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mndnews

NEWSLETTER OF THE MOTOR NEURONE DISEASE ASSOCIATION OF NEW ZEALAND INC.

www.mnd.org.nz

Record Motor Neurone Disease Awareness Month!

This year was our most successful Motor Neurone Disease Awareness Month ever, raising an incredible $245,000 through the MND Ice Bucket Challenge, Cuppa Tea for MND, and the "David's Unusables" awareness campaign. Thank you to everyone who got involved. Your support each year raising awareness of MND helps lead 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 the disease.

Several companies took on the MND Ice Bucket Challenge and set themselves a fundraising goal. A special thank you to Active VMA, who raised over $7,000, Bluff Country Contractors, who raised over $8,000, and Colliers Highbrook, who raised a staggering $200,000!

More than 30 Cuppa Tea for MND events were held across the country to mark Motor Neurone Disease Awareness Month. Funds are still coming in, but already these events have raised over $16,000.

Thanks to everyone who has bid on an item or donated in support of our awareness campaign "David's Unusables". The campaign ran until late August, and all funds raised went to MND New Zealand. To find out more, go to www.mnd.org.nz.

Read more about Motor Neurone Disease Awareness Month on page 3.

COVID-19

We are still here. MND doesn't stop and neither will we. If New Zealand finds itself in a lockdown, our support team members will not be able to offer face-to-face visits but can still provide support via phone calls, text, email, and video calls. Please do not hesitate to contact them.

From the Chair and CEO


Natalie Thain, Interim Chair


Carl Sunderland, CEO

Since our last newsletter we've been busy focusing on Motor Neurone Disease Awareness Month, which was our most successful yet – raising over $245,000!

This year we had three key initiatives: Cuppa Tea for MND, the MND Ice Bucket Challenge, and the "David's Unusables" Trade Me campaign. Thank you to everyone who got involved during June; we are blown away by everyone's support and generosity. Read more about the month's activities on page 3.

We've had a couple of staffing and governance changes within MND New Zealand over the past few months. Following the retirement of our Chair Greg Horton, Natalie Thain was appointed interim Chair in May until a new Chair is announced at our AGM on 30th October. Additionally, two of our Council Members, Nick Molcsan and Wayne Philip have retired, and we said farewell to Emily King our communications specialist, who left us this month to have a baby. Julia Davies has taken over her role and we are excited to have her as part of the team.

We are now in planning mode for this year's Walk 2 D'Feet MND event season, which runs from November to February. These events are made possible by supporters volunteering their time and energy, providing an opportunity for our local community to come together and make a difference for people living with MND. For more information on how to get involved, see page 5.

The Fulton Hogan MND New Zealand Support Fund has just entered its third year, and to date we have processed 110 applications. The fund helps families across New Zealand with additional support to cover transport costs, home improvements and maintenance, respite care, counselling, specialised care, medical equipment, and other practical needs. We are extremely grateful to Fulton Hogan for making this fund possible. To find out more about the support fund, visit our website.

We have also been busy in the research space, with three projects funded by MND New Zealand in the planning stages for research studies this year and in 2022. They include a study looking into the costs associated with MND in New Zealand, the impact of having a MND clinical nurse specialist, and a nationwide population-based study aiming to explore the prevalence of MND in New Zealand. See page 9 for more information.

These are just some of the exciting initiatives we've been working on, and we hope you enjoy reading about them in this newsletter. We are so grateful for your continued support so we can 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,

Natalie and Carl

IN THIS ISSUE

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Motor Neurone Disease New Zealand

Fundraising highlights

MND Ice Bucket Challenge

Greg Goldfinch and the team at Colliers Highbrook raised over $200,000 by taking part in the MND Ice Bucket Challenge – the highest amount ever raised by a single fundraising supporter activity in MND New Zealand history!

In addition to Colliers Highbrook, participants included Bluff Country Contractors, Active VMA, Barfoot & Thompson, and the team at Fulton Hogan Auckland Airport.

Carl Sunderland, CEO at MND New Zealand & Greg Goldfinch, National Director Industrial Sales & Leasing at Colliers

Active VMA and Bluff Country Contractors continued to surpass and increase their fundraising goals throughout the month and raised $7,500 and $8,000 respectively by the end of the month.

Colliers Highbrook set their ambitions high, aiming to raise $100,000. They inspired support from far and wide: across their organisation and from stakeholders, family, and friends. They smashed their goal, raising an astounding $200,000!

Greg Goldfinch, National Director Industrial Sales & Leasing at Colliers, says: "Last year my precious dad was diagnosed with MND. As a family we knew very little about the disease, but in the days that followed we came to learn that it has no treatment options, which was devastating for all of us.

"My colleague Ryan Gibb has also been looking after his dad, who suffers from this same horrible disease, so we thought we would do something about it and rallied the Colliers Highbrook troops to raise awareness, and importantly raise much needed funds for MND New Zealand."

Twenty Colliers Highbrook staff took the icy drenching, while dressed in their suits, on Friday 11th June. Watch the video by visiting the MND New Zealand YouTube channel.

Thank you to everyone who took on the MND Ice Bucket Challenge and contributed to raising over $230,000!

www.mnd-ice-bucket-challenge.raisely.com/

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/

Cuppa Tea for MND

More than 30 Cuppa Tea for MND events were held across New Zealand to mark Motor Neurone Disease Awareness Month. Funds are still coming in, but already these events have raised over $16,000.

Read about Sally's experience of hosting a Cuppa Tea for MND:

"What a good, fun way to raise money. We had afternoon tea at my place recently in Auckland with many of my friends and neighbours, and raised just over $2,600.

"When I realised how many people were likely to come and that I didn't own that number of uncracked cups and saucers, I suggested everybody bring their own very best cup and saucer and we have a competition. A friend happened to have oodles of her mother-in-law's old tea sets under her house, so we happily drank out of Mrs Parker's lovely old cups, including some she won in a Woman's Weekly competition. They have gone back under the house for next year.

"Friends offered to bring food, and I knocked on several neighbours' doors to see if they too could help – the star was a lemon cake with lemon honey and cream on it. Another friend brought over the most beautiful silver tea service and fancy tablecloths. We held the afternoon tea in two rooms: one around a table, and the other perching on easy chairs. One friend poured all the tea, gave a wee speech about MND, and a couple of people handed out food.

"That evening I took a container of leftover cake to drop off to a rough sleeper up the road and I took some to my gym the next day."

Thank you for your support, Sally.

Fundraising event in honour of Morris Edwards

The Masterton community came together and raised an incredible $62,000 in support of MND New Zealand at a sold-out fundraising dinner and auction held at Makoura College.

Tweet Bird organised the event. His friend, Ian MacLennan, died of MND 18 years ago, and his friend Morris Edwards had been diagnosed with MND earlier in the year. Morris passed away in April this year.

Two hundred and eighty people attended the dinner, and between 400 and 500 people were involved in total.

Communications update

Since our last newsletter we have launched our new brand identity and started to roll it out across our marketing and communications channels. This includes a new logo, colour palette, icons, photography, and fonts. We hope you love the new look and feel as much as we do.

We have been busy working on developing our new website, which will make online interaction more user-friendly, so it's easier for our MND community to find the information they are looking for. We hope to launch this in the coming weeks.

We have also created a new Instagram account: @mnd_nz. We plan to add more content to this page, so if you're on Instagram please follow us.

Tweet said: "It was to let the public know what's going on. There are a lot of people now who have connections to MND."

Tweet rallied the community to come together and honour Ian and Morris. Like Tweet, Ian, and Morris, many of the event volunteers had an ex-military background.

A team of at least 12 former army chefs worked together to prepare the night's meal for 300 people. One volunteer said: "We all served, though not at the same time. We have one of those unique bonds between us. When the call came out to help with the dinner, it was an easy answer. I was simply blown away by the generosity of the local community."

Funds were raised from ticket sales and generously donated auction items. Morris's sons, son-in-law, and Bird also auctioned off styling rights to their hair, and the style of choice was created that very evening by a team of hairdressers, with Bird's being the most distinctive design. Morris's labradoodle also got a style to support the cause.

We are so grateful to all those who joined Tweet in donating their time, skills, auction items, and funds, which made this event such a success. At a time of uncertainty in New Zealand, due to a period of COVID-19 impact recovery, Tweet inspired a community to join together and help MND New Zealand to make a difference every day for those living with MND. Thank you!

With thanks to Morris Edwards's family, who gave their approval for this article to be published.

Support Walk 2 D'Feet MND this summer

Walk 2 D'Feet MND is a series of family-friendly summer events organised by MND New Zealand supporters across New Zealand. These events are made possible by incredible volunteers donating their time and energy, providing an opportunity for our local community to come together and make a difference for people living with MND. MND New Zealand offers guidance, resources, and support every step of the way.

If you are interested in finding out more about organising a local Walk 2 D'Feet MND event, or to register a walk you are already planning, get in touch. Email: kate.dalders@mnd.org.nz

Support team update

I really enjoyed hearing about the activities our community participated in during awareness month. Thank you all for your enthusiasm and support. Our team feel very privileged to be part of such an amazing community.

The support team met in Auckland at the beginning of May for our annual Team Days. It was great to be able to gather again, having cancelled last year due to COVID-19 restrictions. The opportunity to spend time together for professional development, and to share ideas and experiences, is always invaluable.

The Fulton Hogan MND New Zealand Support Fund has just entered its third year and to date we have processed 110 applications. It has been fantastic to hear from those who have received funding and to learn what impact this has had on their lives. Thank you to those who have shared their stories and in some cases photos with us. We are very grateful to Fulton Hogan for making this fund possible.

Toni Foster
MND Support Team Leader

Going above and beyond

The lovely team at Fulton Hogan recently helped deliver and stack firewood for one of our Christchurch clients.

The New Brighton Lions Club in Christchurch recently helped assist one of our clients with some gardening work.

Jos's memories

BY JOS

Preface: Jos has MND and lives in hospital-level care in a rest home. She loves to write about special memories from her past, and recently shared this piece about her time working with the New Zealand military stationed in Singapore.

One never knew what would happen next while living and working in Singapore. I arrived at the office one morning to be asked by my boss to deliver some cash to the battalion on exercise in the jungle in Malaysia. The troops had been living on rat packs (dried food) and needed cash to buy fresh food from the local markets. I was duly picked up at the office by an army chauffeur-driven car and with my Naval Petty Officer (Sam) as armed escort. We were taken to the helicopter pad at the Singapore Naval Base. An Air Force helicopter had been sent from the exercise to take Sam and me into the jungle. It was a fantastic ride in the open-side seat of the helicopter over the causeway between Singapore and Malaysia, then over the pineapple plantations and palm oil trees into the jungle. We delivered the money to the NZ military on exercise with the Malaysian troops. We were treated to a lovely lunch in the middle of the jungle and then we were taken back to Singapore again by helicopter. Another wonderful experience and memory for a civilian working for three years with the three forces of the NZ military stationed in Singapore.

Holiday adventure at Huka Falls

Lorraine Darcy, from Gisborne, recently visited Huka Falls and sent us this great photo, which won second prize in an Invacare photography competition.

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 julia.davies@mnd.org.nz if you have any ideas for our next newsletter.

Two-Wheel Racer

Lisa Brown hasn't let her MND diagnosis stop her, racing motorbikes competitively and working with a physiotherapist to help her continue to be able to get on her bike.

Lisa started racing two years ago with her partner Andrew. Since then, the pair have been traveling around the North Island competing in NZ Classic Racing Events, with Lisa taking home Second Place in the 2020 championship season in her 350cc Clubmans Class.

Lisa says it is important for her to feel part of the team; an integral member of the wonderful racing community who have rallied around her since she was diagnosed with MND. The team are even in the process of developing another slightly smaller bike so she can continue to race.

"You've got to have a goal, and you've got to stay positive to help you carry on," says Lisa.

Lisa knows what her goals are and hopes to compete in the next three NZ Classic Racing Events this year. We wish her the best of luck!

MND research in New Zealand gaining momentum

Three projects funded by MND New Zealand are in the planning stages for research studies this year and in 2022.

1. Costs associated with MND in New Zealand

MND New Zealand Community and Research Advisor Claire Reilly and neurologist Alan Stanley have teamed up with senior health economist Braden Te Ao from the University of Auckland to investigate the costs associated with caring for people with MND.

Currently there is no information available about the health and social services used by people diagnosed with MND, and the cost of these to the government and the person with MND and their family. The study's findings will help MND New Zealand advocate for the needs of people living with MND. The survey is aiming to be sent out in October.

2. The role and impact of the MND clinical nurse specialist – a combined quantitative and qualitative study

MND New Zealand is working with researchers from the Canterbury Respiratory Research Group, Christchurch Hospital and University of Otago Christchurch campus, funding a study on the impact of having a MND clinical nurse specialist.

The overall purpose of this study is to assess the impact of changes to care for people with MND since 2006 (when research was last undertaken). The major change since 2006 was the introduction of a key worker/clinical nurse specialist role (2013), and establishment of a multidisciplinary MND clinic in Canterbury – aligning service provision with international best practice.

During the research we will talk with people living with MND in Canterbury to find out what they think about the care they have received. The research team will use interviews and surveys to explore participants' experience of engagement with the MND nurse specialist and the multidisciplinary MND clinic, and how it has affected their care.

In addition, over the summer period a student will complete an audit to collect data around the prevalence and incidence of MND in Canterbury, including survival rates, times to treatment, hospital admissions, and timings of interventions before and after the implementation of a key worker/clinical nurse specialist role and multidisciplinary clinic.

The main output of this work will be a report for MND New Zealand, which will provide information about the service provision in Canterbury.

The research team

Dr Rachel Wiseman – Respiratory and Palliative Care Physician, MND Clinic, Christchurch Hospital, will provide oversight of the complete project

Dr Michael Epton – Respiratory Physician, Director, Canterbury Respiratory Research Group, Christchurch Hospital, will provide oversight of the research process and assistance with data analysis.

Dr Malina Storer – Research Manager, Canterbury Respiratory Research Group, Christchurch Hospital, will be responsible for supporting all research tasks

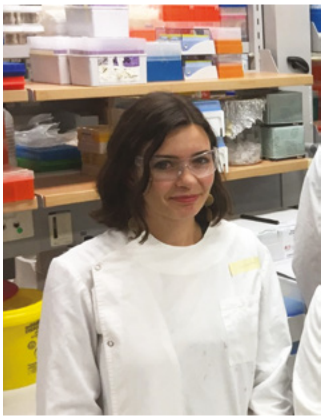
Dr Mandy Wilkinson – Centre for Postgraduate Nursing Studies, University of Otago, will be responsible for the qualitative aspects of the project, including planning and execution of the interview process, qualitative data analysis, and publication.

3. Prevalence study

A key priority of the 2019–2022 MND New Zealand Research Strategy is to improve our knowledge of the epidemiology of MND in New Zealand, including identifying any ethnic differences.

Accurate prevalence data for MND in New Zealand doesn't exist. Prevalence data provides a crucial foundation to identify the scope of the problem of MND in New Zealand, the individuals affected, and the type and distribution of services required. The nationwide population-based study aims to explore prevalence of MND in New Zealand by age, sex, ethnicity, region, and disorder type.

New team member at Motor Neuron Disease Research Lab



In June, the Motor Neuron Disease Research Lab at the University of Auckland welcomed a new genetics study coordinator, Siobhan Kirk, to their team. Siobhan is an early career researcher who recently returned to New Zealand from Queensland. She has been involved with MND research for several years, from growing brain cells in a dish to getting out and raising money for MND research and support. She looks forward to bringing her skills back home in her new role.

New Zealand guidelines for MND care

The final draft of the national guidelines for the assessment and management of MND has been completed and distributed for stakeholder consultation, including Neurological Association of New Zealand (NANZ), Australian and New Zealand Society of Palliative Medicine (ANZSPM) and Thoracic Society of Australia and New Zealand (TSANZ).

The guidelines will be available on the MND New Zealand website later this year.

Part of the MND Clinical Working Group "Improving care, Improving lives" initiative is to work with the Ministry of Health at a national level to effect change in policy that affects people living with MND. MND Clinical Working Group representatives Claire Reilly and Alan Stanley are regularly meeting with Chief Allied Health Officer Martin Chadwick to discuss implementing the recommendations that have arisen from the development of the national guidelines. Current discussions revolve around how timeliness and access to equipment and home modifications can be improved. Discussions have been positive, and we'll keep you informed of any developments.

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.

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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New Zealand

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Members: Alan Stanley, Melanie Glenn, Michael Fuyala,

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.

MND NEW ZEALAND FUNDERS

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

- BlueSky Community Trust
- Community Organisation Grants Scheme
- Dragon Community Trust
- Four Winds Foundation
- Guy Anson Waddel Charitable Trust
- Higgins Bequest Trust
- Maurice Paykel Charitable Trust
- Ministry of Health Vaccine and Immunisation Communication Fund
- Stewart Family Trust
- Pub Charity

Donate to MND New Zealand

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

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

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