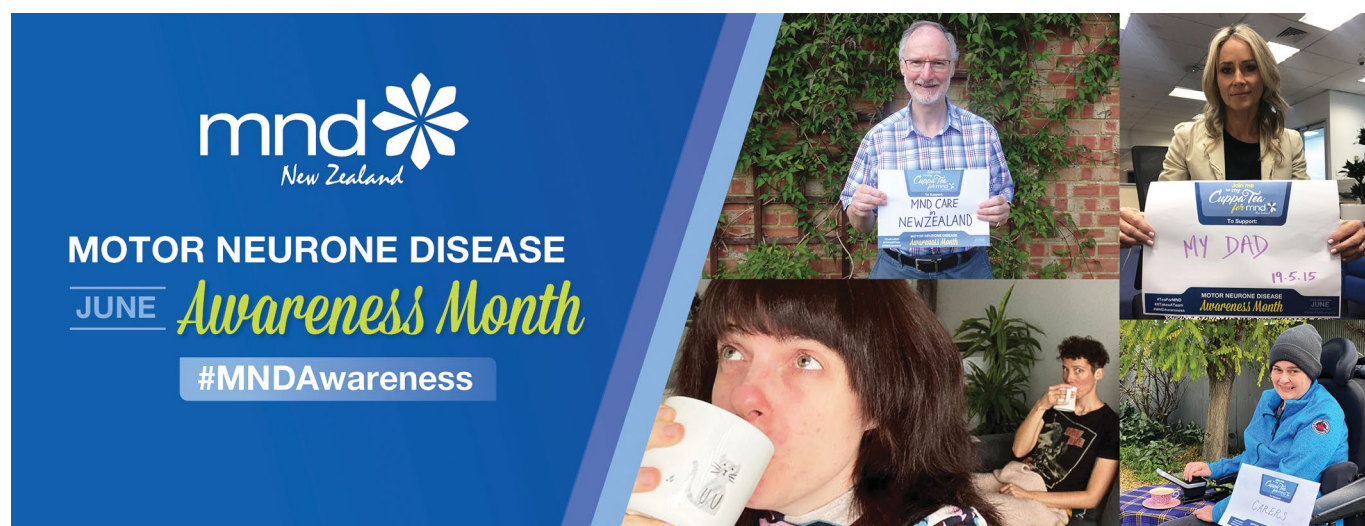


# mndnews

NEWSLETTER OF THE MOTOR NEURONE DISEASE ASSOCIATION OF NEW ZEALAND INC

[www.mnd.org.nz](http://www.mnd.org.nz)



## It takes a team

**Motor neurone disease touches numerous lives, yet many Kiwis are unaware of the disease and its impacts. That's why we dedicated the entire month of June to raising awareness.**



Sarah's Cuppa Tea

The theme for Awareness Month 2020 was "It takes a team", recognising the impact on and involvement of family and whānau, friends, health professionals, researchers, fundraisers, volunteers, and supporters. It takes a team to live with MND.

Throughout June members of the team shared their personal stories, and each week we focused on a different aspect of the "team".

We heard from people living with motor neurone disease like Kylie, a mum and grandmother from Feilding, who is not only living with MND herself but has also lost her Dad, Aunty, and Uncle to the disease.

We shared stories of those supporting a family member with motor neurone disease. We learnt

about Mary's experience hearing about her pregnancy and her mum's MND diagnosis simultaneously. David Seymour, who is living with MND, reminded us that family members also live with the impacts of the disease and need support too.

Health professionals who work tirelessly to improve the quality of life for people living with MND were also showcased. These included the team at Canterbury DHB, and Dr Janet Turnbull from Kapiti, who was awarded a Member of the New Zealand Order of Merit (MNZM) in the Queen's Birthday Honours list.

During National Volunteer Week which also fell in June, we celebrated those who support MND New Zealand's work – volunteers, ►

► fundraisers, and supporters – highlighting people like Taylah West, who has helped organise a Walk 2 D’Feet MND event, and challenge event fundraiser Sara-Jay (Jimmy). Less than seven per cent of MND New Zealand’s costs are covered by government funding. Fundraisers, volunteers, donors, and supporters are an immensely important part of the team.

Global MND/ALS Awareness Day is observed on June 21st each year. With social distancing still a very valid concern, this year we encouraged people to make this a virtual day with My Cuppa Tea for MND, posting selfies to our event page of their at-home cuppa, and donating the price of a good cuppa. We also held MND New Zealand’s first national virtual appeal.

Through these two events alone, supporters donated and fundraised over \$7000! Thank you to everyone who supported us through My Cuppa Tea for MND, those who donated to the virtual appeal, and those who encouraged others to donate.

Motor Neurone Disease Awareness Month may be over for another year, but supporting people living



**Mary Tito shared her experience of finding out about her first pregnancy and her mum’s MND diagnosis simultaneously.**

with MND doesn’t stop. We’d like to encourage you and people you know to still join our team by liking our Facebook page (<https://www.facebook.com/mndanz>) or our newsletter by emailing [admin@mnda.org.nz](mailto:admin@mnda.org.nz).

**Together, let’s continue to support people living with motor neurone disease.** Ma tini ma mano ka rapa te whai (Many hands make light work.) It takes a team!

## Nominations are open now for the David Oliver Beacon Award

The David Oliver Beacon Award has been awarded annually since 2016, recognising either an individual or an organisation that has made a significant contribution to the MND community.

Nominations are now open for the David Oliver Beacon Award for 2020!

The theme for 2020 is “Excellence in Solution Finding”. This could mean finding a solution to caring for people with MND, adapting and creating solutions through the COVID-19 lockdown, or any other solution.

Nominations close at 5pm, 31st August. To find out more, or to make a nomination, visit our website here: <https://mnd.org.nz/david-oliver-beacon-award/>

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# An update from the CEO

This year marks 35 years since the MND Association of New Zealand was founded by a group of very determined volunteers, who all had experience of caring for someone living with motor neurone disease.

Over the years we have seen many changes in the way we operate: the evolution of our organisational structure, improvements in our provision of support and information, and the development of our national fundraising and research strategies. Our growth as an organisation has been significant, and after all this time we remain the only national organisation in New Zealand focused on MND support, advocacy and research. But we couldn't have done it without our founding pioneers paving the way back in 1985, or without the continued support of the MND community.

Despite all that's changed, one thing has remained constant. We have always had a loyal, dedicated, compassionate, and caring team of people offering support and raising awareness, whether paid or unpaid, all over New Zealand. Our community has always worked together to provide the best quality support to MND families, and to tirelessly raise vital funds so we can continue to operate. We are extremely proud to be just one part of this amazing team.

Our 35th year has certainly been one of unexpected change and uncertainty. The COVID-19 pandemic has brought challenges to many, including our organisation. We have had to adapt the way we operate and provide our services, as well as find ways to be creative in reacting to an ever-changing environment, while still remaining focused on our key goals and priorities. The crisis has also provided an opportunity to look at ways we can improve our services, increase efficiency, develop new opportunities, and grow our team of supporters.

Not only has the pandemic brought New Zealand's "team of five million" together, but it has highlighted how well we continue to work together and support each other in the MND community. June's awareness month highlighted that "It takes a team" to live with the impacts of MND (more about this in our cover story). We are in this together. A huge thank you to all team members who helped raise awareness, shared their stories, raised funds, or offered messages of support and encouragement.

These are still challenging times. Now more than ever, it is essential

that we continue this essential teamwork. We need to grow our team of supporters, volunteers, and future pioneers. It is a time for reimagining, new ideas, and hard work.

We look forward to working with you over the next year to make even more Kiwis aware of the devastating impacts of motor neurone disease. As community gathering restrictions have eased, we hope to see many of you at local Walk 2 D'Feet MND events across New Zealand throughout summer.

For those interested in hearing more about our 35-year history, MND New Zealand Past-President Beth Watson will be presenting at the AGM on 31st October. This will be a virtual online event, which will allow more of you to attend. We look forward to seeing you there and will provide further details closer to the date.

Thank you all for your continued support.

*Nā tō rourou, nā taku rourou ka ora ai te iwi. (If we come together, we can make a difference.)*



**June's awareness month highlighted that "It takes a team" to live with the impacts of MND. We are in this together.**

## Chairperson's Update

The last few months have been a challenging time for all New Zealanders, and indeed people around the globe, as we all grappled with the COVID-19 pandemic.

My sincere thanks and admiration goes out to all the staff at MND New Zealand, who adapted to working from their own homes, balancing the convergence of personal and work life. The teamwork, resilience, and commitment to the MND community are truly appreciated.

I'd also like to thank Anna Chalmers, who stepped down recently from her role as Co-Chair to focus on her family. Anna's insight, leadership, and wise counsel over the years has been instrumental in the development of the organisation. Although Anna has stepped down from her role on Council, she will continue to be an active and valued member of the MND community.

Jodie O'Doherty now moves to the new position of Deputy Chair, and

I'd like to thank her and welcome her to that position. Jodie's energy and enthusiasm are an asset to the team.

While life is a bit uncertain for everyone at the moment, our focus remains on supporting people living with motor neurone disease. The lessons in adaptability and creative thinking learnt through lockdown will stand the organisation in good stead for the future.



## Support Team Update

### Toni Foster – Support Team Leader



So far, 2020 has certainly been a very different year to the one we anticipated!

The COVID-19 pandemic meant that everyone had to quickly adapt and change the way they worked, including the support team.

As you're no doubt aware, we were able to continue to offer support through the use of technology, which we were very thankful for.

While we were grateful that we could continue to connect with everyone in this way during lockdown, it's fantastic to be able to visit people once again.

### Jane Kay – Support Team Member for East and Central North Island



The value of technology certainly came to the fore as we were able to keep in touch with clients and health professionals, and even held the DHB /MND multidisciplinary meetings and support groups via Zoom.

It is truly a privilege to be involved in this work and I have so much respect and admiration for our clients. The determination and positivity shown by them is a constant inspiration to me. Those of us who are healthy can so easily slip into taking things for granted and grumbling over trivialities. My mother used to say: "The sunshine can come from within, even on a grey day", and our clients have proved that over and over.

I love to see people in the early stages of MND making an enormous effort to stay engaged and do the things they love. But the lockdown period highlighted how much MND can hamper a person's life as it progresses, with some clients pointing out that lockdown made very little difference to their daily routine.

This saddened me and reminded me of the importance of support from family and friends. That phone call, note, or impromptu visit means so much, and can add brightness to the day, both for the person with MND and their spouse or carer.

## Kapiti geriatrician officially recognised for commitment to healthcare

Dr Janet Turnbull is a familiar face to many people living with MND in the Kapiti region, where she has been based for many years.

A geriatrician who also has a special interest in palliative care, Dr Turnbull was instrumental in setting up multi-disciplinary care for people diagnosed with motor neurone disease in the Wellington region.

Dr Turnbull's significant contribution to healthcare was formally recognised in this year's Honour's list announced on Queen's Birthday, when she was made a Member of the New Zealand Order of Merit.

Dr Turnbull says: "MND is a tough illness to cope with but having seen many people determined to continue despite the challenges is cause for us to keep working and supporting them."

We're really pleased to see Dr Turnbull's commitment to people living with MND and other conditions recognised in such a visible way.

On behalf of everyone at MND New Zealand, a massive congratulations and thank you for your commitment to improving the lives of people living with motor neurone disease.



**Dr Janet Turnbull made this year's honours list.**

## SAVE THE DATE Annual General Meeting

This year's Annual General Meeting (AGM) will be taking place on Saturday 31st October.

For the first time, the AGM will be held via a Zoom video call, so you'll be able to connect and participate from wherever you happen to be.

We'll share more details closer to the time, but for now, pencil this date into your diary.

# Meet Michael Fuyala

At last year's Annual General Meeting we welcomed several new people to the national council. Here we take the opportunity to learn a bit more about one of our newest council members, Michael Fuyala.

Michael first learnt about MND almost nine years ago, when the disease impacted his own family.

"I was very close to my Uncle, Ron Misa. I worked alongside him in our family business and he was also my godfather. I was also at the specialist appointment with him when he received the diagnosis of MND," says Michael.

You can find out more about Michael's experience supporting Ron on page 6.

Along with his wider family, Michael spent time learning about MND, trying to find ways to support Ron as the disease progressed. The whole family became actively involved with MND New Zealand, attending Walk 2 D'Feet MND events and following our Facebook page. Michael says: "We were impressed by the sense of community MND New Zealand has created."

Michael's background is in digital media. He headed up the digital division of Bauer Media until recently leaving to set up two digital marketing platforms, including Rewardhub.

Aside from his business ventures, Michael's two children (pictured with him) keep him busy and entertained. In his spare time, Michael enjoys surfing and computer games.

When Michael saw that MND New Zealand was on the lookout for new council members, his interest was sparked. Michael says: "I'm keen to use my digital skills to help the organisation engage people online, and I enjoy finding new ways to solve problems."

Welcome to the team, Michael. We appreciate your time, effort, and enthusiasm as we all work to improve the lives of people in the MND community.

***"To anyone thinking of volunteering or fundraising, just do it! Don't hesitate or think about the time it's going to take up. If you have a passion or someone you love inspiring you, you can make it happen."***



**Michael's children keep him busy and entertained.**



## Walk 2 D'Feet MND needs you

While winter is upon us at the moment, we're always thinking about what's around the corner. Summer is just a few months away and with it, Walk 2 D'Feet MND, so it's time to get planning!

Walk 2 D'Feet MND is a fun and visible way to raise awareness and funds to help in the fight against motor neurone disease. Walks are between 3 to 5 kilometres, family friendly and accessible. Participating in a Walk 2 D'Feet MND event is a great way to get out and about in your local community, while showing your support for those living with MND.

Walk 2 D'Feet MND events are made possible by dedicated local volunteers who give their time and effort to organise a local event.

Walks can be held by volunteer supporters anytime between November and February. Fundraising Manager Kate Dalders says, "All walks continue to be organised and led by amazing volunteers who give their time freely to make the events happen. To enable even more communities to get involved, this summer season Walk 2 D'Feet MND can be held on any date that work for each community, rather than one particular date as we've done in the past."

Right now, we're looking for supporters throughout New Zealand to start planning a walk in their own community. MND New Zealand offer guidance, resources, and support every step of the way.

Taylah West was part of the group that organised Walk 2 D'Feet MND Hamilton 2019. Taylah has this advice: "To anyone thinking of volunteering or fundraising, just do it! Don't hesitate or think about the time it's going to take up. If you have a passion or someone you love inspiring you, you can make it happen."

If you are interested in finding out more about organising a Walk 2 D'Feet MND event, or to register a Walk you are already planning, email our Fundraising Manager Kate Dalders on [kate.dalders@mnd.org.nz](mailto:kate.dalders@mnd.org.nz).

# Share your story

During Awareness Month 2020, we encouraged our community to share their stories of living with MND and supporting those diagnosed with the disease. Here we share a few of the many insightful stories received throughout the month.

Sometimes it's the simple pleasures in life that are the most enjoyable. For people living with MND, everyday things like going for a walk can be a challenge.



**To help others understand this, Jos from Wellington put pen to paper and came up with this piece.**

**The sun is shining brightly!** Well, that means I can take advantage of the good day with gentle windy fresh air and sunny warmth. Shoes on, shawl on, purse over my shoulder and I'm off!

I will take in some street scenes and look at the windows of the main street shops. The first street I negotiate has a truck parked across the footpath, but after many apologies, the driver moves out onto the road to let me by and then re-parks where he was.

At the bottom of the first hill, I pass a bookshop with the owner and his dog sitting outside. Strange how much the dog objects to my passing his shop. For an old dog, he has a loud bark.

Next, I meet a man on a scooter who decides he needs to help me cross the street, so he parks his scooter in the middle of the road and puts his hand up to stop the traffic while I cross. The man, a familiar face to me by now from my weekly walks, tells me that I should have come down half an hour earlier, then I could have

had a free bowl of soup at the soup kitchen! Last week he challenged me to a race!

Then it's past the street singers and a homeless man. We nod as if each of us is feeling sorry for the other. There are lots of people in many different outfits on the street, all so colourful! Many fast, valuable cars pass the street crossings; I could enjoy a ride in them or just one of them. Now it's time to head back up the other hill, where I can tell who had a party on the weekend from the recycling bins overflowing with interesting empty bottles.

As I return to the entrance of my village, I'm asked by an interested man how the springs cope when one negotiates the "sleeping policemen" (traffic humps). I give a demonstration to satisfy his curiosity and carry on to finish my outing. My wheelchair rides can be quite eventful. In case you hadn't guessed, this is how I "walk", and no, the cops were never after me despite the rumours!

## **Council Member Michael Fuyala reflects on his Uncle Ron's MND Journey.**

**Ron was my godfather.** He didn't have children of his own, but you could say he had lots of children in reality, because many of us nieces and nephews spent years living with him at various stages of our younger years. Ron was also my boss, as I worked with him in the family christmas tree business, and a friend. He'd come over for dinner regularly – always punctual, six o'clock on the dot, and with a bottle of wine in hand, usually a South Australian Shiraz that was good but also cost less than ten dollars.

One day he was at our house for dinner and he mentioned he'd been getting a little more tired than usual

when mowing the lawn. It was a one-hectare lawn that would tire most people, but Ron was very fit and active, so this came as a surprise to him and us. He also mentioned having difficulties swallowing. After a few doctor's appointments he called me up at work to say he was going back in, as the neurologist was concerned it could be serious.

Ron, my Auntie and I visited the doctor the following week. Ron was told by the doctor, in a matter-of-fact way, that the news was not good. He had MND and it was progressing quickly. There were some practical discussions about what to eat, and then we went to the supermarket to buy some Up and Go as an easy way to get liquid calories, as eating solids was getting too difficult.

I distinctly remember going to another aisle to grab something, then coming back to see Ron staring at the shelf. People were hustling and bustling around him, no doubt with their own everyday problems, but his world as he knew it had been stopped in its tracks. From that point things got harder for Ron as the disease took hold, and it always frustrated me how hopeless the situation was, with little progress on creating a treatment, let alone a cure, for MND.

In saying that, things have progressed a lot even in the nine years since that moment, and with continued support from generous people that are in a position to help, we can be hopeful that treatments and eventually a cure will emerge.

As for our Uncle Ron, while he is sorely missed, he is also fondly remembered by us all, and I'm lucky to have had him as a positive role model. He was a very well-liked man, good with his hands and with a sharp mind. He was successful in business



too, but in an old-school way, as he would always value integrity and relationships before quick profits. The kind of guy that used to stop off and buy strawberries for his tree suppliers every time he visited, because he knew they'd be too busy to get them while they were in season.



**Sarah Mathieson with her Dad, Alan.**

### **Sarah Mathieson got in touch during Awareness Month to share her story about her hero: her Dad, Alan.**

**Dad was a hard worker.** He was a jack of all trades and if he wasn't at work, he was outside in the garden or getting a load of wood or away helping someone.

My Dad, Alan Mathieson, was diagnosed with ALS at age 64. We had taken him to the hospital thinking he had had a stroke as he couldn't form his words, only to be shocked to receive a diagnosis of MND.

Dad was so brave and just worried about how everyone else was handling his diagnosis. All I remember was the doctor saying we could expect Dad to be with us for anywhere between four months and two years.

Dad thankfully lasted the two years, giving us more precious time with him. He was so stubborn and struggled through everything that MND threw at him. He was a very strong independent man, always giving and helping others. Dad you're never forgotten. You'll always remain in my thoughts and my heart. I love you.

## **Global research update – Tofersen**

### **An international trial that may have identified a drug to help slow the progression of MND symptoms is gathering momentum and interest.**

Developed by Biogen, the Tofersen trial has received considerable media attention after the promising results of a combined Phase 1 and 2 trial were published recently in the well-respected [NEJM](#). The drug targets the known cause of a familial form of motor neurone disease due to a faulty gene called SOD-1.

Researchers have been aware of the faulty SOD-1 gene for over 25 years but have only recently been able to target it with the development of antisense oligonucleotide (ASO) therapy.

SOD-1 is the known cause for triggering MND in two percent of all patients with ALS, and up to 20 percent of patients who have a family history of the disease. The build-up of the abnormal SOD1 protein is toxic to motor neurones.

Professors Chris McDermott and Angela Genge, speakers at the MND New Zealand Research Conference last year, were both involved in the study, which involved 50 participants from across Europe, Canada, and the United States.

Professor Chris McDermott from Sheffield Institute for Translational Neuroscience (SITraN), and Principal Investigator of the Sheffield trial says, "The primary objective of the study was to evaluate the safety and tolerability of Tofersen, which shows signs of potential efficacy in lowering the levels of the toxic SOD1 protein in the nervous system, something which will reduce damage in the nerve cells and help to slow the progression of symptoms."

At this stage, it is unclear whether Tofersen slows the progression of MND. It's only clear that it is safe and tolerable for participants to take. Nevertheless, preliminary results are promising, and we can look forward to hearing the results of the Phase 3 trial by early 2021.

You can find more information about the other trials included in the International Alliance of ALS/MND Associations briefing notes, on our website here <https://mnd.org.nz/research/research-resources/>.

## **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 in the MND Registry.

It doesn't matter if you are old or young, newly diagnosed or not, born in NZ or not ... we want to enrol people of all ethnicities, from Cape Reinga to Stewart Island.

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](mailto:MNDRegistry@adhb.govt.nz) or**  
**phone 0800 MND REG (0800 663 734).**  
**See [www.mnd.org.nz/registry](http://www.mnd.org.nz/registry) for more**  
**information and the enrolment forms.**

NEW ZEALAND  
**MND**  
REGISTRY

# Rohan rises to the challenge

After watching two family friends battle MND, Christchurch student Rohan Chakrabarti was motivated to do something to help. He decided to organise a charity gala in aid of MND New Zealand, complete with celebrity guest Lesina Nakhid-Schuster of "The Bachelorette" fame.

Rohan says, "Many people have no idea what MND even is, so raising awareness and providing support to MND New Zealand is something that's important to me."

Planning was in full swing, with the gala event due to take place on 27th March at Sixty6 on Peterborough in Christchurch, when the COVID-19 pandemic escalated. The whole country was put into lockdown just days before the event was due to happen.

Not one to shy away from a challenge, Rohan was determined for the event to happen and forged ahead. Challenges Rohan faced included adapting to COVID-19 health and safety measures, securing and selecting a new date, and changing

the venue to the Christchurch Transitional Cathedral.

Rohan adds: "I had lots of help to pull this amazing event together, including theming by Kim Chan Events and auction items generously donated by Emirates Team New Zealand, Countdown and Heritage Hotels."

On Saturday 20th June the event went off without a hitch, and as the photos attest, a fabulous time was had by all. Guests included Christchurch Deputy Mayor Andrew Turnbull, prominent Canterbury Neurologist Dr Debbie Mason, Fulton Hogan team members, and Tracey Prince from Metropolis Magazine.

Samarra Wright, who is living with MND, attended the event as a speaker and had this to say: "The Charity Gala helped to increase awareness of MND. So many people spoke to me on the night, saying they had no idea what MND was and had to Google it. A lot of high-profile

people attended, and it was great for MND to receive more attention in New Zealand."

It's great to see that after all the challenges presented by lockdown and social distancing, life is returning to a semblance of normal. Fundraising Manager Kate Dalders says, "It's incredible when people volunteer their time and energy to support us. Rohan's determination, adaptability, and planning skills are commendable, especially with so many curveballs to deal with!"

Community events are an excellent way to raise awareness and vital funds to help support people living with MND. If you're interested in holding an event in support of MND New Zealand, email Kate Dalders, Fundraising Manager, on [kate.dalders@mnd.org.nz](mailto:kate.dalders@mnd.org.nz).



Samarra Wright poses with attendees.



Rohan poses with Lesina Nakhid-Schuster and friends.



The Christchurch Transitional Cathedral was an excellent venue.





Dr Emma Scotter's team caught up on regular video calls during lockdown.

## How the COVID-19 pandemic has impacted global research

As COVID-19 has swept the globe, temporarily disrupting life as we know it, research into MND has of course been impacted. In many instances research was put on hold, with most countries entering some form of lockdown in a bid to stop transmission of the virus.

Although the current situation may seem a little disheartening, it's important to consider how far MND research has come in the last ten years. There truly have been leaps and bounds made in the progress to understand the disease and its causes.

In 2014 the global success of the Ice Bucket Challenge generated a huge increase in public awareness as well as millions of dollars for motor neurone disease research.

MND research has grown exponentially in the last decade. There has never been such a strong desire to understand the causes and find new therapies for this complex condition.

Over the past three years, MND New Zealand has helped to lay the foundations for a small but rapidly growing field of MND research in New Zealand, playing a key role in the development of the NZ MND Registry (find out more on p.7) and the MND Research Network led by the Scotter Lab at the Centre for Brain Research.

While the world still grapples with COVID-19, the good news is that researchers have largely been able to continue their valuable work. Many have used the opportunity to catch up on analysing data collected from experiments in the lab or designing trials for the future.

Some trials have paused recruitment of new participants, but most continue to follow up current participants, including remote monitoring.

Dr Claire Reilly, MND New Zealand Community and Research Advisor says, "Fundraising for research may be affected in some countries, however the general feeling



amongst the research community is a recognition that MND doesn't stop for patients and neither should research wherever possible. The silver lining may well be increased use of Telehealth and adapting trials to become accessible to more people remotely."

So, what of MND research in New Zealand? Participant safety is of utmost concern, so adaptations have been made to research being conducted at the Centre for Brain Research due to the COVID-19 pandemic. The MRI Scanning study was paused and there was a switch to at-home saliva collection for the genetics study. You can find out more about these two studies on our website:

<https://mnd.org.nz/research/mnd-nz-research-fund/>

Although the COVID-19 pandemic meant research was temporarily put on hold during lockdown, Dr Scotter and her team recently returned to the lab, eager to get back into research, and are actively recruiting participants for the genetics study. Dr Scotter says, "We invite people with MND (familial or sporadic), and people without MND who have no family history of MND and who are over 60 years of age, to participate. We also welcome people without MND, of any age, if their family has a history of MND (two or more individuals affected)." If you are interested in participating in this research email Dr Scotter on [emma.scotter@auckland.ac.nz](mailto:emma.scotter@auckland.ac.nz).

# Advocating for those with MND

**At MND New Zealand our vision is: “Together we provide the best quality support for people living with motor neurone disease.”**

Advocating for the healthcare needs of people living MND is key to achieving our vision, which is why we held the first MND hui at Parliament last September. The hui offered people working in various disciplines across healthcare throughout the country the chance to come together and discuss the clinical needs of people living with motor neurone disease in New Zealand.

An outcome of the hui was that several clinicians volunteered to form a working group to focus on ways to enhance care for people living with MND.

The MND clinical working group is made up of 14 members from all around the country, including neurologists, respiratory and palliative care physicians, nursing and allied health professionals, and MND New Zealand team members.

Group members have had the opportunity to meet four times so far, including one face-to-face meeting in Wellington at the Ministry of Health. Because group members are based all over New Zealand, monthly video calls help them keep in touch and work together on objectives.

*“There is a lot of work to do, but we have made a great start, and we feel very fortunate to have such an amazing team of clinicians volunteering their time because they feel as passionate about improving care for people and families living with MND as we do.”*

At the moment the group is working on drafting guidelines for both general practitioners and specialists around recognising and diagnosing MND. It will then move on to developing guidelines around nutrition and swallowing, communication, and respiratory care.

MND New Zealand Community and Research Advisor, Dr Claire Reilly, who is chairing the group, says, “There is a lot of work to do, but we have made a great start, and we feel very fortunate to have such an amazing team of clinicians volunteering their time because they feel as passionate about improving care for people and families living with MND as we do.”

The MND clinical working group has made an excellent start on its objectives, and we look forward to sharing more about its progress in the future.

As an organisation we have also been advocating for increased government funding for people with MND, following the recent announcement of a package of \$833 million to be invested into disability support services.

Upon hearing this announcement, we engaged with the Ministry of Health to highlight our unique position as the only organisation providing support to people living with MND and their families.

Over the past 10 years, government funding has remained steady, but the number of families we provide support to has almost doubled. We're hopeful that raising these concerns with the Ministry of Health will assist with securing increased funding, helping our vital support service to continue.

## 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 drop us an email on [comms@mnda.org.nz](mailto:comms@mnda.org.nz) if you have any ideas for our next newsletter.



## We would like to acknowledge the following for their generous support of MND New Zealand recently:

- Eastern and Central Community Trust
- Four Winds Foundation
- Frimley Foundation
- Higgins Bequest Trust
- Ministry of Social Development Special Fund (COVID-19)



# Our MND Support Team

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



## **Toni Foster**

Support Team Leader  
DHBs: Waikato, Taranaki, Whanganui (North)  
Mob: 021 230 3038  
Email: teamldr@mnda.org.nz



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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 their sponsorship of printing over many years.

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