

mndnews

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

www.mnd.org.nz

Donate to Light Up a Star



This year for our MND New Zealand Christmas Campaign we have developed a virtual Christmas Tree, and supporters can make a donation to light up a star on it. With many other activities moving online this year, it seemed fitting to host an online Christmas event for our community to share in and contribute to. We treasure the special moments that make the festive season magical, and invite our community to join us in celebrating the year end.



You can choose to leave a personalised message and add a photo to your star, which will be visible for all online Christmas Tree visitors. To donate to light up a star on MND New Zealand's Christmas Tree, click on the QR code above.

Rewardhub

Starting to think about Christmas shopping?

Rewardhub lets you support MND New Zealand through online donations – and it won't cost you extra.

Step 1 – Sign up to support our page. It's free, quick, and easy.

<https://rewardhub.co.nz/mnd-new-zealand>

Step 2 – Browse more than 100 brands, shop as normal, enjoy usual prices and special offers.

Step 3 – Shops donate a percentage of your spend to us to say thanks. It doesn't cost you a cent more!



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.

CEO and Chair Report

2021 has been a busy and exciting year for MND New Zealand, from our Walk 2 D'Feet summer event success, to a record Motor Neurone Disease Awareness Month, and more recently the challenges experienced through lockdowns from the COVID-19 pandemic.



Greg Horton, Acting CEO

The team at MND New Zealand welcomes 2022 with a change in our staffing and governance, with Lucy Haberfield being appointed our new Chair, replacing Natalie Thain, and Greg Horton stepping in as our Acting CEO following Carl Sunderland's resignation.

Lucy has served on the MND New Zealand National Council as Treasurer since 2017 and has a connection to the disease through her family. As our new Chair, Lucy brings significant expertise as well as experience within our organisation. She will be invaluable to us as we navigate the challenges post-COVID 19.

I was also previously on the MND New Zealand National Council for four years, 18 months of which I served as Chair. It is my pleasure to return to the organisation as Acting CEO while we seek a permanent replacement. I have a strong history with the MND Community, having lived with MND myself for six years.

I would like to acknowledge the significant contribution of Carl Sunderland, our previous CEO, who left after four years' service. Carl was instrumental to the organisation's growth. He achieved many things for MND New Zealand and built a great team along the way.

Continuing with our governance changes, we welcome two new members to our National Council, Chris Sawers and Estelle Arts. Lastly, we would like to bid a fond farewell to Kate Dalders, who has been our dedicated fundraiser for the past three years. She



Lucy Haberfield, Chair

will be missed, and we wish her well in her future endeavours.

We are overwhelmed by our 2021 fundraising success. MND Awareness Month raised a record \$245,000, our Cuppa Tea for MND events drove positive results, and our "David's Unuseables" Trade

Me Campaign significantly increased awareness of our cause. Thank you to everyone involved.

We rely on the support from our corporate sponsors, and as the year ends we would like to take this opportunity to thank all the corporates we have a relationship with. To Fulton Hogan, Emirates Team New Zealand, Colliers, and the many more we have listed in this newsletter: we are grateful for your generous support.

As we look to the year ahead, our number one priority is our support service, as well as our role in advocacy and communications. These will always remain the cornerstones of our work.

We continue our research efforts with our upcoming survey on the Costs Associated with MND in New Zealand, the role and impact of the MND clinical nurse specialist study, and an exciting opportunity for a postgraduate student to be involved in the nationwide study on the "Prevalence of MND in New Zealand". These are just some of the exciting research initiatives happening at the moment. You can read more on page 10.

We are so grateful for the continued support of our community. Thanks to you, we can continue to deliver service and care to those living with motor neurone disease in New Zealand.

Wishing you all a wonderful festive season.

Meri Kirihimete

Greg and Lucy

IN THIS ISSUE

- FUNDRAISING HIGHLIGHTS **3**
- DAVID OLIVER BEACON AWARD **7**
- SUPPORT TEAM UPDATE **8**
- STORIES FROM OUR COMMUNITY **9**
- RESEARCH UPDATE **10**



Fundraising highlights



Walk 2 D'Feet MND – February 2022

Walk 2 D'Feet MND is our annual series of family-friendly events organised by MND New Zealand supporters across New Zealand to raise awareness and vital funds.

Historically these events provided an opportunity for us to unite, raise awareness, honour those living with MND, and commemorate loved ones lost to the disease. Plans for physical community events are currently on hold until February 2022, when we hope clear guidance will be available on how our supporters can hold these events safely in a world with COVID-19. But you can still help, in any traffic light level.

Take part in 'Do your own Walk 2 D'Feet MND' on the 27th February 2022 by taking a walk around your local area. Choose a route in your community to walk, run, or roll, and celebrate at your chosen finish line. Add something extra by completing the route in fancy dress, download and pin our "Walk 2 D'Feet MND" sign to your clothes, or get friends to join you via a video chat while you each walk in your own local communities. Raise awareness of MND.

Donate or set up a fundraising page to share with your friends by visiting www.mndwalk.org.nz, and help MND New Zealand continue to make a difference every day for those living with MND.

We would love to see photos of you out on your walk and celebrating at your chosen finish line. Share photos and stories of your DIY walk on MND New Zealand's Facebook page by scanning the QR code (left).



All photos uploaded to the page by 1st March will be entered in a draw to win a MND New Zealand Small Hope Puppy soft toy.

Together we continue to make a difference for people living with MND.



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/>

Corporate Support

MND New Zealand has benefitted immensely from corporate support, from our established relationship with Fulton Hogan, to our recent partnership with Emirates Team New Zealand, and the incredible fundraising carried out by Colliers to mark Motor Neurone Disease Awareness Month. There are so many ways to support MND New Zealand through your business. Here are some great examples:

Campaign Development

Special Group worked with MND New Zealand and volunteer ambassador David Seymour to develop and implement our recent Trade Me campaign: "David's Unusables". This was a Trade Me awareness campaign, where David sold off his personal items which he could no longer use since his MND diagnosis. The audience

SPECIAL

could either bid and buy his items and all donations went to MND New Zealand, or they could donate. Special Group volunteered their skills, time, and connections to produce a multi-channel awareness campaign to reach a wide audience.

"Special has a strong commitment to giving back to New Zealand. We often tackle pro-bono briefs and are pleased to lend our support to MND New Zealand.

We felt awareness and education could go a long way towards helping people living with the disease and supporting the charity. With no known cause and no effective treatments, it's important this cause receives as much attention as possible. We hope that this disruptive approach helped raise mainstream understanding of the illness, and we're proud to have been able to help tell David Seymour's story for a very deserving charity."

Michael Redwood, Special Group Managing Partner

Branding

Said & Done worked with MND New Zealand on our recent re-branding. They used their marketing expertise to help MND New Zealand develop our logo, brand identity, and messaging to better reflect who we are and what we do, enabling us to grow and better inspire support.

Said/ Done

"It was an absolute pleasure to work with the courageous team at MND New Zealand and to learn more about the incredibly important job they do. Our team are very proud of the new MND New Zealand Brand (strategy and visual identity) and can't wait to see it in market. It has been designed to be clear and compelling, and to resonate with MND New Zealand's diverse audience groups, supporting MND New Zealand in their wonderful work. A privilege to be able to give a little to an organisation that gives so much."

Simonne Mearns, Said & Done Co-Founder

MND New Zealand is extremely grateful to these and many other businesses, who have used their time and skills to support us. If your businesses would like to get involved next year, please email admin@mnda.org.nz.

Cause Related Marketing

Fit NZ develop innovative design solutions for the kitchen and home, and recently raised over \$6,000 through cause-related marketing (CRM), by linking a purchase of their products to MND New Zealand and donating an amount for each purchase made. Proven to build brand awareness, maintain customer loyalty, and gain new consumer interest, CRM is a fantastic way to promote your product or brand and raise money for a good cause.

"At Fit, we want to enhance not just living spaces but also lives and communities. Several of our team have family experience with MND, so making MND New Zealand our 2021 charitable fundraiser partner was especially poignant. We're so pleased to have helped in this small way."

Lesley Auchterlonie, Fit NZ Marketing Skipper

*N.B. Please ensure any CRM is agreed upon in writing with MND New Zealand prior to promoting a product.



Fundraising

Property Brokers (Waipukurau, Central Hawke's Bay) held two very successful fundraising events this year: a golf tournament and a horse trek. They engaged their networks and local communities to raise over \$17,000 through these two events.



Donation

Harmos Horton Lusk recently generously donated \$20,000 to MND New Zealand in recognition of one of their founding partners and directors, Greg Horton.

"Our decision to support MND reflects our deep respect for and friendship with Greg Horton, one of the charity's founders, who was diagnosed with the disease around six years ago. He is an inspiration to all who know him as he has battled the disease and adapted to its realities, while retaining his sense of humour and professionalism and giving his time selflessly to support others. We hope that our contribution will assist MND New Zealand in its work and so also assist others afflicted by the disease."

Andrew Harmos, Harmos Horton Lusk Director



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.

Market stall for MND

MND New Zealand would like to thank Sheila from Oxford, North Canterbury for her MND fundraising market stall. Sheila's husband Andy was diagnosed with MND earlier this year.

Sheila had been planning to have a fundraising stall for MND for some time, but had to postpone several times due to COVID-19 Alert Levels. She was able to finally go ahead on the 6th November.

Sheila gathered lots of pots from generous local businesses and filled them with plants from her own garden to sell at the stall, held in Rangiora.

With the help of friends Sheila has decided to run a second fundraiser stall in Shirley, Christchurch, to sell even more things for MND New Zealand.

Thank you, Sheila!



Design

Sue from minimum graphics has been supporting MND New Zealand with

the design of our newsletters and annual reports for the past 15 years, and we greatly appreciate the generous and long-term support she has offered our organisation.



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.

David Oliver Beacon Award

Congratulations to Greg Goldfinch and the incredible team at Colliers Highbrook, who are this year's David Oliver Beacon Award recipients.

Dr David Oliver is an internationally acclaimed physician who has dedicated much of his life to enhancing the quality of life of people with MND through his practice, writing, and teaching. He has generously agreed to his name being associated with this award.

The David Oliver Beacon Award is awarded annually, to acknowledge and celebrate those who have made a significant contribution to the MND community.

The 2021 theme was "making a positive contribution, improvement, or innovation in motor neurone disease support or care". Greg and the Colliers Highbrook team have gone above and beyond with the success of their Ice Bucket Challenge during MND Awareness Month.



Following Greg's father's MND diagnosis in 2020, the team at Colliers Highbrook set out to raise **\$100,000** for MND New Zealand. With Greg driving the campaign, and getting as many people as possible involved, the team managed to raise over **\$200,000**.

This is the largest amount raised from single supporter-organised activity in MND New Zealand's history.

This invaluable support also generated significant awareness for MND New Zealand, with more than 200 people and businesses getting involved and showing support. Greg and his team saw an opportunity and enthusiastically used their skills and network to make a huge impact.

The effects of their fundraising activity will positively contribute to the lives of those living with MND for years to come.

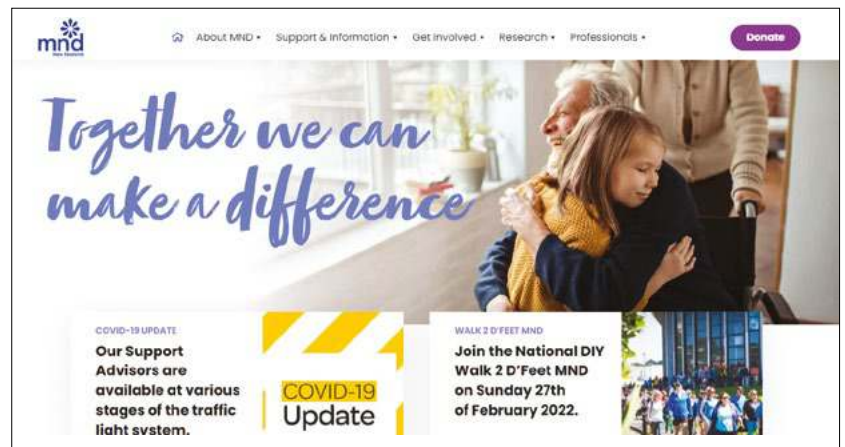
Communications update

The team at MND New Zealand were thrilled to launch the new website, incorporating our fresh new brand identity. The MND community is at the heart of everything we do, and we set out to create a new website with a purpose: to host useful and accessible information and resources, to support those living with MND.

On our new website, you can easily find

- support and information
- the latest research
- how to get involved with fundraising
- support for health professionals.

This wouldn't have been possible without the generous work of our website development partner **Weave**.



Support team update



The announcement that the COVID-19 Delta variant had arrived in New Zealand caught us all a little off-guard. Those of us working at National Office packed a few things so that we could set up to work from home again, for what we thought would be a couple of weeks. Here

I am months later, typing this article from my home "office"!

We hope that our clients have continued to feel well-supported by us during this lockdown. I know that the team were feeling frustrated that they were unable to provide face-to-face support to many of our clients. Our clients' wellbeing is extremely important to us all and we feel that providing support via other means has been the most appropriate action for us to take during lockdowns.

We have been working on the development of an education package for the MND community and are

pleased that we are almost ready for this to be rolled out. This package will include written information that will be available on our website and through the support advisors, including some sessions via zoom. We will start with information and education for people with MND, their carers, and whānau, and will then expand to include information and education sessions for health professionals over the next 12–18 months. We will keep you updated.

The National Office will close for the Christmas Break on December 24th and reopen on January 5th. During this time all support advisors will be on leave. While your own support advisor may also be on leave at other times over the summer, please be assured that her team members will be available to provide support for you during this time.

I would like to take this opportunity to wish you all a safe and happy festive season. Let's hope 2022 is a more settled year for us all!

Toni Foster

MND Support Team Leader

MND New Zealand's COVID-19 Protection Framework and Vaccination Policy

MND New Zealand holds the safety and wellbeing of our community at the centre of all we do. We are conscious that our community is more vulnerable to the effects of COVID-19, and we care about the safety of our staff. Therefore, we support vaccination as a way to increase the protection for our community and we have adopted a COVID-19 vaccination policy.

Our team at MND New Zealand are all fully vaccinated and are happy to answer any questions that you may have about their potential exposure to COVID-19 before you agree to a face-to-face meeting.

Our support advisors can offer support in a variety of ways under the new COVID-19 protection framework. Face-to-face support and home visits can occur at all levels of the COVID-19 protection framework for those who are comfortable with this, however different precautions will be included at the different levels of the framework.

Prior to any face-to-face meetings between clients and our support advisors, your support advisor will inform you about any potential exposure they may

have had to COVID-19 and will ask about any potential exposure you or your household contacts may have had. They will also ask about your vaccination status, you are not obliged to disclose your vaccination status if you would prefer not to.

If you choose not to disclose your vaccination status, it may be required that support takes places online or over the phone. If this is not possible, support may be offered in another way and face-to-face meetings could occur if all parties concerned are comfortable with this.

This policy has been put in place to ensure we can all take steps to offer the best possible protection for all our MND community while continuing to provide an effective support service.

MND doesn't stop, so neither will we. If you need support or have a general enquiry, please get in touch today.

For more information on the COVID-19 protection framework and MND New Zealand's vaccination policy, please visit our website, www.mnd.org.nz

Stories from our Community

Lara and Michael's Story

Michael was 34 when he was diagnosed with MND on Valentine's Day 2020.

There is no good age to get MND, but it's generally and statistically seen as an "older person's disease". MND is rare. Getting MND young seems rarer, but there are plenty of young sufferers out there.

Michael juggles MND and being a dad, and he does it amazing well! But it is very emotionally hard for him; no father wants to leave their child, and he adores his daughter.

Our daughter is about to turn four. We tell her that Daddy's body works differently, his hands and legs don't work like other people's, and he needs a wheelchair to get around.

We also tell her that sometimes Dad needs her help to open the latch on the gate, or to get things on their trips to the supermarket, or to put a straw in his mouth to drink. She's very protective and attentive to him! We don't expect her to help with caring for Michael; she just does these small things as part of our general family life. They both whiz around Invercargill on the wheelchair to the park or to meet me around town, and most mornings he takes her to kindy.

I juggle being Michael's wife and carer and life with a four-year-old, which can be full on. I feel like Mrs Rabbit from Pepper Pig, doing lots of jobs and wearing lots of different hats.

We are so grateful to the Wellington and Southland support advisors. For me they have been a listening ear, understanding what we are going through and supporting us through the ins and outs of the medical care. The MND support advisers allow for honest conversations that aren't judged, and it is so nice to know that there is someone to turn to when we need advice and support.

They understood that we not only needed to cater



for Michael's needs, but also the need for our life, house, and vehicle to not just be accessible but family friendly. This is important because the health service only considers the patients' needs when considering funding modification. They encouraged us to go for all the grants available like a lottery vehicle grant and a Enable New Zealand Home modification grant. This was so helpful.

My advice to anyone newly diagnosed would be that your future will be different to what you imagined, but there are happy times, and you appreciate all those little moments and appreciate them more than before. Just do it a day at a time.

Lara Cockroft

Jan's Story

Jan was diagnosed with MND in July 2020. Her home was up 100 steps, so the health team had to get fitter and wear sensible shoes so they could do home visits. Jan was always at the top of the steps to welcome them with open arms and her gorgeous smiles.

Jan is an extraordinary inspirational woman with a rich life history. She was an avid trumper, conservationist and explorer. Jan was involved with soil work at Cape Bird, and work in Antarctica, which her late husband Arnold explored!

She has just completed documenting her tapestry of life through the biography service at Te Omanga Hospice.

Jan can swim once a week accompanied by her private carer Sandi, and her physio Brian in the hydrotherapy pool at Huia Pool and Fitness.

As you will see, the photo is not that clear but what is clear, is the energy for life that epitomises Jan.



MND Research Updates

Research News

There is a lot happening in the world of MND research, both locally and overseas.

New Zealand Motor Neuron Disease Research Network has developed a timeline on the latest news and research. You can view the timeline of the news and subscribe to their newsletter at <https://www.mndresearch.auckland.ac.nz/mnd-mediareports/>.

The MND Research Blog has been developed to share all the latest news on MND and take the audience behind the scenes of MND research. You can view the blogs at <https://mndresearch.blog/>

Keep an eye out for our MND Survey on the Costs Associated with Motor Neurone Disease in New Zealand. This survey is currently awaiting final ethics approval, expected to launch in January 2022. The survey will be promoted via email to our clients and on social media.

New Zealand Best Practice Recommendations for the Care of People with Motor Neurone Disease

MND New Zealand has been developing the Best Practice Recommendations for the Care of People living with Motor Neurone Disease, to ensure appropriate assessment and management.

These national guidelines are in the final stages, having received endorsement from the Neurological Association of New Zealand, and are pending endorsement from the Australian and New Zealand Society of Palliative Medicine and The Thoracic Society of Australia and New Zealand.

While the endorsement process has taken longer than anticipated, it is hoped that the best practice recommendations will be available on MND New Zealand's website early next year.

MND New Zealand Master's Scholarship



MND New Zealand is excited to announce the funding of a master's opportunity for a postgraduate student with an interest in neurological diseases. The nationwide study on the "Prevalence of MND in New Zealand" will use capture-recapture methodology and demographic information including age, ethnicity, sex, and geographic location. It is anticipated that this project will take place over twelve months.

The successful student will have a strong academic track record and good interpersonal skills. This opportunity will help kickstart their research career and significantly contribute to a rapidly evolving research field.

If you want more information on this opportunity, please email Claire Reilly, MND New Zealand's Community and Research Advisor, on claire.reilly@mnd.org.nz

Medical Alert Cards

MND New Zealand has created a wallet-sized alert card and fridge magnet to aid paramedics and hospital staff, should someone living with MND require urgent care. These will be made available to new MND New Zealand clients in the information packs and existing clients via their support advisors, and will also be downloadable from the MNZ New Zealand website.

	MND Medical Alert My Name Is: _____
I have Motor Neurone Disease which can affect movement, communication, breathing and swallowing.	
It does not generally affect a person's ability to understand and make choices and decisions.	
IF I NEED URGENT HELP, PLEASE DIAL 111 AND SHOW THEM THIS CARD	
Caution: Titrate oxygen therapy to achieve SpO2 88-92%.	
I may need supported ventilation. My Care Plan has more detail.	
I need specialist care if admitted to hospital.	
My contact person's name & number is: _____	
My GP's name & number is: _____	
	

Our MND Support Team

We employ part-time MND support advisors 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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Patron – Ruth Dyson

Medical Patron – Sir Richard Faull KNZM FRSNZ

Honorary Medical Advisor – Dr James Cleland FRACP

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

MND ASSOCIATION OF NEW ZEALAND INC.

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NATIONAL COUNCIL

Chair: Lucy Haberfield

Deputy Chair: Caron Palmer

Members: Alan Stanley, Chris Sawers, Estelle Arts, Melanie Glenn, Michael Fuyala

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.

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.

MND NEW ZEALAND FUNDERS

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

- Acorn Foundation
- Estate of Ernest Hyam Davis and Ted and Mollie Carr
- Geyser Community Foundation
- William Toomey Trust
- Trust Waikato

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: _____

Street address: _____

Town/City: _____

Postcode: _____

Phone: _____

Email: _____

Yes, please contact me about:

Making a regular donation Leaving a bequest

WAYS TO DONATE

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 on the purple DONATE NOW button

Email your completed donation form to

admin@mnda.org.nz or post to the address below.



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Motor Neurone Disease New Zealand

