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mndnews

NEWSLETTER OF THE MOTOR NEURONE DISEASE ASSOCIATION OF NEW ZEALAND INC

www.mnd.org.nz

Congratulations and thank you, Emirates Team New Zealand!

As the official charity partner of Emirates Team New Zealand for the 36th America's Cup, we are so proud of the team for defending the Cup once again, and thankful for their support over the last couple of years.

Since our partnership was announced in June 2019, the team has helped increase awareness and inspire others to join them in supporting people living with MND, through several initiatives.

Millions of people around the country and abroad got to see our logo proudly displayed on Emirates Team New Zealand's boat Te Rehutai. This invaluable exposure continued the support the team has shown, including displaying our logo on the mainsail of their test boat Te Kāhu, providing signed merchandise and money-can't-buy experiences for raffles and events, and contributing generous donations towards MND research and supporting MND families nationwide.

MND New Zealand CEO Carl Sunderland says,"We rely almost completely on the generosity of the New Zealand community to continue to provide free, personalised support to people living with MND, their carers, and families. We are so grateful to the team for helping raise awareness of this devastating disease and the vital work we do to make a difference every day for those living with MND in New Zealand. We are so proud of the team for winning the 36th America's Cup and are thankful for their support."

Emirates Team New Zealand has first-hand experience witnessing the devastation of MND through teammate and former Director Greg Horton.

Emirates Team New Zealand CEO Grant Dalton says, "Through Greg you can see the amazing work MND New Zealand do for the approximately 400 New Zealanders living with MND, so we are really proud to be supporting them and everything they do."

To find out more about the partnership and how the team has got behind MND New Zealand, visit www.mnd.org.nz/etnz/.

From the Chair and CEO

Caron Palmer, Acting Chair

Carl Sunderland, CEO

While COVID-19 has already caused interruptions this year with alert level changes in February and March, we are determined to continue to provide support for our MND community through our support service, education, advocacy, and research.

We've been busy pressing ahead with some key projects, including an organisational brand review and website refresh, which we look forward to unveiling soon. We have also been planning Awareness Month ready for June, including the Ice Bucket Challenge and Cuppa Tea for MND fundraising initiatives, and a new awareness campaign. We look forward to you all getting involved and helping us make this the best Awareness Month yet! Read more on page 3.

As the official charity partner of Emirates Team New Zealand for the 36th America's Cup, we were so proud to see the team race to victory in March. It was great to see our logo on the boat and we are very grateful for all the support the team has shown us since our partnership was announced in 2019. We'd also like to thank the team's sponsor The Heart of Racing (THoR) who made an extremely generous donation, which will help us continue to provide high quality support to MND families. To read more about how the team has got behind MND New Zealand, see the cover story.

Despite uncertain times, our Walk 2 D'Feet MND event season during summer raised over $50,000, thanks to our dedicated volunteers who organised events across the country. Hundreds in our community came together to raise awareness, honour those living with MND, and commemorate loved ones lost to the disease. A huge thank you to everyone who took part and helped make the event season a success. Read more on page 7.

We have had a couple of staffing and governance changes within MND New Zealand since our last newsletter. In February we said farewell to Elise Doyer, who resigned from her role as support team member for Nelson, Marlborough, Canterbury, and the West Coast. Hefina Malone has taken over this position and we are pleased to welcome her to the team. We are sure the MND community in her area will enjoy getting to know her. For more details, see the support team update on page 4.

Sadly, in April we announced the resignation of our Chair, Greg Horton, from Council. Greg joined Council in late 2017 and immediately created a huge team of supporters, raising well over $100,000 at that year's Walk 2 D'Feet MND. He has been the driving force for MND New Zealand by tirelessly working to secure successful corporate partnerships, including with Fulton Hogan and Emirates Team New Zealand, resulting in many donations. His humility, passion, sense of humour, and great legal mind will be missed by everyone at MND New Zealand. We cannot begin to thank Greg enough and we wish him all the very best. We will be appointing an interim Chair and will make an announcement when an appointment has been made.

We'd like to thank the MND community for your continued understanding of the need for us to adapt the support services we offer during the COVID-19 alert level changes. While frustrating for everyone, the health and safety of our community is always foremost in our minds. Hopefully with the vaccine roll-out well underway there will be less disruption this year!

Thank you all for your continued support. Without you we could not continue doing the vital work we do to make a difference every day for those living with motor neurone disease in New Zealand.

Kia kaha,
Caron (Acting Chair) and Carl

In this issue

mnd New Zealand

Communications update

To help us reach our strategic priority to "raise awareness of MND and strengthen our presence and capacity as the leading authority on MND in New Zealand", we have been focusing on building and developing the MND New Zealand story and brand personality.

We engaged an agency to help us review our current brand story, personality, tone of voice, and messaging. As part of this work we have also refreshed our brand identity with an updated look and feel.

At the same time, we have been working on a new and improved website to make online interaction more user-friendly, so it's easier for our MND community to find the information they are looking for.

We are looking forward to unveiling all of this great work soon. Watch this space!

Awareness month June 2021

Motor Neurone Disease Awareness Month (June) is an annual opportunity to encourage more people to join our team and raise awareness of motor neurone disease and its impact. MND awareness leads to a greater understanding of MND in the wider community, which in turn helps to increase levels of support, funding, and research to benefit those living with MND. This year we are launching a new awareness campaign on Global ALS/MND Awareness Day, which falls on 21st June. During the month we will also be running fundraising initiatives, including the Ice Bucket Challenge and Cuppa Tea for MND.

NEW ZEALAND
MND
REGISTRY

Join the MND Registry!

The New Zealand MND Registry connects people living with MND to researchers. If you have MND, we encourage you to enrol. The Registry aims to capture information about every single person with MND in New Zealand. If one of your family members has had a positive genetic test for MND or frontotemporal dementia, you can join the Registry even if you have no symptoms of MND and have not had a genetic test yourself. If you have questions, email MNDRegistry@adhb.govt.nz or phone 0800 MND REG (0800 663 734).

See www.mnd.org.nz/registry for more information and the enrolment forms.

Get involved…

MND Ice Bucket Challenge

Will your business, school, or group take on the challenge and aim to raise $1,000?

Sign up and appoint one willing recipient in your organisation (e.g. CEO, principal, or group leader) to get an icy drenching when you reach your fundraising target, or recruit a selection of willing staff/group members and ask for a donation per vote. The person with the most votes receives the soaking.

Visit www.mnd-ice-bucket-challenge.raisely.com/ to sign up or find out more.

Cuppa Tea for MND

Everyone loves a good cuppa. Hold a Cuppa Tea for MND event during June to raise awareness of MND and funds to support the work of MND New Zealand. The event can be big or small, and can take place anytime and anywhere. Simply invite your friends, colleagues, or family to a morning or afternoon tea, lunch, or get-together, and donate the proceeds.

Visit https://mnd.org.nz/awareness-campaigns/ for more information and resources.

Support team update

Toni Foster

Hefina Malone

No doubt most of us were hopeful that the end of 2020 would see the end of COVID-19 lockdowns, but sadly this has proven to not be the case. I would like to thank our community for their continued understanding of the need for us to adapt the services that we offer according to the alert level in each part of the country. I am sure that you all find this as frustrating as we do, but please be assured that the health and safety of our community is always foremost in our minds. Please remember that we are only a phone call, text, or email away.

Sadly, Elise Doyer resigned from her role as the support team member for Nelson, Marlborough, Canterbury, and the West Coast in February. Elise started with MND New Zealand in April 2019 and was the first support team member to be based in Nelson. She has worked hard to increase awareness of MND in the general population and to build networks of support for the MND community, particularly in the Nelson, Marlborough, and Tasman areas. We will miss Elise's gentle approach and sense of humour, and wish her well in the future. Some of you may still see Elise as she intends to volunteer at the Nelson support group.

Hefina Malone joined the team at the beginning of March, taking over Elise's role. Her orientation was a little delayed by a COVID-19 lockdown, but she has completed the first part of her orientation at National Office and is now starting to get out and about in her area to meet with clients, families, and health professionals. Hefina is based in North Canterbury and will provide support for those in Christchurch, Nelson, Marlborough, and the West Coast. Immediately prior to joining MND New Zealand Hefina worked as a registered nurse at Oxford Private Hospital, but for many years she worked as an occupational health nurse in various locations throughout New Zealand. We are very pleased to welcome Hefina to the team and are sure the MND community in her area will enjoy getting to know her.

I would like to thank those who have shared their stories and tips with us. I am sure these will be enjoyed by our community. Happy reading!

Toni Foster
Support Team Leader

The Fulton Hogan MND New Zealand Support Fund – helping MND families

Cycling fun

Paula received a new bike in January thanks to the Fulton Hogan MND New Zealand Support Fund. She has enjoyed getting out and about in her local neighbourhood, cycling with her family.

Americarna

Thanks to the Fulton Hogan MND New Zealand Support Fund, car lover Bruce got to take part in Americarna, an event held in the Taranaki region that celebrates American car culture. Here he is pictured with the car he took along to the event.

"Tom"

By Jos

Preface: Jos has MND and lives in hospital-level care in a rest home. She spends many hours a day sitting reclined, watching the world through her window. A friend gave her a bird feeder as a gift, which she asked to be placed in the garden outside her window. The birds it attracts have been her constant companions and a source of life, beauty, and cheekiness. She sent in this lovely piece of writing about the birds and a tomato plant she named Tom.

The birds are so persuasive that they need a treat. They dance and chirp to let you know they're just outside watching you eat something they like too, hence the reason for a partly eaten tomato sandwich being thrown outside for them to share. Imagine the surprise when a tomato plant about six inches tall was spotted growing in the garden just outside the window. That was one seed the birds missed eating. Well, as it was the middle of winter the gardener predicted it wouldn't come to full life. It's now the middle of summer, and Tom has produced 41 tomatoes. He has a fan club who keep count of the tomatoes, have tied him to a stake as he grows taller, have watered him daily, and have given him little treats of extra food. What fun it has given to those who visit and care for me in my hospital room. I now have Tom and the birds for extra company and sweet ripe tomatoes to soon share and enjoy. Just another medicine that can be found in hospital!

How a tube can keep you on the road … and the Hauraki Gulf

by David Innes

I'm one of the MND bulbar palsy team. And if you are too, you'll understand the frustration that arrives sooner or later with the difficulty of "traditional" eating. Teeth and tongue won't process food bits properly. Throat won't accept everything. Spluttering. Coughing. People at the next table wondering if you've got COVID-19. Choking on small bits of food. Rest of the table going to sleep waiting for you to finish. Weight falling away. I won't go on…

As I approached this frustrating stage in mid-2020, I received a strong recommendation from my neurologist to undertake gastroenterology. In laypersons' terms, tube access to the stomach.

At the time, eating was problematic, but I still felt I could manage it if I tried hard enough – not wanting to give in, yet again, to bloody MND. But I accepted her recommendation and had my tube inserted in August.

Well, you wouldn't want to do it in a restaurant, but the feeding process is easy and quick, taking about 11 minutes almost every time, three times a day.

David and his wife at Lake Ohau

You or your partner don't have to worry all the time about the nutrition count of every meal. It's easy to control and maintain weight. And at least for now, I can still have a little nibble of lunch and dinner with my wife, enjoying the taste, without worrying if she will go to sleep waiting for me to finish.

But perhaps best of all was the freedom to travel without having to worry about where and when to get food you can manage. We did a road trip to the South Island in November. We ordered the tube food before leaving, for collection in Christchurch. (You wouldn't want to carry three weeks of Fortisip!) I could even feed the tube on the road, though you wouldn't want to do that all the time. Here's a pic of us at one of our favourite spots on the mainland, beautiful and remote Lake Ohau. Tube breakfast about an hour earlier. Water clear and clean but about eight degrees. No swimming.

David sailing on the Hauraki Gulf

When summer arrived, we were off on our yacht. I wonder if I'm the first person ever to have had a Fortisip tube dinner at Te Kouma Harbour on the Coromandel? As with driving, you wouldn't want to feed yourself while moving all the time, but on a long sail you need sustenance, and in the photo of us passing Rangitoto Lighthouse I'd had a tube-feed at sea about 20 minutes earlier and it was blowing a bit. To the sailors amongst you: 15–20 kts, broad reach, so a bit lumpy.

So…there aren't many wins in the battle with MND, but tube feeding makes sure you're getting the right amount of nutrition no matter when and where you are. And it's quantum easier than mouth and throat.

A great application of medical technology.

Antarctica next (maybe).

LIKE US ON facebook

Keep up-to-date with all the latest news, research, and events from MND New Zealand. Like us on Facebook and visit our page, where we regularly post updates and share information about living with MND. Find us on Facebook at: https://www.facebook.com/mndanz/.

America's Cup adventure … and an MND diagnosis

by Graham Lake

A notice seeking volunteers for the America's Cup Course Marshal programme appeared in September 2019. A keen yachtie for many years, I completed my application and submitted it in a heartbeat. The Course Marshals would control and manage the spectator fleet, lay the boundary marks for the racecourse, and keep spectators outside of the course. There were qualifications required: Boatmaster (tick), a Seafarers first aid qualification, VHF radio, and a medical. By early February 2020 all these were in place. Course Marshal-specific classroom sessions followed before COVID-19 brought things to a halt. When we resumed, the nine-metre Protector RIBS we were to use had started to arrive. Funded by the Lotteries Commission, all 24 are going to various coastguard units around the country after the America's Cup. We started practising the things we would need: boat handling, mark laying, navigation, safety at sea, crew coordination, comms, and dealing with the public. We worked with courtesy, humour, and tact, with a big stick available if required. With more than 500 volunteers, this was pass/fail stuff, and not all made the grade. We ended up with around 130 who graduated. A typical boat crew is three or four people.

By July 2020, my voice had started to change – stumbling over words, slurring and so on. I went to my GP, and it started: trip to hospital, endless tests and waiting, and eventually the diagnosis of MND. Apart from losing my voice, I was physically fine. I kept the organisers appraised of my issue, progress, and the eventual diagnosis. Of course I could continue. We did the Christmas regatta with no issues other than my voice. I had a Boogie Board writing tablet and sign language worked out; I made no secret of my diagnosis. After Christmas came the Prada Cup and here things started to unravel. I had been getting muscle weakness in my right arm and legs and got to the stage where I needed help getting on and off the boat. Time to give it away.


Graham Lake

A number of crew members stepped up and promised to get me through to the end. One of the leaders had lost a friend to MND and was determined to help. They would provide all the assistance I would need, and they organised an automatic life jacket instead of the usual manual units. The Course Marshal management were aware of this and were supportive. The support and care I have received has been outstanding, and my family and I are very grateful. I have participated in the Prada Cup races and the Superyacht Regatta. Next, the real thing.

I am very embarrassed and humbled by the support I have received from good people. I am proud to be part of the group.

Note: this article was written before the 36th America's Cup races took place.

We need you!

Have you got a helpful tip or idea, or a personal story that might inspire others? We love to share ideas and stories from our community, so please email emily.king@mnd.org.nz if you have any ideas for our next newsletter.


INVERCARGILL

Walk 2 D'Feet MND raises over $50,000!

This summer we changed the format of Walk 2 D'Feet MND and held our first ever event season, instead of all the walks being held on one day. Despite unprecedented times, volunteers in Tauranga, Palmerston North, Invercargill, Nelson, Greymouth, Christchurch, and Napier rose to the challenge and organised some great events. The season closed with a national Virtual Walk 2 D'Feet MND on Sunday, 28th February.

All around New Zealand, hundreds in our community came together to raise awareness, honour those living with MND, and commemorate loved ones lost to the disease. Together, we raised over $50,000!

Walk 2 D'Feet MND events are made possible by local volunteers who donate their time and skills. This summer we saw many experienced Walk 2 D'Feet MND volunteer organisers continue to offer their support, and several new volunteers step up to the challenge and organise a local event.

If you would like to learn more about organising a Walk 2 D'Feet MND in your community next summer, visit www.mndwalk.org.nz.


CHRISTCHURCH


CHRISTCHURCH


TAURANGA

Fundraising highlights

Property Brokers Waipukurau, Central Hawke's Bay, continued their support after raising over $12,000 last year at their annual golf tournament. They organised a horse trek for more than 110 riders, raising a further $5,000.

Sai is raising funds as part of her ninth birthday celebrations, in memory of her uncle. She also took on the 10K challenge at Great Forest Events, completing it in 1:26:56. Sai raised almost $2,000.

Paramedic Geoff Lewis took on the Tour of Aotearoa, cycling 3000 kilometres from Cape Reinga to Bluff. Geoff raised over $5,000!

Katie Burley took on the Wellington Round the Bays Half Marathon in February and raised $2,067.

Christchurch Casino chose MND New Zealand as the January beneficiary for customer redemption kiosks' change, donating over $3,000!

Carl Seaward raised awareness of MND at the Shands Road Christmas Lightshow in Christchurch, with road signs and the MND New Zealand logo proudly on display. More than 30,000 people attended the show over Christmas.

COMING UP

Rohan Chakrabarti is organising an exciting event called the Christchurch MND Gala 2021–Silk Road. Dance the night away on 3rd July, 2021 at the Christchurch Art Gallery and let us transport you to the Far East. An oriental night of music, dancing, food, and drinks. Tickets cost $150 and can be purchased through Eventbrite.

© PAGADALA PHOTOGRAPHY

Donations by cheque

From June this year several banks will be discontinuing the use of cheques. If you would like to make a donation to MND New Zealand from 1st June, we encourage you to donate via direct debit or automatic payment. For more information on how to donate, visit www.mnd.org.nz/help-us/donate/. If you have any questions, please don't hesitate to get in touch with National Office by email admin@mnda.org.nz or phone (09) 624 2148.

Some of the Clinical Working Group on a recent Zoom catch-up

MND Clinical Working Group update

The MND Clinical Working Group was formed following the national MND New Zealand Hui in 2019. The group consists of 16 clinicians across multiple disciplines from all around New Zealand, who have an interest in improving care for people with motor neurone disease (MND) and their families.

It is co-chaired by our community and research advisor Claire Reilly, and council member and neurologist Alan Stanley. A big thank you to previous co-chair Chris Drennan for the time and effort he put into the group. His vast knowledge and experience has been invaluable.

The group met regularly throughout 2020 via teleconference and are developing national guidelines for the assessment and management of MND. The first draft of the guidelines has been completed and is currently being edited. The guidelines will then be distributed to various professional organisations for review and feedback. The group hope to have the guidelines finalised by the middle of this year. They will be available for all health professionals on our website.

While developing the guidelines we established a term for motor neurone disease in Te Reo: "Mate Tauheke Ioio". This was created with the assistance of Graham Cameron and approved by the Maori Language Commission. Graham is Pou Tikanga (cultural advisor) at the Bay of Plenty District Health Board, and we are very grateful for his assistance in ensuring the guidelines are reflective of our diverse multicultural society, and acknowledge our obligations under Te Tiriti o Waitangi.

Genetic study update

by Dr Emma Scotter, Centre for Brain Research (CBR) Motor Neurone Disease Research Lab

It's been a challenge to conduct this study, which aims to understand the genetic causes of MND in New Zealanders, with the disruptions caused by lab closures thanks to COVID-19 alert level changes. We thank those who participated in the study. We are so proud to be working with you to either find or rule out certain genetic causes of your MND.

Some of you will have been telephoned with your results, while some results are still pending. Skin biopsy donors (controls and with MND) will be pleased to know that we grew your skin biopsies into millions of cells and have them safely banked in ultra-cold storage to conduct experiments soon. And thank you to our controls, to whom we do not return genetic results, but who generously give us their DNA and skin biopsies.

We gained consent from 119 people, collected DNA from 109 people, returned results or have results ready to return to 49 people, and have collected 20 skin biopsies. Most of our participants have sporadic MND, but we are also working closely with a number of MND families.

Our overall aim is to conduct genetic testing of 300 New Zealanders with MND, and while we are doing well, we are very keen for more participants. People from anywhere in New Zealand of any ethnicity or gender can take part. We can communicate with people through their preferred method, and participants can choose whether or not to learn their result. If you are interested or have questions about taking part, please contact Jules Devaux via email: j.devaux@auckland.ac.nz.

Results of swallowing study released

A summary of results from a study investigating a new type of swallowing therapy for patients with motor neurone disease, has been released. Led by researcher Paige Thomas, the study was completed at the end of last year and was based at the Rose Centre for Stroke Recovery and Research, Department of Communication Disorders, University of Canterbury. You can view the summary online at https://mnd.org.nz/skill-based-swallowing-training-for-patients-with-motor-neurone-disease/.

Paige investigated a new type of swallowing therapy, which used technology to allow participants to visualise their swallowing and learn to control the strength and timing of swallowing. Researchers saw improvement in two of the 22 outcome measures they investigated. Although the results from this study did not provide conclusive evidence that the therapy used was beneficial, the changes that were observed demonstrate that there may be potential benefits, and more research with a larger group of individuals with MND would be beneficial.

Paige says, "I would like to thank the 19 individuals with MND who took the time to participate in this research. I enjoyed working with each and every one of you and your contributions will help us to continue to improve the way that swallowing is managed for those with MND. I would also like to acknowledge the New Zealand MND Registry for their assistance with providing information about this research to help with the recruitment of individuals around New Zealand. Having the registry makes research in our small country much more achievable. Finally, thank you to MND New Zealand for all of your support with carrying out these studies."

Your tips and tricks

CaringBridge

CaringBridge is a free online platform made for those who are undergoing difficult health journeys. It provides a secure place for you to share health updates with family and friends, where they can leave comments and messages. There are also additional resources like a planner. Find out more at www.caringbridge.org.

MND New Zealand client

Obi

In 2019 I started using an Obi feeding machine as my arms weakened further. It's easy to use and has allowed me to eat our normal meals without me relying on others, whether it's with my wife, with family and friends over, or at restaurants. If anyone's arm and hand control is causing eating issues, I'd highly recommend one. Available through www.mortonperry.co.nz, 0800 238 523.

Ken Fry

Please send us your tips, tricks, and innovations that help ease life with MND. Email emily.king@mnd.org.nz.

MND NEW ZEALAND FUNDERS

MND New Zealand would like to thank the following organisations for their recent contributions towards our work:

- Bendigo Valley Sports and Charity Foundation
- Community Capability and Resilience Fund
- Community Trust South
- FH Muter Trust and EM Pharazyn Trust
- Foundation North
- Four Winds Foundation
- Frimley Foundation
- Grassroots Central Trust
- Iris & Eric Wilfred Nankivell Charitable Trust
- Lindsay Foundation
- NZ Lottery Grants Board
- One Foundation
- Oxford Sports Trust
- Rata Foundation
- Trust Waikato
- W. Duncan Bickley Trust Fund

Our MND Support Team

We employ part-time MND support workers around the country. If you live some distance from your regional support team member, contact will mainly be by phone, email, and text, with occasional visits. We are not able to provide out-of-hours or emergency services.

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The MND Association of New Zealand Inc. is a registered charity number CC35320.

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NATIONAL COUNCIL

Acting Chair: Caron Palmer
Treasurer: Lucy Haberfield
Members: Alan Stanley, Melanie Glenn, Michael Fuyala, Nick Molcsan, Samarra Wright-Scott, Wayne Philip.

PLEASE CONTACT US

- If you have any suggestions for inclusion in the next newsletter
- If your address has changed
- If you would prefer to receive MND News by email or post only, or no longer wish to receive MND News.

Our thanks go to minimum graphics for design and layout of MND News and to Stewart Motorsport for sponsoring the printing.

DISCLAIMER

This newsletter provides information only. Content should not be taken as a recommendation for any individual, or as an endorsement by MND New Zealand. We strongly advise you discuss options with those who know you best before making any changes to your routines.

Donate to MND New Zealand

Yes, I want people with MND to have the support they need, when they need it.

Mr/Mrs/Ms/Miss/Other: First Name:

Surname:

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Town/City:

Postcode: Phone:

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Yes, please contact me about: ☐ Making a regular donation ☐ Leaving a bequest

Ways to donate

☐ My cheque is enclosed made payable to MND New Zealand

OR ☐ By Internet Banking: Account Name: Motor Neurone Disease Association

Bank: Westpac Banking Corporation

Account Number: 03 0539 0195083 000

Reference: Donation

Code: *Surname*

OR ☐ By credit card: visit mnd.org.nz and click DONATE NOW

Email your completed donation form to admin@mnda.org.nz or post to the address below.