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mndnews

NEWSLETTER OF THE MOTOR NEURONE DISEASE ASSOCIATION OF NEW ZEALAND INC

www.mnd.org.nz

Walk 2 D'Feet MND this summer!

The Walk 2 D'Feet MND event season has started! Tauranga, Greymouth, and Palmerston North are hosting Walk 2 D'Feet MND events as this newsletter goes to print. Walks are also planned over the summer in Invercargill, Christchurch, Dunedin, and Nelson.

These events are family-friendly accessible walks, organised by amazing volunteer supporters to raise awareness and funds, honour those living with MND, and commemorate loved ones lost.

Walks will take place throughout summer, peaking on Sunday, February 28, 2021, when we invite all our supporters to mark the end of the Walk 2 D'Feet MND event season by participating in our "virtual" walk. This involves setting up an online fundraising page via mndwalk.org.nz and taking a walk around your local neighbourhood to raise funds. To find out more or to register, ▶

From the Chair and CEO

Greg Horton, Chair

Carl Sunderland, CEO

What a year it's been for all of us! No one could have predicted the challenges 2020 has presented. We were all very grateful when the country moved back to Alert Level One in early October, meaning our support team could resume face-to-face visits with our MND families again. Thank you to everyone for your understanding as we moved through the different alert levels.

As 2021 fast approaches, we're looking forward to the summer months and another successful Walk 2 D'Feet MND event series. This year walk events are taking place throughout the country over November to February. Some walks have already taken place as this newsletter goes to print, and will wrap up on 28 February. Thank you to all our volunteers who have organised a walk event so far. Find out how to get involved on page 1.

As the official charity partner of Emirates Team New Zealand for the 36th America's Cup, we'll be watching the lead-up to the big event in March with interest. The team has generously donated a hospitality experience for two during the Challenger Selection Series in Auckland, and we are raffling off this once-in-a-lifetime experience! To find out more and to be in to win, see page 3.

Planning is underway for next year's Awareness Month, set to take place in June. We look forward to working with you to make even more Kiwis aware of the devastating impacts of motor neurone disease. Keep an eye out in the next issue for an update.

Since our last newsletter there have been a few staffing and governance changes within MND New Zealand. We said farewell to our Communications Manager Sarah Tora and Support Team Member Carol Matthews. In August we welcomed Emily King, who replaces Sarah, and Megan Te Boekhorst, who has taken over Carol's role providing support in the Waikato and Taranaki regions. At our recent AGM we announced three new members of our Council: Alan Stanley, Melanie Glenn, and Samarra Wright-Scott. At the same time, we said farewell to Steve Green, Jodie O'Doherty, and Fiona Hewerdine, who have retired from their roles. A big thank you to them for their hard work and dedication to MND New Zealand. We wish them all the very best for the future. Read more on page 3.

At our AGM we also announced Fulton Hogan as the recipient of the David Oliver Beacon Award. This year's theme was "Excellence in Solution Finding", and Fulton Hogan met this year's theme perfectly through the Fulton Hogan MND New Zealand Support Fund, which helps with practical support for MND families. It's partnerships like this that help us make a positive difference in the lives of those living with MND. Read more on page 10.

A huge thank you to all our volunteers, supporters, fundraisers, and MND New Zealand team for your valuable contributions this year. Without you we could not continue doing the vital work we do, providing a free, personalised support service to people living with MND and their families. We look forward to working together in 2021.

After a challenging year, everyone has earnt a well-deserved break. We wish you all a safe and Happy Christmas and New Year. We will be closed from Thursday, December 24th, returning Tuesday, January 5th.

Kia kaha,
Greg and Carl

▶ visit mndwalk.org.nz. Make sure you share photos from your walk on our Facebook Event page!

It's not too late to organise a local Walk 2 D'Feet MND in your community this summer (November–February). Get in touch for support and guidance on how to organise your walk. We ask that you register your event with MND New Zealand at least six weeks in advance of the event date, to enable us to best support event logistics, registration, and promotion.

Please note: Walk 2 D'Feet MND events will only take place if the region is at COVID-19 alert level 1 or below. Should the region be in COVID-19 alert levels 2-4, we will endeavour to postpone the event to a suitable alternative date, but when this is not possible we reserve the right to cancel the event.

In this issue

mnd New Zealand

Communications update

Our strategic goal of ‘improving information and engagement’ has been a big focus for us this year. We’ve been busy developing an information and communications plan to ensure all families have easy and immediate access to relevant information, at the right time, and in the right way.

Earlier this year we partnered with Point Research to take a more in-depth look at feedback in our 2018 Community Survey, which highlighted an issue of unmet information needs. We also reviewed our current information, including the information pack, our website, newsletters, and social media, as well as how information is communicated directly via our support team and presentations.

Following this, we worked with Point Research and a strategic communications agency to develop our information and communications plan, which considers all of our channels, from digital to in-person. Throughout this process we worked with a consumer reference group of clients and carers to make sure their feedback was incorporated.

We’re also in the process of reviewing the MND New Zealand story and our brand personality and messaging, and increasing our awareness and advocacy work by building and developing relationships with key stakeholders and decision makers, including media.

One of the first big projects, refreshing our website, is already underway, and we look forward to implementing the rest of our plan next year. Watch this space!

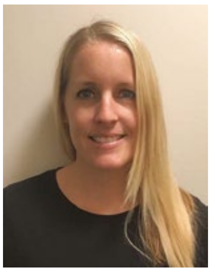
New faces at MND New Zealand

New council members

We are pleased to announce three new members of our Council – Alan Stanley, Melanie Glenn, and Samarra Wright-Scott. We also say farewell to Steve Green, Jodie O’Doherty, and Fiona Hewerdine, who are retiring from their roles. A big thank you to our departing members for their valuable contribution to MND New Zealand, and a warm welcome to our new members. We look forward to you being part of the team. To find out more about our new members, go to www.mnd.org.nz/our-organisation/.

Alan Stanley, Melanie Glenn, and Samarra Wright-Scott

Emily King, Communications Specialist



Emily started with us part-time in August. She holds a Bachelor of Communications Studies and has worked in both agency and in-house communications roles for a range of organisations and industries. “It’s great to be working for a not-for-profit again and I’m looking forward to getting stuck into some exciting projects,” says Emily.

Win a hospitality experience for two hosted by Emirates Team New Zealand!

A chance for you and a friend to enjoy an experience that money can’t buy.

As MND New Zealand’s charity partner for the 36th Americas Cup, Emirates Team New Zealand have generously donated a hospitality experience for two during the Challenger Selection Series in Auckland. We are raffling off this once-in-a-lifetime experience!

In accordance with legal obligations, these raffle tickets can only be sold in person. Tickets cost $50 each (maximum of 2,000 tickets available in total) and are available to purchase from the MND New Zealand National Office in Auckland, as well as at some businesses and yacht clubs. A full list of sales sites can be found by visiting www.mnd.org.nz/ETNZraffle.

Sales close on the 20th December and the winner will be drawn and announced the following day.

If you or your business would like to volunteer as a raffle ticket seller in your area, please get in touch with kate.dalders@mnd.org.nz.

Support team update

2020 has certainly been a year of change in the way the support service operates. Thankfully we have been able to maintain contact with our community through the use of technology. The team were all very thankful to resume face-to-face visits when we moved to Level One in June, and extremely disappointed when COVID-19 re-emerged in the community and visits had to be stopped again. While our community have been very accepting of our conservative approach, we are aware that this has been frustrating for many people and are grateful for the understanding that everyone has shown. For more information on our services at the different COVID-19 alert levels, visit www.mnd.org.nz/covid-19-updates/.

New support team member for Waikato and Taranaki regions

Sadly, Carol Matthews resigned from her role as the support team member for Waikato and Taranaki regions in June. Carol worked as a support team member for just under three years and built strong relationships with the MND community in these areas. She was passionate about her role and worked tirelessly to ensure that her clients received the care they needed. We will miss Carol's warm smile, compassion, and sense of humour in our team. We wish her all the very best for her future endeavours.


Megan Te Boekhorst

In August we welcomed Megan Te Boekhorst, who is based in Te Awamutu and will provide support in the Waikato and Taranaki areas. Prior to joining MND New Zealand, Megan worked in various roles in the health care sector, including time as a community stroke advisor.

Toni Foster, Support Team Leader

Online forum closure

We have made the decision to close our online forum, due to uptake being lower than anticipated. We are currently looking at the development of education and support programs following a recent review of our support services. If you have any questions about MND please ask your support team member, or email us at admin@mnda.org.nz. If you are interested in joining a community-led MND support group you can find a list of current groups at www.mnd.org.nz/mnd-support-groups/.

End of Life Choice referendum

The End of Life Choice Act 2019 is due to come into force from November 2021 after 65.1 per cent of New Zealanders voted 'Yes' in the recent referendum. The Act gives people with a terminal illness the option of requesting assisted dying.

MND New Zealand has a neutral stance on assisted dying as an organisation, out of deeply held respect for the varied beliefs, culture, values, and personal experiences that inform the mix of views in our community.

In March 2018 we made a submission to the Select Committee to ensure that any rights that may be created by the End of Life Choice Bill do not discriminate against those people with MND whose speech and/or motor skills have deteriorated. Communication using assistive speech technology should not be a barrier to accessing or discussing assisted dying. Our second purpose in submitting to the Select Committee was to request a substantial increase in funding for and improved access to palliative care services all over New Zealand. We believe the Government should ensure that the very best palliative care is available to all those who need it. Only then will anyone considering assisted dying genuinely have a choice.

We are committed to ongoing support for the right of people with motor neurone disease to take any decision or action that is lawful. We will continue to strive for improvement in New Zealand's palliative care systems.

For more information on the End of Life Choice Act 2019, visit www.legislation.govt.nz

MND New Zealand would like to thank the following organisations for their recent contributions towards the support services we provide:

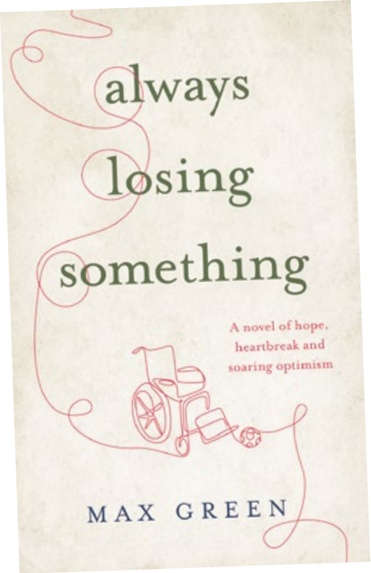
- Guy Anson Waddel Charitable Trust
- Lion Foundation
- Louisa and Patrick Emmett Murphy Foundation
- Maurice Paykel Charitable Trust
- Pub Charity
- Southern Trust
- The Trusts Community Foundation

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.

New book: Always losing something

Always Losing Something *is an empowering, fast-paced, and thought-provoking exploration of the relationship between people living with ALS, big Pharma, business, and government…and just what can be achieved when everyone wants the same thing. Max Green is the pseudonym for Marcus Gerbich, who has lived with ALS since 2016.*



Max Green has lived a blessed life. An ex-football star turned corporate businessman, Max looks to have it all until the day he is diagnosed with amyotrophic lateral sclerosis (ALS), also known as motor neurone disease (MND) or Lou Gehrig's disease. But Max is lucky. The year is 2030. Incredible scientific innovations have already taken place that make his life bearable. Now they just need a cure. When Max's powerful friends – Tim Thompson, a former football colleague and Prime Minister of Great Britain, and Jay Castle, a no-nonsense businessman and self-made billionaire – also contract the disease, suddenly everyone is interested in finding a cure. Helped by Dr Brad Sternberg, a high-profile neurologist at Columbia University Hospital's ALS Centre, the trio embark on the adventure of their lives to put an end to a disease that's causing terrible suffering around the world.

Always losing something is available to purchase on Amazon.

About the author: Marcus Gerbich (under pseudonym Max Green)

This is Marcus' first novel, which he wrote to help raise awareness of what he believes is required to cure MND in the next 10 years. We asked Marcus a few questions about his journey in writing the book.

When and why did you decide to write the book?

On my last trip to Columbia University ALS Centre in 2018, my breathing level had dropped to below 30 per cent (which ruled me out of clinical trials), and I started thinking about a novel that would raise awareness around what was required to solve ALS/MND in the next 10 years.

How did you come up with the storyline?

The book is fiction with a sprinkling of fact: some of it is based on factual personal experience, but has been fictionalised or exaggerated for the purpose of the story. I have two close friends with MND (Greg Horton and Nick Ward, in the photo on the back of the book), and I was thinking: Could the right three guys with MND (who would need a lot of resources and government connections) create a strategy that would push forward a cure? So, the storyline of a billionaire and ex-Prime Minister, along with a regular guy, all diagnosed with MND, combining to change the world, was born.

How long did it take you to write the book?

Because I use voice dictation, and only worked on the book on the weekends, it was fairly slow going. But the COVID-19 lockdown allowed me to focus on it in 2020.

Is this the first book you've written?

This is the first novel, but because I have a PhD in finance from Cass Business School in London, in the past I did publish several academic articles in international refereed journals.

Marcus (centre) with his friends Greg Horton (right) and Nick Ward.

Your tips and tricks

Electronic door

We recently had an electronic door fitted and it's amazing. Ken uses a button which he presses with his hand or hip and the door opens and closes automatically. If necessary, we can have a thermal sensor fitted if he can't use the button.

Ken and Caryn Fry

Phillips Hue lighting

We have a Phillips Hue system to turn lights on and off using an app on Ken's phone. We bought bedside lights and standard lamps for the family room and fitted them with the Phillips Hue globes. You only need one light per room as they are bright.

Ken and Caryn Fry

Sensor lights

We have sensor lights plugged in along the passage, bathroom, and hallway and they light up as you walk past.

Ken and Caryn Fry

Use a builder's apron for a sturdy carry all on the side of a powerchair.

MND New Zealand client

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

New inclusive tourism experience – the TrailRider

Accessible travel writer and advocate Kimberly Graham recently tried out the new inclusive tourism experience, the TrailRider, with her family in Rotorua.

The TrailRider is essentially a modified wheelchair with the ability to travel on hiking trails and up and down small hills with the aid of volunteers acting as "Sherpas".

Kimberley's family love to get out and about and discover new places. But, finding new places can sometimes be a challenge in terms of accessibility as her older son is in a wheelchair. Kimberley's family found the TrailRider a fantastic experience and she has written about their adventure in her blog at www.grabyourwheels.nz, which is worth a read.

Kimberley and her family trying out the TrailRider in Rotorua

Booking the TrailRider

The TrailRider is available to book in Rotorua, Mount Maunganui, and Dunedin.

- Rotorua: Contact the Forest Recreational Management via email at Forest.Recmanagement@rotorualc.nz
- Mount Maunganui, Tauranga: Contact Tauranga City Council
- Dunedin: Contact Kelly Nooy from Parafed Otago via email at sdo@parafedotago.co.nz. These TrailRiders do not have the power-assist option.

Recommended trails

Lake Tikitapu (Blue Lake) track – 5.5km loop
Hemo Gorge Mud Pool – 4km return
Hannah's Bay – 1.2km loop
Lake Ōkareka – Boyes Beach – 1.5km one way

Mullet Dudes raise $42,000 in memory of community legend

It all started when Tobi (aged 13) and a few of his mates decided to shave off their mullets to raise money in support of MND New Zealand, after Tobi's uncle George passed away because of MND.

Tobi's mum Vanessa and friend Jan (whose son Ryan also shaved his mullet off) put their heads together with the local Kirwee Rugby Club, and Malvern Mullet Dudes was formed. A date was booked in for the mullet shave, and everything went from there.

"MND is very close to my heart after losing my brother-in-law and true legend George Redmond to this horrible disease back in January this year. George was a very well-known and loved family man in our community," says Vanessa.

"The whole community came together for Malvern Mullet Dudes raising money for MND New Zealand. We had such a fun night, lots of mullets shaved, and two ladies even shaved their hair off! Many items were donated for auction and we were lucky to have All Black and Canterbury Crusaders rugby player Jack Goodhue come out, not only to shave the Mullet Dudes' hair, but also to donate a signed Canterbury rugby jersey to be auctioned, raising over $1,200!"

In total, the Malvern Mullet Dudes raised $42,000 in support of MND New Zealand. We are extremely grateful to Vanessa, Jan, George's late wife Kathy, Tobi, and all the Mullet Dudes for this incredible support.

A big thank you to everyone in the community who so generously contributed to the event.

"The amount we raised shows how wonderful our community is and how well George was loved in our community. He will be missed so much by us all. It's great to know that the money will go towards helping other families that are having to go through a terrible time with this horrid disease," says Vanessa.

"We are super proud of our Kirwee community and everyone involved in the Malvern Mullet Dudes' fundraising for MND New Zealand in memory of our legend, George Redmond!"

"We are super proud of our Kirwee community and everyone involved in the Malvern Mullet Dudes' fundraising for MND New Zealand in memory of our legend, George Redmond!"

Meet Dympna Mulroy

Q&A with the new curator of the New Zealand MND Registry and Manager of the MND Research Network, Dympna Mulroy.

Tell us a little bit about your career background.

I graduated as an occupational therapist in 2008 and worked in Dundee Hospital, Scotland for two years before moving to New Zealand. I spent a year working on the acute wards at Wellington Hospital before joining the Muscular Dystrophy Association (MDANZ) in 2012. I spent the last eight years working for MDANZ in a variety of roles, including as a fieldworker for the lower North Island for six years. In 2015 I was seconded onto the Muscular Dystrophy prevalence study as a research assistant while continuing to work part-time as an MDANZ fieldworker. I moved to Auckland in 2018 to take on the position of Member Services Manager and Practice Leader, based at the national office. I completed my master's in 2019 and started a part-time role as an occupational therapist at Auckland City Hospital while continuing to work part-time with MDANZ as a practice leader and project manager. I'm currently working one day a week as the curator of the MND Registry, and one day a week as manager for the MND Research Network, and I'm continuing my occupational therapy role the remainder of the week.

How did you get involved with the MND Registry and MND Research Network?

I used to work alongside the curator for the MDA registry, so I was aware of the purpose and importance of these registries. After completing my master's last year, I was keen to become more involved in research. In my clinical practice I knew the importance of research and access to clinical trials for individuals who have life-limiting conditions. I was keen to promote opportunities for research in New Zealand and support the MND community to gain access to trials and research studies.

What does your role entail?

As the curator for the New Zealand MND Registry I'm responsible for developing, managing, and maintaining a New Zealand-wide database to include genetic and clinical information on people with motor neurone disease.

When a person signs up to the registry, I gather the necessary genetic and clinical information around how MND has affected them from when they were diagnosed, and keep this up-to-date over time. This information is necessary when responding to researchers' enquiries to identify any participants eligible for specific trials or studies. I also identify research studies where New Zealanders with MND could most usefully be linked to and approach researchers to consider New Zealand participants. I work closely with the New Zealand Motor Neurone Disease Registry Steering Committee when a researcher sends an enquiry to the registry. An enquiry can include recruitment to a trial or a survey study. The committee decide whether enquiries are in line with the interests of the New Zealand MND Registry and their participants. I contact and share information with any identified eligible participants about a study for which they qualify. I communicate regularly with MND New Zealand to raise awareness of the registry and keep the MND community updated on any research developments.

Tell us a little bit about yourself and what you get up to outside of work:

I am originally from County Mayo, on the west coast of Ireland. I'm the youngest of six children and come from a close-knit family. I moved to New Zealand in 2010 with the intention of staying one year, and will be celebrating my 10-year anniversary this December. After spending eight years in Wellington I'm still adjusting to life in Auckland. I recently moved into an apartment in the city and am taking advantage of the local amenities (swimming pool, sauna) to unwind after work. I enjoy going on hikes, running, reading, yoga, having friends over for dinner, and baking. I was delighted to get back on the ski slopes this season after a 10-year break and thankfully I came home in one piece!

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.

Riluzole update

A recently published paper reviewing 15 studies that investigated the effectiveness of riluzole as a treatment for MND in real time has suggested that the drug extends survival in people with the disease for much longer than the two to three months proposed in the original clinical trials. Riluzole (sold by the brand name ''Rilutek'') is currently the only drug available to people with MND in New Zealand that is known to extend survival time.

In 2020, Jinsy A. Andrews from The Neurological Institute, Columbia University, and colleagues identified 15 population studies that reported average survival time of people who were treated with riluzole compared to those who were not. Most of the studies found significant differences in survival between the two groups: between six and 19 months in people who had taken riluzole, which is substantially longer than survival times found in the original trials of the drug. The authors also highlight research that suggests that riluzole may work in different ways in people in the early stages of MND compared to those in more advanced stages.

This evidence points to the benefits for both early intervention and prolonged treatment with riluzole, with the rationale that delaying motor neurone damage, and therefore delaying muscle degeneration at earlier stages of the disease, will prolong those stages associated with the best quality of life. Observations also support that survival benefits continue into later stages of the disease.

While this is an interesting new development, caution is advised in interpreting meta-analyses of this nature. There was wide variability in the findings of individual studies. Also, not every person with MND will be suitable, or meet the criteria, for the prescription of riluzole. That being said, it might be time to have a fresh look at the effects of riluzole and consider it with more enthusiasm than might have been the case in the past. Because it is an older medication, it is unlikely at this stage to be subjected to a robust large randomised clinical trial, and therefore clinicians and patients will be left to their own judgement as to its best use.

For more information, visit www.mndresearch.blog. Please email claire.reilly@mnd.org.nz if you have any questions or require further information.

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Keep up to date on 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/

The latest from the Motor Neuron Disease Research Lab

We are very proud of our collaboration with the Centre for Brain Research (CBR) Motor Neuron Disease Research Lab. Recently, Principal Investigator Dr Emma Scotter provided us with an update.

- The first year of a three-year genetics study aimed at understanding the genetic causes of MND in New Zealanders has been completed. In addition, the study aims to test how certain MND gene mutations affect human cells.
- Protocols for collecting DNA and skin fibroblasts, and gaining consent from participants, were developed and implemented. DNA was initially obtained from blood samples, but the COVID-19 pandemic saw a change to at-home saliva collection.
- To date, 117 out of the 330 participants have been recruited to the New Zealand MND genetics study. Unfortunately, COVID-19 has led to significant delays processing results.
- The team are also doing MRI scanning studies and research on brain tissue from people with MND who have donated to the Neurological Foundation Human Brain Bank. More than 150 people with MND have been involved in the clinic studies so far, together with 18 staff, including PhD students and post-doctoral fellows.
- The team have also been busy publishing in various journals internationally and are collaborating with teams in both Australia and the US.

CENTRE FOR BRAIN RESEARCH
THE UNIVERSITY OF AUCKLAND
Te Whare Wānanga o Tāmaki Makaurau

Motor Neuron Disease Research Lab wins award

Dr Emma Scotter and her colleagues won the CBR Collaborative Science Prize at the CBR's 10th anniversary celebration dinner late last year. The award recognises a team of researchers, in any area of brain research, for excellence in developing cutting-edge collaborative research.

Pictured, from left to right: Sir Richard Faull, Dr Emma Scotter, Kerry Walker, Governor General Dame Patsy Reddy, Dr Christina Buchanan, Chitra Vinnakota, Professor Mike Dragunow

David Oliver Beacon Award

Congratulations Fulton Hogan, this year's recipient of the David Oliver Beacon Award!

Fulton Hogan is this year's recipient of the David Oliver Beacon Award. The decision was announced at our AGM on Saturday, 31st October.

The purpose of the award is for MND New Zealand to honour, acknowledge, and celebrate individuals, groups, businesses, or services providing a positive contribution to service, care, improvement, or innovation in the management and support of people living with motor neurone disease.

This year's theme for the award was "Excellence in Solution Finding". Fulton Hogan was nominated for finding a solution to a huge problem highlighted by our clients and families in the 2018 Community Survey. We found that 40 per cent of people with MND (and their family and carers) had unmet practical support needs. This included assistance with work around the home and equipment for home-based care and movement.

When Fulton Hogan generously became our Foundation Corporate Sponsor in early 2019, a solution was found and the Fulton Hogan MND New Zealand Support Fund was born. The fund provides additional support to people living with MND, their immediate families, whānau, and carers, to maximise their quality of life. To date we have provided additional assistance to over 60 MND families nationwide, providing grants totalling over $50,000 towards much-needed support, including home maintenance and modifications, specialised equipment, mobility assistance, and respite care.

"Being in and contributing to our local communities means a lot to our employees and stakeholders, so we are delighted to receive this award in recognition. More importantly, it is great to see our support and assistance making such a positive difference to the people and families who need it. The help we have provided reflects only a small part of the overall support provided and I would like to acknowledge all those who work tirelessly on the frontline and in the background to help – together better," says Fulton Hogan Managing Director Cos Bruyn.

The award committee unanimously agreed that Fulton Hogan met this year's theme perfectly. Our community presented a need, and they provided the solution.

Congratulations and a huge thank you to Fulton Hogan for their continued support of the MND community.

For more information on the David Oliver Beacon Award and past recipients, visit www.mnd.org.nz/david-oliver-beacon-award/.

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

Quality sister-time

Thanks to the Fulton Hogan MND New Zealand Support Fund, our client Reinette's trip to the South Island earlier this year was made a little bit easier. Reinette and her sister, who was visiting from South Africa, enjoyed spending precious quality time together while taking in some of the breathtaking sights the South Island has to offer. The fund helped provide mobility transport for Reinette during the trip.

Afternoon tea in Wellington

Support team member Moira organised for two of our Wellington-based clients, Diana and Jos, to meet for afternoon tea, as they were unable to attend the local monthly coffee group for MND families. Diana travelled by mobility taxi, accompanied by her carer Sharon, to the care facility where Jos resides. Thanks to the Fulton Hogan MND New Zealand Support Fund, the cost of the taxi was covered.

"The weather was wet and cold, but this didn't dampen our motivation and determination to meet for a chin-wag and coffee. Thanks to the carers at both facilities for helping the ladies get ready on time. Thanks to Peter for his careful driving and to Sharon for her 'can-do' approach," **says Moira.**

Jos says it was lovely to meet Diana after a couple of unplanned delays: ***"To have the opportunity to compare notes on the limitations MND puts on living was most comforting and supportive. I still think about the delightful companionable afternoon I had with Diana, Sharon, and Moira. Many thanks Moira for the initiative – may it be possible for others to copy and for us to do it again,"*** **says Jos.**

Diana was also grateful for the visit: ***"It was so good for Moira to organise the get-together to meet and chat with Jos. For some of us, getting to coffee mornings is not possible. Having opportunities to share stories and experiences with others is invaluable. Thank you, Moira!"*** **says Diana.**

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.

Toni Foster
Support Team Leader
Mob: 021 230 3038
Email: teamldr@mnda.org.nz

Sally King
DHBs: Northland & Waitemata
Mob: 027 202 8166
Email: sally.king@mnd.org.nz

Linda Oliver
DHBs: Auckland & Counties Manukau
Mob: 021 036 0218
Email: aklfieldwork@mnda.org.nz

Jane Kay
DHBs: Bay of Plenty, Lakes, Hawkes Bay, Tairawhiti
Ph: 029 777 5588
Email: jane.kay@mnd.org.nz

Megan TeBoekhorst
DHBs: Waikato, Taranaki, Whanganui (North)
Ph: 029 773 6662
Email: megan.t@mnd.org.nz

Moira Young
DHBs: Capital & Coast, Hutt, Wairarapa, Mid Central, Whanganui (South)
Mob: 021 0278 4494
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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.

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