

Our first “Do It Yourself” Walk to D’Feet MND

Our fundraising events for 2022 are off to a flying start, setting us up to grow and expand our support for our MND community throughout the year. Starting with the “Do It Yourself” Individual Walk to D’Feet on Sunday 27th February, our supporters gathered their teams to walk, run, cycle, and wheel around their chosen tracks across the country.

The annual Walk to D’Feet event raises vital funds for MND support, information, advocacy, awareness, and research. The walk provides an opportunity for people impacted by MND to come together, honour those living with MND, and commemorate loved ones lost to the disease. While the format this year shifted from large group events to individual or small group walks to protect our community while New Zealand is in the red level of the COVID-19 Protection Framework, we still had enormous support from our incredible teams.

From team “One Love” doing walks spread out across Whangarei, Orewa, Weymouth, Karaka and Tuakau; to teams in Auckland walking through the City Centre and Shakespear Regional Park; to others across the Hauraki Plains, in Whanganui, in Hagley Park in Christchurch, and through Queens Park in Southland – these wonderful supporters and advocates enjoyed many beautiful locations across the country.



Sinel-Broad Families

With 16 teams made up of 42 supporters, we managed to raise over \$34,000, which goes towards supporting those living with MND in New Zealand. We are so fortunate to have such a wonderful and dedicated community ready to support and participate in our annual Walk 2 D’Feet Events, no matter the format. Thank you everyone who participated, donated, and got involved!

COVID-19

We are still here. MND doesn’t stop and neither will we. Our support advisors are available at various stages of the COVID-19 protection framework. If face-to-face visits are not possible, our support advisors still provide support via phone calls, text, email, and video calls. Please do not hesitate to contact them.

CEO and Chair Report



Scott Arrol, Chief Executive

Welcome to our first MND News for 2022! Our team has been determined to keep things moving safely for our community, whilst still providing support to those living with MND despite the ongoing COVID-19 interruptions.

I was thrilled to join the team in March and contribute to the amazing work this organisation does for those living with MND. Additionally, we were fortunate to start this year off with a few more new faces. We welcomed Rob into the newly created Events and Fundraising role, and two new board members, Chris Sawers and Estelle Arts. Lucy Haberfield, who was our previous Treasurer, stepped in as our new Chair. We also farewelled Toni Foster, our Support Team Leader, after four years with the organisation. We wish her well in her future endeavours. I would like to thank our Support Advisors, Sally, Linda, Jane, Megan, Moira, Kate, and Hefina, who have all had a busy start to the year now they are back out and about in our community doing incredible work.

2022 fundraising efforts have already kicked off to a great start with the DIY Walk to D'Feet individual walks. We are so grateful for our amazing community and supporters from all over the country who completed their walks in cities, parks, and beaches, to raise funds for our organisation to continue to provide support to those living with MND.

With the Walk to D'Feet complete, we're now looking ahead to how we can continue to raise awareness and education for MND. With MND Awareness Week coming up in June, we're already underway with how we can build and grow our MND advocacy and support. Keep an eye out for updates as to how you can get involved.

Our national office staff have been very busy recently, with Dr Claire Reilly supporting many MND research projects, including the study on the costs associated with MND in New Zealand, which will support our advocacy efforts. You can read more about her MND research and updates on page 10. On the communications front, we recently launched a new Instagram account, to act as a dedicated hub of personal stories from people within our community to share, reflect, and help raise awareness. See page 4 for more information.

Thank you for your continued support. Your efforts ensure we can continue doing the vital work we do for those living with MND. I look forward to sharing updates throughout the year as we continue to grow the organisation and increase public education, awareness, and research for MND.

Kia kaha

Scott

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New staff welcome

As our organisation grows, so does our staffing team. We are delighted to welcome new faces to MND New Zealand as we continue to build and grow support and advocacy for the MND community. We welcome our new Chief Executive, Scott Arrol, and a new Chair, Lucy Haberfield. Chris Sawers and Estelle Arts joined our Council late last year, and Rob Bloch joined us as our Events and Fundraising Coordinator in January. A big thank you to Greg Horton (previous Chair and Council Member) and Caron Palmer (Deputy Chair), who stepped in as joint Acting Chief Executives and worked with the team to ensure a seamless delivery of service to our MND community while we went through the recruitment processes.

Scott Arrol, Chief Executive



Scott has significant experience in the health and not-for-profit sectors, most recently as the Chief Executive for Dementia New Zealand. Prior to this, Scott was the Chief Executive of NZ Health IT, and has previously held leadership roles across home-based care, aged care, and disability services. Scott

is a board member for Health Informatics New Zealand and has been involved in working groups associated with the current health sector reforms. Scott has a strong network in the health and corporate sectors and will be an excellent leader for MND New Zealand. Scott and his wife Anna have been married for 44 years. They have a daughter, Rebekah, son-in-law Paul, and two fantastic sons, Josef and Lucas. Originally from the South Waikato (born in Mangakino), Scott has lived in the Bay of Plenty and Waikato (Hamilton), and currently lives on Auckland's North Shore (Albany) where he has been for the past 15 years. Scott is a keen runner, having participated in several half marathons, and is a strong supporter of the parkrun community that is operated by volunteers providing free 5km timed events on Saturday mornings at many locations around New Zealand. Scott is very excited to join the MND New Zealand team and contribute to the incredible work they do to support people living with MND, their whānau and carers.

Lucy Haberfield, Chair



Lucy is an experienced corporate services manager with a background in finance. She has been a chartered accountant since 1995 and holds a diploma in marketing, and has a particular interest in strategic

and business planning. Lucy is a keen trail walker and mountain biker. Her father passed away with MND in 1999, and she is keen to give something back to her community.

Chris Sawers, Council Member



Chris is an independent consultant with a background in management and governance in both the health and science sectors. She is a member of the Institute of Directors New Zealand. Chris' research and

training in microbiology and immunology at Otago University led to a close and continued association with BLIS Technologies. Her career pathway developed into senior lecturer roles in health and on to advisor and consultant roles in science and business for both the Dubai and New Zealand governments and for private companies. Recently, Chris has been supporting Dementia Hawke's Bay Charitable Trust (DHBCT) as a Chair, and latterly Change Manager. DHBCT provides community support and education across Hawke's Bay and day respite at their facilities for those affected by dementia. Chris is looking forward to being able to support MND New Zealand.

Estelle Arts, Council Member



Estelle started her career as a nurse and continued on a part-time basis while raising three children. She then started her own business in the wool industry. After 10 years she sold the business and moved into the non-for-profit sector as Development Manager at St Peter's College, until moving to

the Maritime Museum as the Commercial Manager. Since then, Estelle has been NZ Manager for a variety of international brands like Swarovski, Guess, Monte Blanc and currently Calendar Club.

Estelle was always aware of MND and became more intensely aware 2 years ago when her husband was diagnosed with MND. Estelle says that being able to assist with support, education, research, and advocacy for people with MND and their families is an honour.

Rob Bloch, Events and Fundraising Coordinator



Rob is an expat from the United States. His educational background is focussed on business administration and project management. Prior to making the move across the world to New Zealand, he enjoyed quite an eclectic professional background, ranging from teaching ski lessons in the

mountains of Colorado to project management for construction firms around Boston, Massachusetts. Since arriving in New Zealand almost a decade ago, he has worked exclusively in-house fundraising for charities including Greenpeace, Oxfam, and UNICEF. "I have found an unbelievable sense of fulfillment in fundraising for charities and am humbled and honoured to be able to do so for such a beautiful community here at MND New Zealand."

Share your Story on Instagram

MND New Zealand is excited to announce the re-launch of our Instagram page! Every month, we receive wonderful, inspiring, and emotional stories from members of our community living with MND, their whānau, and friends. We have turned our Instagram page into a hub where all these stories can be hosted and shared, to help make the public aware of the lived experiences of MND and to promote advocacy.

Our Instagram page can be found on Instagram at [mnd_nz](https://www.instagram.com/mnd_nz)

To share your story, please visit

<https://mnd.org.nz/get-involved/share-your-story/>



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/>



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.

Fundraising highlights

DIY Walk 2 D'Feet

If you've been following along, you might know that this year's walk 2 D'Feet MND event has been a wild ride well before it even began. For a little while, we worried the pandemic would stop it from happening altogether! But the MND New Zealand community won't be held back, and we quickly switched formats to "Do It Yourself" individual and small group walks. While this was a deviation from the huge events of the past, as a community we overcame every obstacle, including the red level traffic light protection framework, and the DIY walks were approved to go ahead. Our teams from across New Zealand organised unique walks through parks, paddocks, and tracks, all while raising vital funds for MND New Zealand. We walked in solidarity, to honour and support those living with MND. Thanks to the collective efforts and dedication of our incredible community, and the generosity of all their donors, we were able to raise over \$34,000 dollars. This was such an inspirational day and will go a long way towards ensuring we can continue our support, advocacy, and research for those living with MND in New Zealand.



Rachelle Stroud and Family



MicklePicklePancakes (nickname from his daughter)



Steve Broad with friends in Christchurch



Hope Puppy at Shakespear Regional Park



Robyn and Denise Glynn



Bloch family at Shakespear Regional park

**MND
FUNDRAISE
YOUR WAY**

You can plan your own fundraising event or adventure to raise funds for MND by scanning the QR code below.



Whanganui DIY Walk 2 D'Feet MND

On Sunday 27th February, 25 people gathered at Virginia Lake in Whanganui to set out on their DIY Walk 2 D'Feet MND. They were walking in memory of Eris Matson (Mum, Nanny, Aunty, and friend) who passed away in 2015 after a courageous battle with MND. The children hid cornflower-blue painted rocks for other children to find as they walked around the lake. It was a beautiful day for a stroll, finishing off with a heart-shaped MND cookie for crossing the finish line.

Lana Hook



Lana Hook and Team Eris

Cruisaders: Sounds 2 Sound

Robin and his friend James are a part of four-person endurance bike-packing team, the "Cruisaders". Fundraising for charities during their adventures is nothing new to them, but when Robin's MND diagnosis came through late last year their efforts to raise funds for MND New Zealand



Left to right Dave Harris, Robin Manderson, James Cairns and Grant Diftord



Viv and Robin Manderson at Milford Sound



Robin Manderson at Lake Dunstan

became near and dear. On 2nd February they embarked on a new trail called Sounds 2 Sound: Marlborough Sounds to Milford Sound: riding 15,000km, climbing 20,000m of hills, and 13 days of riding in total. "We are doing this ride to not only raise funds for MND New Zealand, but also to show others that you can continue to achieve massive milestones with MND," says James. Along the way the team was routinely humbled and awed by the generosity of strangers, who not only gave donations and free bike repairs, but also offered Robin and James encouragement to see the journey through to the end. It wasn't easy for them by any stretch, and Robin fell down almost every day of the trip, but he got back up every single time and kept going – not just for himself, but for every person in New Zealand living with MND. Throughout the trip they were supported by Robin's wife Viv and their friend Kay, who helped keep everyone sane and on track. After wrapping up their incredible journey, James had this to say: "Robin Manderson is an incredible example of how we respond to an almost impossible task. We are so proud of him and what he has achieved." Robin and James raised an astounding \$15,000 for MND New Zealand. The Cruisaders team want

to extend the biggest thank you to everyone who supported them.

Nettie and the Crazy Bunch

Nettie and her bike-packing team, "The Crazy Bunch", decided to take on "Tour Aotearoa": New Zealand's longest bike-packing trail stretching 3,000km from Cape Reinga to Bluff, in honour of Nettie's husband Kevin who passed away with MND nine years ago. Her new partner Michael and a few of her closest friends were there beside her to make it happen. Before even setting foot to pedal, they'd already raised over \$3,000 in support of MND New Zealand.



Annette "Nettie" Wright and The Crazy Bunch

Shaving for MND



Devon Heath recently organised a unique fundraiser for MND in honour of his friend Cade, in honour of

his stepfather Kendall Payne who passed away with MND in August 2020. Devon shaved his head and raised over \$1000 for MND New Zealand.

Philanthropic funding: A pandemic overview

BY GRANTS ADMINISTRATOR PATRICIA BELL

On the back page of every newsletter we give a shout-out to the charitable trusts and other philanthropic organisations that support us.

Without the support of these organisations, as well as the generosity of individual donors and those who take part in our events and fundraise on our behalf, our work simply would not be possible. We receive some funding from the Ministry of Health, but you may be surprised to know it only represents around six percent of our total funding each year.

Our most pressing need has consistently been for ongoing operational funding, including salaries. Other needs are identified and prioritised on an ongoing basis. These can include but are not limited to: training, capital expenses, specific projects, printing, website costs, and research.

We are limited by the criteria set by charitable trusts, which are often narrow and specific, and the amount of funding available overall, which in many cases has declined (due to increased competition, changing philanthropic priorities, and, of course, COVID-19) and is hotly contested.

Funding activity has slowed down dramatically during the pandemic, with most of the pub charities, which rely on funds from pokie machines, slowing or shutting down. Some are coming back online now, but many are stressing the reality that there may not be as much money to go around for some time to come.

Other trusts have continued as normal with their funding programmes. When the pandemic began, a number immediately simplified their application process so charities could quickly and easily apply for funding.

Some other organisations launched support funds specifically geared towards helping charities during COVID-19. Competition was high and we missed out on some of this funding, but were successful with one, to the tune of \$32,000 (from the Ministry of Social Development).

The impact of the pandemic on our grants funding is likely to be felt in the medium to longer term: for the remainder of this year and into 2023 as the country slowly recovers.

According to a recent survey of New Zealand charities and how they have fared over lockdowns, the

charities that have emerged in the healthiest position are those that are relationship based, and with a broad fundraising portfolio mostly centred on major gift and individual donor work, as well as grants. Those that have suffered are the charities that are more transactional, relying on events, street collections, mail appeals etc.

These findings are informing our planning going forward, and point to the need to diversify and personalise our fundraising work. Grants will remain an important part of the mix but may not fully recover to pre-COVID levels for a year or two.

The relative success of our grants programme is largely down to our powerful (and unique) work, the way we tell our stories, and our detailed record keeping and reporting, as well as our commitment to ongoing evaluation. These things are vital and make a huge difference. Trusts want to see real, tangible results and outcomes, and we can deliver that.

I am proud to work for MND New Zealand, grateful to our supporters, and confident that we will come through this testing time for our fundraising. *Kia kaha.*



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.

Stories from our Community

Team One Love

The first year of Dad's diagnosis, nothing really changed. We noticed he had picked up a bit of a lisp in his speech and that his arms were a little weaker. But that didn't stop him from having one last hit out down in Queenstown at the national firefighter's rugby tournament. I remember being on the wing when the opposing team got on a break, and I noticed an overlap where we didn't have enough players. Suddenly Dad, who wasn't supposed to be playing, came out of nowhere and basically scared this poor skinny fellow into tripping up without even needing to tackle him. I was surprised yet frightened to see him there, especially with his new condition, but he proved that his diagnosis wasn't going to stop him. He even nearly scored a try later in the game.

In the second year after his diagnosis we started to notice more things were getting harder to do. Dad's speech was worse, and although he could talk it was very hard to understand him. He would get frustrated by this, and after a while of us not understanding what he was trying to say, Dad would usually roll his eyes



Wilson Family – Joshua, Anthony, Louise and Caleb

and say something like "For F's sake," and we'd all crack up. One thing that his condition has not changed is his sense of humour. By the third year, things had changed a lot. Dad had lost the ability to speak and eat, so we had to feed him through a peg in his stomach. Mum and I got good at this, creating a schedule and adopting a routine over lockdown for Dad's different feeding times. We did have some mishaps, where I would try to go too fast and push air bubbles through, which would make him burp. This annoyed him, and he sometimes gave me a little kick. It was also this year that Dad started getting a few new toys such as a new recliner and an electric wheelchair. Since his legs weren't as strong anymore, he started using the wheelchair to zoom around the house.

Today Dad can't really function without his helper,

my wonderful mother. It's sad to think about how strong he used to be compared to now. Yet this has not stopped him from enjoying everything life brings. He loves spending time with his mokopuna, Te Rongopaatutaonga and Te Ahoterangi. He loves watching movies and shows on TV and keeping up with everyone through Facebook. He is also writing short stories about the history of our tupuna for my cousin, who is drawing pictures alongside them to put into a book.

From Louise Wilson, written by her son Caleb Wilson



Motor on for Motor Neurone Disease

Cars of varying quality were cleaned up and kitted out for a fast and furious weekend of "Lemons" racing at Hampton Downs Motorsport Park in February.

Amongst them was the Abernethy family, on a mission to raise funds for the University of Canterbury Rose Centre and awareness for MND. When Malcolm Abernethy, a cardiologist in Wellington, was diagnosed with MND in March 2021, the family hatched a plan and began working on a Peugeot 206 GTI to make it race-ready. Malcolm swapped the operating theatre for the workshop and got stuck in with his sons to create a car



ready for the Lemons race. Race day in February delivered all the action the team had been waiting for, and after 16 hours of racing over two days (over 500 laps) the car was still running strong!

Since March, the Rose Centre has helped Malcolm to retain as much



speaking and swallowing ability as possible, for as long as possible. The progression of the disease means that Malcolm has now lost his speech, and communicates through a text-to-speech app on his

phone. Eating and drinking are the toughest parts of the day as MND continues to limit his muscle function and ability to swallow.



Coffee and Catch Ups

A group of clients from Foxton beach, Otaki, Paraparaumu, and Lower Hutt were finally able to get together with Support Advisor Moira after five months of rescheduling due to COVID-19 restrictions, and with some even travelling as far as 76kms to attend! Neil and Helene, Maria, Bev, Bruce, Michelle, and Moira had a wonderful time connecting, chatting, and having fun. Moira says the group were on best behaviour, so they were allowed back to the café next time – although no one owned up to doing a wheelie in the V8 truck!

Thank you Fulton Hogan

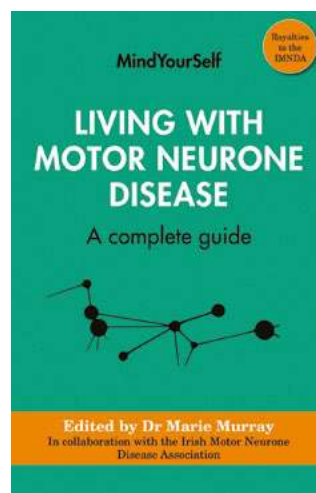
Donna and Peter Harris would like to thank the Fulton Hogan MND New Zealand support fund for assisting them to purchase a mobility scooter.



This has made such a huge difference to Donna's life. Instead of watching Pete head off for a walk with the dogs each day while she sits at home, she is now able to join them.

They get up early each morning and take the dogs for a walk through the park opposite them and down the scenic Papamoa Beach.

Living with Motor Neurone Disease: A complete guide



Cork University Press, in collaboration with the Irish Motor Neurone Disease Association, has recently published *Living with Motor Neurone Disease: A Complete Guide*, edited by Dr Marie Murray.

Living with Motor Neurone Disease: A Complete Guide is written by many of the most distinguished Irish experts on MND, bringing safe, reliable, practical information and reassurance to everyone affected by motor neurone disease.

This is a step-by-step guide for everyone. It explains what MND is, how it is diagnosed, how it affects the individual and the family, the psychological dimensions of the condition, the caregiver experience, living with the condition, and facing the future. It explains how to talk to children and adolescents, how to tell family and friends, and how to adapt working conditions and home life, and it describes all the supports – medical, psychological, technological, and practical – to cope with the daily impact of living with MND.

The book is available on www.corkuniversitypress.com or you can request a copy from our MND New Zealand library, where we have lots of wonderful resources. Get in touch with our national office at admin@mnda.org.nz for more information on borrowing MND resources and books.

MND Research Updates

Best Practice Recommendations

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.

The final draft of the national guidelines has been completed, with endorsement received from the Neurological Association of New Zealand and the Australian and *New Zealand* Society of Palliative Medicine. We're hoping to get the last endorsement from the Thoracic Society of Australia and New Zealand in the coming weeks before we share our work with our community.

Costs Associated with MND

MND New Zealand together with **Dr Alan Stanley**, Neurologist; **Dr Braden Te Ao**, Senior Health Economist at the University of Auckland; **Dr Tony O'Connor**, Director at Point & Associates; and **Dr Claire Reilly**, MND New Zealand Community and Research Advisor, have undertaken a study to determine the costs associated with MND in New Zealand. Currently there is no information available about the health and social services used by people diagnosed with MND and the cost of these to government and to the person with MND and their whānau. This study aims to estimate the economic costs associated with the care of people with MND for future public policy making and planning. The research team aims to quantify the one-year direct health care and indirect productivity loss, including informal care cost, of MND per capita in Aotearoa New Zealand in 2021. This cross-sectional study will identify health care and community care services' resource use and out-of-pocket expenses over the last six months. The Cost of Illness model will be developed using a survey linked with the Ministry of Health and NZ MND Registry data. It's hoped that the study's findings will help MND New Zealand advocate for the needs of people living with MND.

Findings from the study will be published later in the year.

University of Otago Summer student: Justin Jordan

MND New Zealand is sponsoring a research project at the University of Otago, Christchurch campus, on the impact of having a specialist MND Clinical Nurse Specialist within the hospital, and the use of a multidisciplinary model of care. These changes

were introduced in Canterbury in 2015 in keeping with international guidance. The soon-to-be-released New Zealand Best Practice Recommendations suggest that Health NZ provide people with MND with a single point of contact or a care coordinator, in each region, making this piece of research particularly relevant.

Justin Jordan was the successful summer student applicant to be involved in the research project. One of Justin's aims was to investigate whether there was any change in hospital or emergency department use and timing of interventions before and after the Clinical Nurse Specialist role was introduced in 2015. He found that although there were no significant differences between when patients in each cohort received feeding tubes or commenced non-invasive ventilation, those diagnosed from 2015 to 2019 were likely to have had fewer emergency department or hospital admissions, and spent fewer days in hospital. We look forward to sharing more results with you as the study progresses.

2022 MND Research Symposium

FightMND and MND Research Australia are excited to announce that they will both be hosting the first ever Australian and New Zealand MND Research Symposium. The Symposium will take place in Brisbane, on Thursday 28th and Friday 29th April 2022. Many of our New Zealand researchers will be attending and presenting, and we look forward to strengthening our connections and collaborating further with Australian researchers. To find out more or register, please visit www.mndaustralia.org.au/research/2022-research-symposium

Updated SAC briefing notes: Amylyx, NurOwn, CNM-Au8, and oral Edaravone

MND New Zealand is a member of the International Alliance's Scientific Advisory Council (SAC). A key resource produced by the SAC is a series of "Briefing Notes" that provide background and updates on important advances and issues related to MND research. These have been written and approved by the SAC members and provide sound advice around the various topics. The council has recently released updated briefing notes on four potential MND treatments: Amylyx, NurOwn, CNM-Au8, and oral Edaravone.

All updates can be viewed on the International Alliance's website: www.als-mnd.org/support-for-pals-cals/drugs-in-clinical-trial/

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

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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:

- Four Winds Foundation
- Frimley Foundation
- Nankivell Trust
- Trust Waikato
- W. Duncan Bickley Trust Fund

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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Bank: Westpac Banking Corporation

Account Number: 03 0539 0195083 000

Reference: Donation

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☐ 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

