

S. NEWSLETTER Perosis AUTUMN 2023



From the corner desk



Hi all

It is hard to fathom the devastation Cyclone Gabrielle brought to our shores. My thoughts are with you and our Community as we try to make sense of it all and rebuild. It will take time and please know, we are here to support you anyway we can.

I would also like to take this opportunity to thank you Julie for all of your hard work with welfare checks, support and keeping everyone informed with all the relevant updates.

A couple of things we are looking forward to in the coming weeks. Our President Jeff Silvester along with his side kicks from MSNZ, Neil Woodhams and Graham Walker (Team Keep Smyelin) will be setting off in Betty Beetle on their much awaited 'Bangers to Bluff' trip. This fundraising rally is in its 8th year and organised by the Rotary Club of Half Moon Bay. I am reasonably confident Betty Beetle is ready for the big trip... its all downhill isn't it? Jeff will set off to Auckland on 18th March, meet up with Neil and Graham and then begin the trip down on 21st March. Finishing in Bluff 1st April, where they will auction off the cars. We will keep you posted of their trip on Facebook. It will be fun and we wish Jeff and the team a safe journey.

Another date to save is Saturday 20th May. Where we will be holding our annual Clothes Sale. More information within newsletter.

Sending out a big hug to you all. Lets hope we can enjoy a few sunny warm days (without rain) before the colder weather sets in

Keep safe and take care.

Jackie

Hello everyone.

Christmas and the New Year seem like so long ago. With a rubbish summer and then the devastation following Cyclone Gabrielle it would be nice to push the reset button in the



hope for a settled autumn. February has been particularly busy for me. It has been so good to touch base with so many of you post cyclone. Please remember if there is anything we can support you with then let me know, however trivial it may seem.

It is normal to feel overwhelmed after a disastrous event such as Cyclone Gabrielle whether you have lost everything through to having minimal damage to your property or disruption to your life, it is ok to have these feelings. If you need to chat then get in touch or reach out to family or friends or contact your GP for advice. For information online check out this link: https://www.healthnavigator.org.nz/healthy-living/m/mental-health-topics/

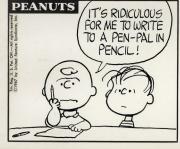
With winter on our door step it is a good time to start preparing for winter. Flu vaccines will be available from April. I have heard that there may also be another covid booster available to cover the current variants that are circulating but will share this information when it is distributed. Cleaning heat pumps and getting your chimney swept is important to do too. Fixing drafts around windows and doors also helps to improve the energy efficiency of your home. Here's a handy link to help you prepare: https://www.healthnavigator.org.nz/healthy-living/w/winter-wellbeing-topics/

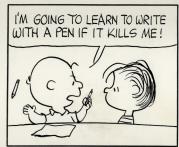
Groups will be up and running again in March. I am hoping to set up a Wellness Seminar. I will keep you all posted with dates once everything has been confirmed.

Please get in touch if you would like a review too. Either by email: mscommunitynurse@gmail.com or phone/text 027 733 0304.

Take care.

Julie









Disclaimer: The views and opinions expressed in this newsletter may not necessarily be the views and opinions of the Hawke's Bay Multiple Sclerosis Society or it's members.

NOTICE BOARD

Book thongs for sale. A great gift for those book lovers. \$10ea. With Thanks to VT Designs for donating. All proceeds to MS Hawke's Bay. Please contact Jackie if you are interested.







Postal changes

Due to the increasing costs of the postal service, as of 1 April we will no longer hold a Post Office Box. Should you require to send anything via post, please send to our physical address;

174 Hyderabad Road

Ahuriri

Napier 4110





Save the date!!

MS4MS23

Wednesday 25th October

Coffee Morning

Hastings: Divine Café Summerset in the Orchard, 1228 Ada Street,

Hastings. Thursday at 10.30am

9 March, 13 April, 11 May, 8 June

Napier: Divine Café Summerset in the Bay, 79 Merlot Drive,

Greenmeadows. Tuesday at 10.30am

14 March, 11 April, 9 May, 13 June

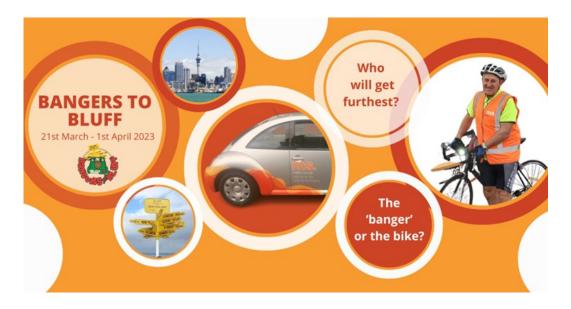
CHB: Zinc Café Northumberland Street, Waipukurau

On hold till further notice.

Payments

If you wish to make payments directly to MS Hawke's Bay, please pay into account number: 02-0700-0013646-000

Please remember to include your name the payment is referring to.



Our Team - 'Keep Smyelin'

'Keep Smyelin' did such a great job in 2021 they are back for 2023! The team consists of our most dedicated volunteers, our President Neil Woodhams and National Executive Committee Members Graham Walker and Jeff Silvester. Our enthusiastic team are really looking forward to raising awareness of MS and the necessary supports those affected by the condition require to live well.



Exercise is Medicine

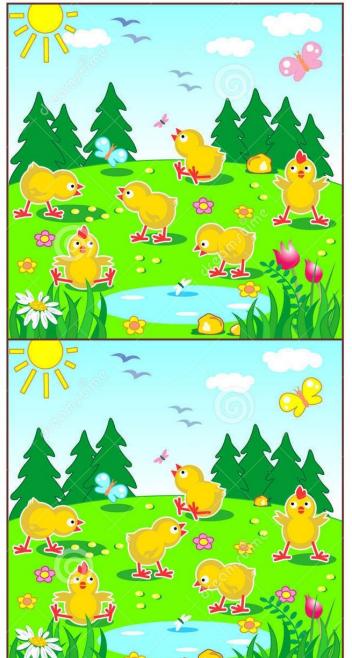
One of our team members, Graham, was diagnosed with Primary Progressive MS. In his early days of diagnosis, Graham had it impressed upon him the importance of exercise in being able to take control of his condition. "Use it or lose it" the Neurological Physiotherapists said. "So it really was a no-brainer, neurological condition and all, to pursue cycling as my exercise vehicle."

Therefore, every morning Graham has committed, once more, to head out the starting gates at the crack of dawn, ahead of the cars, to cycle as far as possible before getting caught. Who will get furthest? The 'banger' or the bike? "My reasons for attempting this are 3 fold; to raise awareness of Multiple Sclerosis, to raise money for the combined Bangers to Bluff charities and, lastly, quite simply, because exercise is medicine".

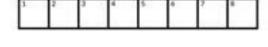
Rally Route

- Day 1: Tuesday 21st March Auckland to Te Kuiti, via Raglan and Kawhia.
- Day 2: Wednesday 22nd March Te Kuiti to Wanganui via New Plymouth area and down the coast.
- Day 3: Thursday 23rd March Wanganui to Martinborough.
- Day 4: Friday 24th March A day in Martinborough.
- Day 5: Saturday 25th March Martinborough to Blenheim.
- Day 6: Sunday 26th March Blenheim to Hanmer Springs via the Molesworth Station or via Kaikoura.
- Day 7: Monday 27th March Hanmer Springs to Geraldine.
- Day 8: Tuesday 28th March Geraldine to Mt Cook.
- Day 9: Wednesday 29 March Mt Cook to Oamaru.
- Day 10: Thursday 30 March Oamaru to Balclutha via Danseys Pass and Ranfurly.
- Day 11: Friday 31st March Balclutha to Invercargill with opportunities to explore the Catlins.
- Day 12: Saturday 1st April Invercargill to Bluff for photos and then back to Invercargill for the grand finale.

Spot 7 differences







Special thanks to our most recent funding supporters





Oceans of Hope - Kirsten Kelly

In late November 2022 I took part in an adventure of a lifetime. I sailed for five days from Auckland to the Bay of Islands on the iconic Round the World racing yacht Steinlager 2.

Sailing is not something I have done a lot of; in fact, the last time I was on a boat was a relatively benign Interislander crossing, and the rescue remedy was required! But the reason I challenged myself to take this trip is that of the 29 people on board – 23 of them live with Multiple Sclerosis. The trip was part of a worldwide programme called Oceans of Hope. 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.'

I was diagnosed with MS in December 2019. I had been experiencing symptoms since 2014, yet the diagnosis still came as a shock to me. With the combination of lockdowns and COVID 19 in the following years I struggled to come to terms with my diagnosis and found it hard to remain positive. I also had limited opportunities to meet other people with MS.

When I saw this opportunity come up on the MSNZ Facebook page I was intrigued. Could I really do something like this? Even the thought of applying was challenging for me! However, I did apply, and Ingrid who runs the NZ arm of Oceans of Hope was very encouraging.

Leading up to the trip we had a Facebook group where we could chat and ask questions. What gear do we need? How do we get home from Opua? Is there coffee on board?! When the day finally came to leave Napier for Auckland, I was really excited. A whole week off my normal routine, doing something just for me! This does not happen very often.

The night before we sailed everyone met for dinner at a restaurant on the Viaduct. We could see Steinlager 2 moored across the way. It looked really small for this many people! It was great to meet some of the people I would be spending the next 5 days with. I learned that many of them had participated in Oceans of Hope before. Some here in New Zealand and others in the UK, Denmark, and Turkey! Back to the hotel for an early night.

The next morning, I was up early and had a long hot shower at the hotel (there are no showers on the boat, only the sea to jump in). I then made my way to the briefing at the Viaduct. After a quick welcome from MS Auckland and Ingrid from Oceans of Hope we met our skipper Jo, a woman with incredible experience and skill at sailing.

We then boarded Steinlager 2 and claimed our bunks. The bunks are tiered – three high and make for a cosy experience with your bunkmates! After a quick introduction and safety briefing on the boat we were off. While motoring out of Auckland harbour we were given a tour of Steinlager 2 and introduced to the rest of the crew. These five amazing human beings are skilled not only in sailing a huge round the world yacht, but also encouraging, gently teaching, looking after, and entertaining a bunch of people with MS.

We were soon sailing, having a go at grinding to hoist the sails, and learning to move to the high side of the boat when tacking. I was learning a lot of new terminology pretty fast! We had a beautiful sail to Kawau Island and anchored at Mansion House Bay where we anchored for our first night. I went ashore in the inflatable boat to have a look at Governor Grey's mansion (uninhabited) and meet the descendants of his pet peacocks. Some people swam and kayaked, some walked the tracks on the island, and some stayed on board. No compulsory activities on this trip – everyone was able to take things at their own pace, and many day naps were had.

That evening we watched a movie Maiden, about the all-female crew who sailed the Whitbread Round the World race in 1989. It was inspiring and great to see a similar yacht sailing in its full glory, and the footage of sailing in the Southern Ocean was breath-taking.

The next day we set sail to Aotea Great Barrier Island. Before we set off, we were allocated our duty groups. Duties included cooking and galley duties, cleaning the interior of the boat, cleaning the deck and sailing (spending time with the skipper and crew learning about navigation and being at the helm). A gorgeous day with amazing sailing. We followed a whale for some of the way, before a short stop to collect firewood and then anchored at Smokehouse Bay for the night. Everyone made the trip to shore to share a woodfired BBQ dinner and marshmallows around the fire. A magical evening and a much better sleep, nodding off to the lapping of the water on the side of the yacht.

The following day I finally got in the water for a pre breakfast swim. The water was cold but so refreshing – I swam around the boat. My group was on sailing, so we got to spend time at the helm (steering). The weather was much better, and we sailed out past the Poor Knights Islands before turning towards Cape Brett and the Hole in the Rock, the gateway to the Bay of Islands. We saw a huge amount of shearwaters as well as an 8ft Bronze Whaler shark swim right next to the boat. We anchored at Oke Bay for the night, a gorgeous bay just inside the Bay of Islands. A quick trip to the beach for a leg stretch and then an early night (I was quite fond of my hammock bunk by now!)

Our final day dawned with clear skies. Another swim around the boat to start the day right (and get clean). We motored to Motuarohia (Roberton) Island and some of us walked up to the cliffs to see the amazing view of the Bay of Islands. We had pasta for lunch aboard and then set off for Opua – our final destination. As we headed in, we were joined by a pod of dolphins. The dolphins swam with us for about 30 minutes which was just magic. The crew have a few tricks up their sleeves to encourage the dolphins to swim with the boat – they were doing flips and diving under the boat, just magic. What a wonderful way to finish off a trip of a lifetime! As we entered Opua Marina I think everyone was feeling pretty emotional. There were some tears and a lot of laughter.

Being able to spend time with a group of people with MS was a real privilege. We shared stories, compared notes on symptoms and treatments, gave each other assistance when needed and had many laughs. Meeting people from many ages and stages of life (and MS) was a hugely positive experience for me. Being on Steinlager 2 made me feel more capable than I have for a long time. The crew were very respectful, helpful, and caring. And thankfully there was plentiful plunger coffee!

Thank you to Oceans of Hope, the NZ Sailing Trust and the wonderful crew Jo, Steph, Hallie, Rod, Craig, and Tony for this incredible opportunity. I would do it again in a heartbeat. If you get the opportunity and the time is right for you, I would definitely recommend having a look at Oceans of Hope. As someone said, this is one of the few perks of having MS, so make the most of it!



The Neurological Foundation is a charity that funds vital research and ongoing education into neurological conditions, which includes diseases and disorders of the brain, spine, and nerves.

Brain Awareness Week is a global campaign to raise awareness of neurological conditions and bring to public attention the importance of brain research.

Here in New Zealand we celebrate Brain Awareness Month during the month of March to help highlight these conditions and the importance of funding research today that will save lives tomorrow. Together with the Universities of Otago and Auckland we arrange events across March to share with members of the public the exciting advances of brain science, start conversations about neurological health, and raise awareness of the importance of research on the pathway to hope. Check out this link to see what events are coming up: https://neurological.org.nz/get-involved/brain-awareness-month/

Other useful Neurological websites are:

Multiple Sclerosis New Zealand: https://www.msnz.org.nz/

New Zealand Multiple Sclerosis Research Trust: https://msresearch.org.nz/

Dementia NZ: https://dementia.nz/

Here are some tips and tricks on how to keep you brain healthy: https://www.healthnavigator.org.nz/healthy-living/p/proven-ways-to-keep-your-brain-healthy/

Article completed by Julie, MS Community Nurse.

Annual Subscription 2023

As you know the Hawke's Bay Multiple Sclerosis Society is a small society, which relies on donations and member subs. Your subs help fund the running of our services.

We receive money from Ministry of Health to fund our operational costs but, did you know that the amount we receive, only covers approximately 12% of our total running costs each year. Therefore, we rely on your subs as well as successful funding applications and our fundraising events.

The annual sub is currently \$20.00, which equates to less than four take-away coffees. We believe it is a small cost to pay to continue providing support and the programmes we do.

Access to our swimming groups in Napier, Clive, Hastings and Waipukurau, plus various workshops offered throughout the year, you are required to be a financial member of the Society.

If you have any queries, please do not hesitate to contact Jackie on 06 835 8542 or email: officehbms@gmail.com

Hawke's Bay

Hawkes Bay Multiple Sclerosis Society

174 Hyderabad Road, Ahuriri PO Box 3136, Napier 4142 P: 06 8358542 or 06 8433000 E: officehbms@gmail.com

2023 Membership Invoice

Annual subscription fees (Tick One)

Subs can be paid by cash or via Internet banking:

Bank A/C number: 03 0700 0013646 000

Bank A/C number: **02-0700-0013646-000**

Particulars: Name Reference: Donation

Clothes Sale Fundraiser

In support of 'Hawke's Bay Multiple Sclerosis Society' \$5.00 a ticket



Saturday 20th May 2023
12.30pm till 3.30pm
St Thomas More Parish Church Hall
92 Wycliffe Street, Onekawa, Napier
Contact Jackie at officehbms@gmail.com
or call 027-6315-114 for tickets

Time for a fresh wardrobe? Bring in the clothes you no longer love and are currently clogging your draws and closet. Then buy a new wardrobe for \$2 per item. Bring your clothes in on the day. Or if you have clothes to donate only, please contact us on 835-8542 or 027-6315-114

Is there something you like to share on our next issue?

Please contact Jackie by 14th May. officehbms@gmail.com



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