

ms. voice

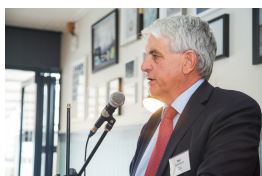


Newsletter

June 2021

Welcome to our June 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



[MSNZ President receives Queen's birthday honour](#)

Multiple Sclerosis NZ is thrilled to announce our President, Neil Woodhams, has received an honour in the Queen's Birthday List for recognition of his services to people with Multiple Sclerosis.

Neil is a leading advocate for New Zealanders with MS, so we were proud to support the application made by MS Auckland of this well-deserved title. All of the work Neil does is on a voluntary basis and he is instrumental in leading the organisation to the strong and positive position it is in today.

Neil is a passionate advocate and Multiple Sclerosis NZ has been fortunate to have his skills, knowledge and drive on our advocacy team. Despite being a small organisation, it is with those skills that we can achieve big things.

Yesterday he received his Officer of New Zealand Merit (ONZM) - a most well deserved honour.

[Read more](#)



[World MS Day Webinar - The Covid vaccine and MS](#)

The New Zealand Covid Vaccine Programme is currently being rolled out and will soon be available for those with disabilities and high-risk health concerns.

We acknowledge the high level of interest within the MS Community for information about how the vaccines are impacting people with MS globally, and when they will be available.

To mark World MS Day, Multiple Sclerosis New Zealand and the Ministry of Health were pleased to co-host a webinar on Wednesday 2nd June where we addressed the questions you had and detailed the set process for accessing the vaccination.

You can [view the recording here](#).

[Read more](#)



[Update: Ocrelizumab for Primary Progressive MS](#)

At the November 2020 meeting of PHARMAC's *Pharmacology and Therapeutics Advisory Committee (PTAC)* further information was reviewed to support the application for funding of Ocrelizumab for Primary Progressive MS.

At this meeting PTAC recommended listing with **low priority** and have requested further advice from the Neurological Subcommittee and the Multiple Sclerosis Treatments Advisory Committee (MSTAC).

MSNZ is pleased to see acknowledgement that there is supporting evidence

for the use of Ocrelizumab for those with PPMS and recognising the high unmet health need. However, there is still substantial work to be done to progress the recommendation higher up the priority list.

[Read more](#)



[McDonald 2017 criteria finally receives PTAC recognition](#)

Still unfunded, but finally acknowledged, McDonald 2017 criteria for diagnosing MS is one step closer to being used in NZ for accessing treatment.

MSNZ have been advocating for Pharmac to update the Special Authority criteria since 2017. This would align NZ practice with international recommendations. Pharmac continue to use the old definition of clinically definite MS, which requires two clinical attacks. They have declined all requests by MSNZ, despite diagnostic methods and the understanding of MS having progressed.

[Read more](#)



[Special Authority Criteria Amendment for DMTs](#)

Multiple Sclerosis NZ received several reports from concerned patients regarding the ambiguity of the Special Authority Criteria for DMTs.

With the support of Dr John Mottershead, Pharmac were approached for clarification.

[Read more](#)



[Thank you](#)

Thanks to the support of our donors, the recent changes Pharmac approved, which MSNZ advocated for, will keep people on treatment for significantly longer. We are already hearing reports about the huge impact this knowledge is having on people with Multiple Sclerosis.

Your support helps us to continue advocating for the MS Community.

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

[Donate here](#)



[Petition to make aHSCT available in New Zealand 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.

Since 2017, Multiple Sclerosis New Zealand have been advocating for the introduction of aHSCT in NZ based on the overwhelming evidence to support it.

[Read more](#)



[Have your say - MS information review](#)

To live well with MS, information is vitally important to understand and best manage your condition.

Multiple Sclerosis New Zealand are currently reviewing the resources we make available to New Zealanders impacted by MS.

Please help us ensure the information we provide is relevant and valuable to those diagnosed and supporting someone with MS by completing the relevant category of the surveys. Each survey should take about 20 minutes.

[Read more](#)



[Oceans of Hope Challenge](#)

Ingrid Robertson and Gail Leonard started 2021 in great style, taking part in the Oceans of Hope Challenge event this Easter, in Auckland.

During 2020, when all the world's sailing plans were being cancelled, thanks to Covid, Ingrid was planning and organising a group of 23 Kiwis to set sail, on board the world beating Steinlager 2. With the help of [New Zealand MS Society](#) they filled the boat with a crew of MS participants. All Covid 19 safe, they were ready to discover and explore the North island.

[Read more](#)



[The end of cheques - are you and your family ready?](#)

Did you know that NZ will stop processing cheques this year? For MSNZ this means that **from July 2021, we will no longer be able to use our bank to process any cheque donations.**

This is a big concern for us as many of our amazing donors use this preferred method of payment. We appreciate that this is a big change and would like to help make it as easy as possible for our supporters to carry on supporting us as their charity of choice.

Review our article to find out others ways to donate and other supports available to assist you and your family with the changes being implemented.

[Read more](#)



[New Zealanders urged to consider careers in care and support](#)

The vast majority of New Zealanders believe people working in community support roles are important to society but less than half of New Zealanders would recommend it to family as a career, according to new research.

Not only are care and support roles hugely rewarding, interesting and fun, but they are also flexible with opportunities for full-time, flexi-time and contract roles that can be managed to fit around personal commitments.

[Read more](#)



[Bangers to Bluff - by car and by bike!](#)

One of our team members, Graham Walker, has Primary Progressive MS. In his early days of diagnosis, Graham had it impressed upon him the importance of exercise in being able to take control of his condition. With this in mind, Graham decided to really take part in this years [Bangers to Bluff challenge](#), fueled by pedal power!

We are still receiving donations for this fundraiser, and will update you all on the outcome soon. For now, though, we really wanted to congratulate Graham on his accomplishment of cycling between Auckland and Bluff and give our sincere thanks to The Rotary Club of Half Moon Bay for supporting MSNZ, and to the sponsors of our banger - you are all amazing.

[Read more](#)



[Donate to show your support](#)

With kind regards and best wishes,



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



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