to live their best life.

[Contact your local society here](#)



[Understanding MS Course - Registrations now open](#)

Understanding Multiple Sclerosis is a free online course from Menzies that aims to improve understanding and awareness of MS. It is available to everyone worldwide.

Each module ends with a short quiz to enable you to gauge how much you have learned, and on completion of the course you will be provided with a certificate of achievement.

Educational videos of academics and health professionals deliver evidence-based information on the disease risk factors, progression and management, while interviews with people living with MS provide personal perspectives on diagnosis, symptoms and symptom management.

[Read more](#)



Thursday, June 24 [Register Today](#)

INTERNATIONAL
PROGRESSIVE MS ALLIANCE

More than hope. Progress.

[Progressive MS Alliance Webcast](#)

The latest advances in progressive MS research and treatment are addressed during this global webcast. An international panel of MS experts answered questions submitted by people affected by MS from throughout the world.

From symptom management and well-being to the development of treatments that can slow progression and rebuild myelin, this webcast provides information to help improve quality of life and keep you informed.

[Watch Webcast](#)



[Jeremy's story](#)

Anyone diagnosed with Multiple Sclerosis is in for a rough ride, says Captain Jeremy Seed, RNZAEC. He lives with this debilitating disease every day, and this is his story.

The MS diagnosis, when it finally came, scared me – 'surely I will be discharged from the Army?' I thought.

Over the last few years, there have been some big developments with medication which does not restore lost body functionality, but stops things getting worse. In 2017, I removed all dairy and gluten from my diet and that has made a big difference to how I have felt, but the biggest impact of MS, by far, was on my mental health.

[Read more](#)



[Gold Star Award](#)

Connect Neuro Physiotherapy's Jen Hewson is a Senior Neurological Physiotherapist. In this article she introduces us to Lynn, the Gold Star Award recipient for June 2021.

Lynn was diagnosed with Multiple Sclerosis in 2007 and has been using a power wheelchair since Christmas-time 2019. Lynn's biggest battle is her spasticity which limits her ability to stand, to walk, and to selectively move her limbs. Over the past two months Lynn has dedicated herself to a physiotherapy rehabilitation programme working on her strength, and functional mobility.

Lynn's tenacity and motivation to maintain her independence is extremely inspiring and it's been a real pleasure working with her. She has pushed herself, to be able learn a new transfer technique, and has worked hard on ways to help manage her spasticity.

[Read more](#)



[Stay healthy this winter](#)

There are lots of coughs, colds and tummy bugs doing the rounds at the moment, so we do hope you are well. It can be all too easy to want to hide away under the covers when you are unwell, but remember to still eat well and stay hydrated. Then, rug up, head outdoors and get some vitamin D from the sunshine or you might like to speak to your doctor about whether you require a supplement.

If you need any tips to stay well this winter, we have some on our website which can still be relevant, even if you do not have MS. Diet and exercise are two very important factors to consider for everyone.

[Read more](#)



[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.

See [here](#) for other ways to gift.

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With kind regards and best wishes,

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



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