

Bangers to Bluff Special Edition











e-Newsletter

April 2024

Kia ora.

Welcome to the April edition of MS Voice, your source for the latest updates, information and inspiring stories from Multiple Sclerosis New Zealand.

Bangers to Bluff 2024 reached it's final destination on Saturday 20th April, with all crew present and accounted for.....but one or two cars were replaced along the way! There were many kilometres driven, trials to participate in and laughs throughout the event. Read the update below, then head to our <u>Facebook page</u> to see all the wonderful images of the fantastic teams that participated and tune in for further updates next month.

We're getting close to reaching our goal of raising \$20,000 of vital funds to support people impacted by MS, so please donate, if you can.

When asked his thoughts at the conclusion of the event, Jeff, our team 'Keep Smyelin' rally driver said "It was a great experience with a fantastic group of people. They were very keen to learn about MS. The general consensus was that they were so much more aware of MS. The other very successful part was the interaction with the regions".

Bangers to Bluff wouldn't be as successful as it is without all the hard work from the Rotary Club of Half Moon Bay, our rally crew, regional MS Societies, followers, supporters and of course sponsors, THANK YOU all.



Clarification on Purchasing Rules from Whaikaha



Clarification on Purchasing Rules from Whaikaha Ministry of Disabled People

On 24 April, following significant feedback from the Disability and Carers communities, Whaikaha has made amendments and changes to the purchasing rules and clarified changes and some of the uncertainties. These relate to purchasing rules for support services, equipment and modifications.

On 30 April the new Minister for Disability Issues, Louise Upston has announced that there will be a review into disability support services funded by Whaikaha following the recent events and changes.

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Graham's Bangers to Bluff Challenge &

Wow....that is how we sum up Graham's effort during 2024's Bangers to Bluff Rally. He has cycled 170 kms during 12 days, since leaving Auckland on the 9th April.

Graham got up at the crack of dawn and set off on his road bike to cycle as far as he could before being caught by the bangers. Jeff, who was our MSNZ amazing rally driver would then pop Graham's bike on the bike rack attached to the rear of our very own rally car, a silver VW Golf and they would carry on to the next location before doing it again.

If you would like to show your support for the team's amazing mahi, please head to <u>Graham's challenge web page, here</u>.

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Bangers to Bluff 2024

The rally travelled hundreds of kms over the 12 days, between Auckland and Bluff taking roads less travelled. Not only did this route make it more interesting for the rally participants, but it also gave team 'Keep Smyelin' the opportunity to meet with people off the beaten track, spread awareness of multiple sclerosis, MSNZ and our regional societies.

There are some wonderful photos on our <u>Facebook page</u> which give a great insight into what the teams saw en-route. We are so very thankful to the Rotary Club of Half Moon Bay for choosing MSNZ as their masthead charity and are thrilled to hear they are supporting us again next year.

Funds raised are still coming in, but if you would like to donate, please go to our Bangers to Bluff website or send your donation direct to our account:

Multiple Sclerosis Society of New Zealand 02-0500-0355668-00

Many thanks to <u>William Todd & Co Auctions</u> for making the auction such a success. This year saw more people than ever before arrive for the auction. All vehicles were sold, as was Graham's bike and bike rack. One lucky bidder won the Panasonic auction to have their choice of item delivered to them, and the mystery envelopes from MS Southland were a huge hit.

A final thanks to everyone involved, the rally participants, those the rally met onroute, the regional societies involved and of course our sponsors. **THANK YOU**.





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I HAVE MULTIPLE SCLEROSIS

Multiple Sclerosis New Zesland

My speech may be slurred and my mobility and balance may be affected.

I may need to sit down, require your assistance or need to use your facilities.

I APPRECIATE YOUR ASSISTANCE AND UNDERSTANDING

0800 MS LINE www.msnz.org.n

info@msnz.org.nz

MS Diagnosis Cards

We recently introduced you to our new <u>Living Well with MS</u> resource. This month, we're highlighting our 'MS Diagnosis Card'. You can pop this card into your wallet, phone case or handbag to carry around with you to help you get assistance when you need it whilst out and about. Complete yours today and carry with you.

Hard copies are available via your local regional society, so make contact with your community advisor, or download the PDF's from our <u>website</u>.

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Dorothy Newman Recipient, Ashley!

Congratulations to Ashley, one of our 2024 Dorothy L Newman Scholarship recipients. We are so pleased to be able to support you during your studies and look forward to watching your journey to becoming a teacher. We have no doubt you will inspire and guide the children in your classroom in an encouraging, supportive, and fun way.

The Dorothy L Newman Scholarship is co-funded by MSNZ and the Dorothy L Newman Trust. If you would like to learn more about the scholarship, head to our website here, or click on the link below where you can read Ashley's full story.



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🞉 Superhero Colouring Competition! 🧸 🞉



We are super excited to announce the winner of our MS Superhero Colouringin competition is none other than 11 year old Louisa, who's creation we shared with you last month. Her drawing was just too good to beat! Ka pai Louisa.

If you missed it, her Superheroes name is Vitamin K and their superpowers are being kind and brave 🥦.

Louisa's Mum, Kirsten said:

"It was a lovely way to encourage learning about how to care for her without being too serious or boring. It was a fascinating to get a child's view of MS, and of her mum".

We hope you enjoy your \$50 Prezzie Card Louisa! 🐇

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Our Fabulous Fundraisers

Congratulations to Colleen & Sean 1

They've done it! Enduring all weathers and terrains, our intrepid explorers have walked over 1,000kms, carrying everything they need across Spain. Raising much needed awareness and funds for multiple sclerosis in Aotearoa.

Please show your support of this amazing achievement by helping them reach their fundraising goal, thank you.



Support Colleen & Sean

Support Us



Mother's Day Special

Are you still looking for the perfect Mother's Day Gay gift? Give the gift of endless experiences with an Entertainment Membership, filled with thousands of exclusive offers perfect for spending quality time with loved ones.

For a limited time, receive additional value with a bonus eGift Card of up to \$40 when you purchase a Membership. Not only will you be supporting our fundraising cause with 20% of your Membership cost, but mum will also receive a bonus \$40 e-gift card with your purchase! Join today and create more cherished memories together whilst contributing to our cause.

Thank you for your on-going support!

*Subject to Terms and Conditions. Offer available from Wednesday, 1 May 2024 at 8:00 pm - Friday, 31 May 2024 at 1:59 pm

Purchase Savings

Let's Get Your Registry Party Started!

Ever thought about giving back your special event for good?

What if your **birthday** could raise funds to provide information resources? What if your **wedding** could raise funds for access to education for local community advisors? Or if your **farewell** could raise funds to advocate for those with MS to have access to the treatments and services that they deserve?

Create a Good Registry today to get the party started with your go-to solution for spreading joy to causes you care about.



Learn More



Fancy Fundraising for MSNZ?

Why not use Givealittle, 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.

Fundraise

Looking after you

Health Insurance For Pre-Existing Conditions

Nib is here to help Kiwis and their families live healthier, happier lives by offering health insurance that's easy to use and affordable while also helping connect you to the right tools and services to improve your health and wellbeing.

PLUS, for a limited time only many of your pre-existing conditions will now be covered after 3 years on nib's Ultimate Health and Ultimate Health Max plans.

MSNZ are not endorsing nib, and advise that individuals contact their independent advisor for advice.



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Making Sense of the System - Webinar Series

Next in the series of free webinars from <u>Flying Kites</u> in making sense of the disability system is 'Finding Great Staff'.

If you have Individualised Funding you might want to hire your own staff. This session will cover some tips and tricks that can not only help you find someone, but make sure they are the right person for you.

Follow the link below to register to attend, and to view the recorded sessions for their sessions on 'Navigating the disability system' and 'Individualised funding: Clarifying the Basics'.

There will be a session on the 16th May to learn how to 'Prepare for a Needs Assessment' and on the 30th May to 'Prepare for Your Future'.

Amplify Your Voice

Sativex and Medical Cannabis

We are preparing a submission to Pharmac calling for the funding of Sativex for MS patients. While we will present the clinical evidence we have available to us, data does not tell the patient views and needs. Critical to our submissions are patient stories highlighting the real-world problems and impact that access has.

We're reaching out to you to please share with us your story about spasticity.

We are happy to keep stories anonymous to maintain your privacy as we know for many this can be a barrier to being open to share your story. Please share your story with us by emailing it to info@msnz.org.nz by Friday 24th May 2024.



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Webinars for World MS Day

This World MS Day, 30th May, tune in to hear some great speakers talking about updates in research as well as MS Brain Health and the impact of diet in managing MS.

The seminars are free, and the stream links and agenda are on the poster below. Register your space at: hnelhd-msclinic@health.nsw.gov.au



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Regional MS Society News

Michael Brennan Marathon Walk

On the 4th of May in Rotorua, Michael will do the 42 km marathon walk to raise funds for the Rotorua and Districts MS Society. He has set up a Givealittle page where you can donate to this cause, titled "MS Society 42 km marathon walk by Michael Brennan". Click here: https://givealittle.co.nz/cause/ms-society-42km-marathon-walk-by-michael-brennan if you feel you can support Michael in this great effort.

MS Rotorua & Taupo will be around the route of Lake Rotorua to provide Michael with support and motivation!



Support MS Rotorua



MS Hawkes Bay Quiz Night

Join MS Hawkes Bay on Thursday 2nd May at 7pm for their Charity Fundraiser!

Tickets are \$10pp and can be purchased by emailing info@mshawkesbay.org.nz or call 06 835 8542

Create a team of 6, or just turn up on the night to be added to a team



Join MS Auckland and Zoe Dyer this World MS Day

MS Auckland welcome our members and a guest to join free of charge at the Remuera Club for afternoon tea, on Sunday, 26th May \sim RSVP is essential by the 17th May.

We are lucky to have **Dr Zoe Dyer**, Neurologist, Auckland Hospital, who will speak about **aHSCT** including current research and patient experience. It's the perfect opportunity to connect with the community and hear fellow members inspiring stories.

We look forward to seeing you there! Don't forget to RSVP by the 17th May. This event will be recrded



Learn More

Get Involved



Mastering Mountains Charitable Grants

Mastering Mountains wants to see people with Multiple Sclerosis and Functional Neurological Disorder experience hope, connection and positive, life-long change through self-directed outdoor adventure.

For many living with these neurological disorders, a life of adventure in the outdoors can feel far from reach. That's why Mastering Mountains assists everyday people to overcome these challenges by helping them achieve their adventure dreams, experience hope and connect with community, thereby inspiring hope in others.

Learn More

Oceans of Hope Challenge 2024 __

Are you ready for a life-changing sailing adventure? Oceans of Hope's aim is to help you gain self-confidence and a renewed sense of empowerment.

The camaraderie of sailing a boat with people who have similar experiences creates an environment where people can comfortably share their hopes and fears. The Oceans of Hope experience is a catalyst for creating lasting friendships and a sense of community.



Learn More



Bone Health in MS

You are invited to take part in the research project: 'Improving bone health in Multiple Sclerosis'. Drs. Lisa Grech and Ayse Zengin from Monash University are conducting a study to enhance the understanding of bone health management, osteoporosis, and fracture risk in individuals living with Multiple Sclerosis.

If you are a person with MS over 18-years of age, we invite you to participate in this research by accessing the link below

Complete the Study

Storms Ahead by Rick Dodson

We enjoy sharing the accomplishments of the MS Community like Rick Dodson's book 'Storms Ahead'. This review by Jenny describes it as 'gripping, funny, scandalous and heartrending in equal measure, filled with anecdotes from the likes of Russell Coutts, in his youth a bitter competitive foe of Dodson, and other members of Team New Zealand'.





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In the Spotlight

MSNZ would like to again show our appreciation to our amazing sponsors of this years Bangers to Bluff Car Rally.

Thank you!



Without the Rotary Club of Half Moon Bay, Bangers to Bluff wouldn't exist and to them we are eternally grateful for choosing to support MSNZ as their masthead charity.

Thank you!



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:

info@msnz.org.nz

Thank you for your continued support, it has helped us to achieve so much for those impacted by MS.





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