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mndnews

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

www.mnd.org.nz

MND Awareness Week and The Ice Bucket Challenge

Kiwis have embraced the tradition of the MND Ice Bucket Challenge since its inception in 2014. The initiative began in the US as a vehicle to raise awareness and much needed funds for MND/ALS and it has since taken the world by storm, becoming the fastest growing fundraising and awareness building campaign in MND history.

While the connection between an icy bucket of water over the head and motor neurone disease is not precisely clear, what is clear is that it has become an extremely powerful tool for spreading information about MND and raising funds to help fight this disease and support those living with the diagnosis.

This year we kicked off our annual MND Awareness Week and our own Ice Bucket Challenge campaign in style with MND New Zealand's new CEO Scott Arrol donning his best suit to take on the first icy drenching. This year's campaign also benefited from the support of six high profile Kiwis who all share close connections to MND in some way. Annabel Langbein, Bernadine Oliver-Kerby, Te Radar, Sam Johnson, Simon Dallow, and Craig Waalkens all graciously lent their talents and profile to help raise awareness for MND.

Within days of the launch of our star studded MND Awareness Week video, dozens of Kiwis had registered to help raise vital funds for MND New Zealand. All together around 50 people, businesses, schools, and even local politicians took on the 2022 MND Ice Bucket Challenge raising more than $50,000 to support Kiwis living with MND.

Extra kudos should also go to our New Zealand supporters as unlike our Northern Hemisphere counterparts, who enjoy their icy dunking in the middle of their northern summer, we front up to the MND Ice Bucket Challenge in the middle of winter!

A note of thanks from the MND New Zealand team…

"This campaign has become a powerful tool for our organisation, we want to acknowledge the significant role it plays in boosting awareness for MND and helping us communicate the true cost of this disease on our community.

Thank you to all those across Aotearoa who took up the challenge and supported us this year. With your help, our team can continue to deliver the support services that are critical to Kiwis' living with MND as well as helping us fulfil our vision of funding medical research to help fight this disease in the future."

A special thanks to our sponsors Hobbiton Movie Set Tours, Hampton Downs, Huski, Whittaker's, and Megazone Mt Wellington for generously donating prizes for the donor draw!

CEO and Chair Report


Scott Arrol iced

I have been with Team MND for five months, and it's been fantastic getting to know as many people as possible, learning about the great work we do to support people living with MND and developing plans that will build on the legacy of the past and present.

Since joining the team, I have heard many refer to MND as *the bastard of diseases*. Yet as I meet our clients, their whānau and carers, I have been blown away by our community's brave and tenacious attitude. You are all ultimate "Kiwi battlers" – you bring so much grit and determination to this MND battle, no matter what!

I believe it is this determined 'battler' spirit that inspires so many to join us in this fight against MND and get behind our fundraising campaigns. These donations are crucial to us being able to provide our services across all New Zealand. We do not receive any government funding to provide these services. We are reliant on the generosity of our fellow Kiwis.

During June we ran our annual MND Ice Bucket Challenge, a campaign that not only mobilises people to raise funds for our cause but also helps raise awareness for MND and the challenges our community face.

Many Kiwis stepped up to be 'iced' and in return over $50,000 was raised. Having been dunked with ice several times this year already, I can honestly say I have enjoyed every minute and encourage you to give it a go too! It's the least any of us can do to show we care and to help spread the word about this fight.

When it comes to generosity, special mention must also go to our amazing partners at Fulton Hogan. The Fulton Hogan MND New Zealand Support Fund is instrumental in helping us support our clients and their whānau. We are therefore thrilled that they have decided to extend their support for a further 4 years and we are looking forward to growing this relationship and exploring more ways the great folk at Fulton Hogan can get involved with our community.

Our next major national fundraising campaign is our popular *Walk 2 D'Feet MND!* event on Sunday 20th of November. Covid disruptions have made it difficult for us to get together over the last two years, but we are looking forward to bringing this sociable fundraising occasion back into our calendar of events this November. Please join us, to participate, volunteer or even take the lead and organise a walking event in your own neighbourhood, town or city.

As a direct result of these fundraising efforts, MND New Zealand is proud to be able to sponsor the delivery of the Lighthouse II phase 3 trial here in New Zealand. This trial is the first of its kind to be offered across multiple sites in New Zealand. While the number of participants is limited, being invited to take part is a sign that New Zealand is seen as a credible player in the global MND research community. MND New Zealand's vision to establish and fund an independent NZ MND Registry five years ago should be commended. This registry is a crucial tool for connecting people living with MND in New Zealand with the best international research teams.

In governance news, we are making excellent progress changing the legal status of our organisation from an incorporated society to a charitable trust. The trust deed has been approved by Charities Services and we are now finalising the remaining legal requirements. Chris Sawers, who joined the Council in late October last year has recently resigned and I am pleased to share that Patricia Sloan has joined the

IN THIS ISSUE

mnd
Motor Neurone Disease
New Zealand

Board and will attend her first meeting on the 20th of August.

Like many charitable organisations, the times ahead will be challenging. Reforms to the health and disability sectors, coupled with the inflationary economic climate means we must navigate a careful path forward. But we are not deterred. We are committed to providing quality community-based services to those living with MND who trust us to be a part of their support network. It is an honour to be fighting this disease and standing by all those who are living with MND in New Zealand.

Kia kaha
Scott
Scott Arrol, Chief Executive

Board of Trustees Vacancy

Are you interested in contributing to our work by being a Trustee, or know of someone who might be?

We are looking to add to the Board's skill set and broaden the diversity of representation around areas such as – people living with MND, Māori, Pacifica or technology.

If interested in knowing more then please contact our CEO, Scott Arrol on 021 414 681 or **scott.arrol@mnd.org.nz**

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https://www.facebook.com/mndanz/

New staff welcomes

Jo Kelly, Support Service Manager

Jo has joined Team MND New Zealand following more than 10 years with the Stroke Foundation of NZ. She has an extensive history of supporting people within hospital and community settings, including 12 years as a practising podiatrist. Jo has always been involved in the health and fitness sectors, adapting her skills to admin roles including national aerobics and JumpJam competition judge for over 20 years when injuries spelt an end to her love of sport aerobics and half marathons. Jo enjoys music of all genres and gets a lot of joy from supporting her many talented musical friends. Jo lives in Franklin, South Auckland with her 3 children and a large fluffy white dog. Based at our Auckland office as Support Service Manager, Jo is always on hand to listen, guide and advise not only our immediate team but also the wider MND community and service providers.

Tricia Sloan - Council Member

Patricia (Tricia) brings to the MND New Zealand Board, extensive health and business expertise. She has held senior management roles in the National Health Service (UK) and worked in developing countries prior to coming to New Zealand. Tricia is General Manager – Services Group at Technical Advisory Services (TAS) in Wellington where she has worked since 2010. In this role she has been responsible for service delivery of key functions such as Māori Health outcomes, employment relations, workforce services, national contracts commissioning, regional service planning, communications, media management and governance services.

Tricia has been closely involved in the recent health and disability reforms and established relationships with Te Whatu Ora – Health New Zealand and Te Aka Whai Ora – Māori Health Authority. The cornerstone of Tricia's work ethic is to drive better health outcomes for all New Zealanders through a culture of innovation and improvement. She is joining the MND New Zealand Board of Trustees at an important time and we are looking forward to having her skills and knowledge to guide us through the changing landscape of the health and disability system over the coming years.

Lighthouse II Phase 3 Trial

By October of this year, a small group of Kiwis living with Motor Neuron Disease will begin their journey as members of the first international phase 3 MND clinical drug trial to be offered in New Zealand, across multiple locations.

The Lighthouse II phase 3 trial looks at whether human endogenous retroviruses (HERVs) play a role in motor neurone disease. Invitations to participate were extended to MND research teams across all regions in New Zealand.

Four centres: **Bay of Plenty**, **Wellington**, **Christchurch** and **Dunedin** elected to take up this opportunity and the trial will be overseen in New Zealand by Principal Investigator, Dr Alan Stanley, Hawkes Bay neurologist and MND New Zealand Council member.

"There are **20 places** available for NZ-based people with MND, but even though this trial is relatively small in reach, Lighthouse II is a significant milestone in our plans to access more clinical trials for our community here in New Zealand" explains Dr Claire Reilly, MND Community & Research Advisor.

"Being invited to participate in this international trial is a direct result of our fundraising successes and represents nearly a decade's worth of work by MND New Zealand."

The New Zealand MND Registry, established in 2017 to connect MND patients with international research opportunities, is one of the key mechanisms that captured the attention of the International Lighthouse II trial team.

"We are urging all of those living with MND to join the registry if they haven't already. Whether you are eligible for this Lighthouse study or not, having a comprehensive central register will be critical to securing other research opportunities for Kiwi's living with MND in the future."

There is a range of criteria researchers will apply when selecting participants for the Lighthouse II trial, but first and foremost, for clients to be considered, they must be part of the NZ MND Registry. Screening participants for this trial will commence in September, with the trial starting in October.

In keeping with research best practice the NZ MND Registry will make direct contact with those who are eligible and will work with them on the next steps required by the four research centres.

To learn more please visit our website: mnd.org.nz/research

NEW ZEALAND
MND
REGISTRY

People in New Zealand living with MND who wish to be considered for the Lighthouse II trial must be enrolled with the NZ MND Registry as soon as possible before the end of August. If you have already enrolled with the Registry you don't need to enrol again.

Enrolling with the Registry can be done online here: **mnd.org.nz/research/take-part-in-research/mnd-registry/**

or contact the Registry Curator, Dympna Mulroy, via email **MNDregistry@adhb.govt.nz** or phone on 0800 MND REG (0800 663 734).

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 **rob.bloch@mnd.org.nz** if you have any ideas for our next newsletter.

Fundraising highlights

Stacey and Kelly's Backyard Ultra at Spencer Park Christchurch

Stacey Garrett and Kelly LaValley decided to take on the Backyard Ultra in honour of their friend **Gary Boot** who is living with MND. Gary was an avid runner pre-diagnosis and always encouraged his friends to take on bigger, crazier challenges, so that's exactly what they did!

The 'Ultra' event saw Stacey, Kelly and friends each complete a 6.7km lap, every hour on the hour - until they simply couldn't run anymore! Finish a lap within the hour time limit, and the remainder of that hour becomes your rest period. Stacey and Kelly were eager to fundraise in support of MND New Zealand and used their friend Gary's diagnosis as their motivation to do "one more lap."

Kelly completed a whopping 16 laps, totalling more than 107kms, to finish as the second-place female runner. Stacey came in at an astounding 20 laps equalling 134kms! Between the two friends they ran for about 36 hours and raised nearly **$5,000** for MND New Zealand**!**

Tony's Fun Run/Walk for MND

MND New Zealand client **Tony Gill** is known throughout the Rotorua region as the friendliest person you'll ever meet, with a smile ready to go for everyone. During his time as manager of the Rotorua Trust, Tony helped distribute millions into the local community each year. So, his sisters **Jane and Helen** felt it fitting to hold a 5km community fun run/walk to honour their dear brother and raise funds for MND New Zealand.

On Sunday 1st May the Rotorua community came out to show support for Tony. People dressed head to toe in MND blue, walked or ran the 5km course then finished up with a sausage sizzle and waiata. It was a truly special event which brought people together and raised an astounding **$10,179.94** for MND New Zealand.

Tony's family and MND New Zealand would like to extend a special thank you to **Lake City Athletics Club** for the use of their facilities. **Robyn Skelton** and **Paul Woolaston** who organised the run route, bar, and clubrooms. **Nicola Smallwood** who ran the online fundraising page and blog, and the **Rotorua Trust** for generously donating the sausage sizzle and afternoon tea.

Nettie and the Crazy Bunch

In the last newsletter we introduced **Nettie Wright** and her bike-packing team "The Crazy Bunch." Since then, the team have conquered New Zealand's longest bike-packing trail spanning the 3,000 km length of Aotearoa. Team members **Don** and **Joyce** joined the North Island leg, while **Laura, Libby, Hillary, and Jill** rode with Nettie for the full North and South Island length.

The inspiration behind the ride was **Kevin**, Nettie's husband of 35 years and father of their three children. Kevin passed away from MND on 6th April 2013 but nine years on Nettie was keen to honour his legacy and show support for those living with motor neurone disease now.

"This has been the adventure of a lifetime," said Nettie. "Kevin would have totally approved. He'd done a South Island ride just before he was diagnosed. Even after his diagnosis in 2012, he still pushed on and did the 165km Lake Taupo ride, an event we had done annually with friends. Kevin was gutsy and I wanted to show the same determination and positive outlook he showed MND."

Nettie had already raised $3,000 before setting off on the ride, and with her new partner **Michael** by her side to help make it happen, the team was ready to go. The Crazy Bunch's motto for the adventure was "expect the unexpected" and according to Nettie that's exactly how the trip panned out. With no shortage of incredible moments, the trip highlighted the generous spirit of Kiwis from Cape Reinga all the way down to Bluff. On top of lifelong memories, Nettie and her "Crazy Bunch" raised a remarkable **$10,300.64** for MND New Zealand.

"You never know who might be impacted by MND, and my hope is that the medical professionals learn why this disease happens and that a cure is found so others don't have to go through it. We had a blast doing this for Kevin, this trip will not be forgotten."

The Witch King of Angmar Half Marathon

Allan Bullot's quest started with a broken rib, covid lockdowns, and too much time on his hands. With all this playing on his mind, he decided "why not build a three-metre-tall, 15-kilogram costume of the Witch King of Angmar from Lord of the Rings?". The aim was to wear it while running the Hobbiton Halfling Marathon but when the event was postponed due to covid Allan took matters into his own hands and set up his own half marathon along the Auckland waterfront.

Allan's motivation? His old friend from Uni, **Greg Horton** who now lives with MND and has been a constant champion for the MND community. Allan saw that Greg never let MND hold him back from doing great things, so what better way to honour that determination, than to fundraise for MND New Zealand.

Allan's half marathon began in St Heliers and continued the length of the Tamaki waterfront. After reaching Silo Park Allan then looped back along the same scenic route to his original St Heliers start line. Allan's attire, his three-metre-tall Witch King of Angmar costume drew large numbers of curious onlookers, many of whom were eager to donate to this Lord of the Rings villain turned good. As the day progressed, interest on social media grew too, catching the attention of actor Lawrence Makoare, who played the original Witch King character in the film trilogy. Lawrence insisted on riding out upon his own fellbeast(motorbike) to meet Allan and snap a few photos as well.

Five hours of walking and two hours taking photos with curious members of the public and Allan had successfully completed 22.3kms dressed in his towering Witch King costume. His efforts raised a staggering **$10,201.95** for MND New Zealand and did a phenomenal job raising awareness for MND.

With covid restrictions easing Allan was finally able to take his costume to the Hobbiton Halfling Marathon. News reporters from TVNZ's Seven Sharp captured Allan in action, helping to raise even more awareness for MND in New Zealand. Thank you for your great work, Allan!

Triumph Herald Rides Again

The gift of a 1964 Triumph Herald from her brother was supposed to be a fun restoration project for Classic Car enthusiasts **Johnn Jaspers** and his wife.

Sadly, their plans were upset when his wife received her MND diagnosis. According to Johnn, she was the healthiest person he had ever known, making the shock of her MND diagnosis even more difficult to handle. After her passing in 2019 Johnn decided to sell their Triumph and donate the proceeds to MND New Zealand. Even the sales listing helped push the MND cause.

The car was purchased for **$2,300** by fellow car enthusiasts **Jeannette** and **Brad** who are keen to complete the rebuild together. In a special coincidence it turned out Jeanette's grandfather **Ken** had also passed away from MND in 1994 and had been a Triumph aficionado throughout his own life too.

John has found great comfort knowing that their Triumph has not only helped raise funds for others battling MND, but it has found its way into a new home with a couple who understand MND and share the same love for classic cars.

Take your donation further with TaxGift

Did you know your donations to us are eligible for a 33% tax credit from IRD? Taxgift's simple platform lets you gift those back to MND New Zealand, meaning your original generous gift can go even further. It takes less than a minute to sign up, and there's nothing more for you to do. It's the easiest gift you'll ever give us.

An inside look at our Support Advisor Service

By Megan Te Boekhorst
Support Advisor to Coromandel, Waikato, Taranaki, Whanganui North


Taranaki


Matamata


Sisters Tongaporutu

As a support advisor I cover a large section of the North Island, from Thames all the way to Taranaki. So, what makes these outreach trips special? For me, it's a host of things: I see myself as the link between home, hospital, families, and carers.

Caring: I am a shoulder to lean on, and an ear to listen when a client or their spouse needs to talk, sharing laughter or tears. I let each person know just how important they are to me as their Support Advisor and to the people around them, whether a client, carer, or family member.

Advocating: I provide MND information, education, and palliative support for people within the MND community. I receive and make referrals to various therapists within the neurology team such as Clinical Nurse Specialist, Neurologists, Respiratory Nurses, Occupational Therapist, Dietician, Speech & Language Therapist, Physiotherapist, GP's, Hospice and Counselling. I also act as a support person when people living with MND need someone to join them at a specialist appointment.


Owharoa Falls

Small town hospitality: Even though the family are tired, they still make the time to welcome me into their home and sometimes with a beautiful gesture of thanks like home baking or a cup of coffee.

Sharing the good times: A client recently played the most beautiful piano recital for me and while I listened, it made me aware that even if his speech has changed, his hands still work and he is able to continue playing the piano, which still brings so much joy to his life.

It's in times of sickness and grief that I see true love and caring among spouses, family members and friends for the person with MND. This usually comes in the form of a letter, a meal, a pop-in visit, a phone call or a community fundraiser and it truly warms my heart to see the awesome people my clients were before their diagnosis and just how special they are made to feel now that they need support.

Gratitude: I am always so grateful that I can be part of each family's individual MND journey.

I may not have all the answers or a magic wand, but I can most certainly be there for them to make life more comfortable. On reflection, life is short – if this role has taught me one thing, it's that I should never take anything for granted. When I take long walks in the forest or on the beach, I do it on behalf of my clients who would love to be out in the open air but who are no longer able to go out or walk. When I enjoy an ice-cream on a hot day or a coffee on a cold day, I think of my clients who would love to have the opportunity to enjoy a good meal or a treat, but who cannot eat or swallow anymore. When I enjoy a conversation with my son, I think of my clients who would love to do the same with their children and grandchildren, but who can no longer speak.

I drive vast distances to provide this support, between 400–700km per outreach trip but at the end of each busy day, I feel happy in my heart knowing that I have made a difference in the lives of those living with MND.

Let's cherish every moment and always make the most of every opportunity we have!

Nominations are open for the 2022 David Oliver Beacon Award

This annual award acknowledges and celebrates individuals, groups, or organisations who have made a significant contribution to the MND community. The criteria for this year's award:

> **Providing strong leadership and going above expectations to enable MND New Zealand to continue providing support to people living with MND, their whānau, family and carers during the very difficult period caused by the Covid-19 pandemic.**

Submit your nominations by email: **admin@mnd.org.nz**. Be sure to include nominees name, contact details, as well as a blurb about why you are nominating them. Nominations must be received by 30 September 2022 to be eligible for consideration.

Last year, The David Oliver Beacon Award was presented to Greg Goldfinch and the team at Colliers Highbrook (pictured). Greg and the Colliers team were recognised for their phenomenal 2021 Ice Bucket Challenge campaign which raised over $200,000.

Recognition for Greg Horton MNZM.

Greg Horton, an integral part of the MND New Zealand team was recognised in the recent Queens Birthday and Platinum Jubilee Honours. Greg is now a Member of the Order of New Zealand, honouring his work in philanthropy and governance. Greg has filled a variety of roles with MND New Zealand, always going where the need was greatest. He has helped steer the organisation through challenging times and in 2021 as Council Chair and as acting Chief Executive, Greg, who lives with MND, personally raised $750,000.

In addition to his work with MND New Zealand, Greg has contributed to the University of Auckland Foundation, Saint Kentigern Boys' School Roselle Foundation and has been a board member of Emirates Team New Zealand since 2013. He is a former director of Fulton Hogan and continues to provide business advisory support to Fulton Hogan and other entities including Silver Fern Farms and Seeka. Thank you for all you do, Greg.

Make your online shop count with Rewardhub

Rewardhub lets you earn free donations to MND New Zealand every time you shop online, without costing you a cent. Whether you're ordering food, drink, groceries, or goods online, when you do it via Rewardhub it makes giving back to MND New Zealand easy.

Earn free donations every time you shop online.

Sign up to support us at Rewardhub.co.nz

MND FUNDRAISE YOUR WAY

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

Stories from our Community

Brent's Story

Six years on from his diagnosis at the age of 45, **Brent Wilson** has lost his ability to speak but can get around home with the aid of a walker or his trusty electric wheelchair.

Finding work has been a struggle so Brent took the next step which was to see what sort of welfare support he might be eligible for. To his surprise he was offered just $168 per week. With the average weekly rent and mortgage repayment in New Zealand around $400 and inflation on the rise, $168 was not going to cut it!

So, Brent began creating steel artwork to sell on Facebook. His business is called **Metalworkz** and some of his most popular works feature hearts with family surnames inscribed or New Zealand Ferns with custom script. The personalised nature of his art makes them popular gifts for weddings and anniversaries.

When he's not creating, Brent is advocating for the MND community putting pressure on ACC to include people who have become disabled through no fault of their own. While this advocacy work might never impact him, Brent hopes his efforts will deliver change for others MND.

Joshua's Story

My dad, **Anthony Wilson** strove to be the best he could be. Levelheaded and thoughtful of others, he was a leader within our whānau and iwi.

He had many notable achievements during his life. While a student at Saint Stephens College his talents and personality made him a prefect. He also played for the first XV and was likened to a "gun" on the rugby field. After leaving school he continued playing rugby for various clubs and working as a firefighter. He became crew chief at Auckland International Airport on the first response team, excelling at this job, always prepared for any emergency.

He held other important leadership roles such as mentor for disadvantaged youth and the negotiator for Ngati Paoa Treaty settlements. He was a highly revered speaker in English and Te Reo Māori.

As a kid, I remember being so proud of dad. He taught me the haka "Ka Mate" so I could teach my primary school class. He'd come on our school camps and trips and the other kids would always say "oh man your dad is cool as."

MND stole my dad's ability to do so much. He was the main speaker for events at the Marae, until he lost the ability to speak. It's heart breaking to think of his two grandchildren who are still so young, he would have been an incredible grandparent and my heart goes out to my mother, **Louise Wilson** who looked after him so well and after 38 years of marriage had to watch him go through this.

I wouldn't wish MND on anyone and I hope researchers can find a cure soon, so others won't go through what my dad did.

Myles MacDuff MND Awareness Rugby Game

After receiving his diagnosis last November Myles MacDuff and his family moved home to Ngatea to be closer to family. While the causes for MND are not well understood, Myles has wondered if the head injury he received while playing Rugby ten years earlier, may have had some effect. Regardless, Rugby and the community that surrounds the game, have both played a steadfast role in supporting Myles and his family at this time.

A mad keen Rugby player, Myles spent part of his mid-20s playing for Fishguard and Goodwick RFC in Wales. When old teammates heard of Myles' diagnosis, they launched **#4miles4myles**, a campaign where supporters could walk, run or cycle to raise funds. Good friend John Miles, physio for Wales Rugby team, rallied old rugby mates to get involved, including Springboks captain Siya Kolisi, and former Wales coach Warren Gatland.

Back home in New Zealand, Myles' community have also united, hosting a **#longarmschallenge** that brought families together to entertain each other with funny skits while raising money for one of their own.

Just last month, Andrew Williams, Captain of Hauraki North RFC and David Harrison, Coach of the Thames Valley Swampfoxes also delivered on their promise to host a charity rugby game in support of Myles and to raise awareness for MND.

On July 23 Thames Valley Rugby Union, where Myles had been player of the year in 2003, took on Hauraki North RFC, where Myles had coached in 2007. The Ngatea community were all there to witness the clash and be part of the community event of the year! As good friend Karl Davis said, "Rather than do nothing, because it's really easy to do nothing, quite a few people are doing something!"

Myles, humbled by the attention, was glad that the game could boost awareness for MND. Invited to speak about MND on several occasions ahead of the game Myles described how shocked people were when they realised how little government support was available to those living with the disease. Myles explained that if he were to get hurt in a car accident, access to carers and support would be funded, but when it's an MND diagnosis "you get bugger all."

Myles' heartfelt words of thanks on the club's facebook page summed up the day; "Being away for 12 years and coming back to be treated like this is beyond words and emotions! Huge thank you to all […] It was a great day beyond anything I could have imagined."

MND Research Updates

From MND Community and Research Advisor Dr Claire Reilly

NZ first multi-centre clinical trial launches

Lighthouse II Phase 3 is an international clinical trial that looks at whether human endogenous retroviruses (HERVs) play a role in motor neurone disease.

MND New Zealand is proud to fund this trial but is not involved in screening or selection of participants. To be considered for this trial, people living with MND must first be registered with the independent NZ MND Registry.

The NZ MND Registry will contact eligible patients directly. Trial centres will then screen potential participants ahead of the trial commencing in October.

Who is eligible? Participants must be on the NZ MND Registry, reside in one of the four site locations, and meet the inclusion criteria set by the trial. For inclusion and exclusion criteria visit: **clinicaltrials.gov/ct2/show/NCT05193994**

Why only four sites? Each site needs a neurologist and a research nurse. The number of sites reflects those locations that have staff available.

Why only 20 participants? This is the first time New Zealand has collaborated in a large international trial. With limited numbers of staff available, the number of participants has been restricted to ensure the trial is conducted safely and effectively.

A legacy of this first multi-site trial will be the establishment of systems and processes that can be scaled to accommodate larger trials in the future.

How can I find out about research happening in Aotearoa? The MND Research Network publishes a full list here: **mndresearch.auckland.ac.nz/research/**

To access future trials, people living with MND must also be registered with the NZ MND Registry. This is a separate process to becoming a client of MND New Zealand.

Register online: **mnd.org.nz/research/take-part-in-research/mnd-registry/** or contact, Dympna Mulroy, via email **mndregistry@adhb.govt.nz** or phone **0800 MND REG (0800 663 734)**.

How can I learn more the Lighthouse II phase 3 trial? FAQs, links and more detailed info is available on our website: **mnd.org.nz/research/take-part-in-research**

Australia & New Zealand MND Symposium

The first trans-Tasman MND Research Symposium took place in Brisbane in April, marking a step towards greater collaboration with global MND research. Dr Claire Reilly presented the New Zealand MND Research Strategy and called on her Australian counterparts to join NZ colleagues and build a virtual "MND Research Bridge" between the two countries. Dr Emma Scotter and her lab presented on the genetics of MND in NZ and TDP-43 pathology associated increase in microglial CD68 expression. Participation in this event helped MND New Zealand gain access to the Lighthouse II Trial, commencing in September.

NATIONAL RESEARCH STUDIES CURRENTLY RECRUITING

Genetic Screening in Motor Neuron Disease

The University of Auckland and Auckland City Hospital teams are recruiting for their nationwide MND Genetics Study. The purpose of this study is to understand the genetic causes and origins of MND in New Zealanders. The reserach team are keen to work with people who have MND without a genetic diagnosis and people who have already received a genetic diagnosis for an MND-causing mutation (affected and unaffected). To learn more email: **MNDresearchstudy@auckland.ac.nz**

Focus-C9

This study is evaluating the safety and tolerability of WVE- 004 in people with MND or FTD with a documented mutation in the C9orf72 gene. This study is recruiting across Europe, Canada, Australia and New Zealand. There are several inclusion and exclusion criteria for the trial. Email **mndregistry@adhb.govt.nz** to see if you are eligible.

INTERNATIONAL CLINICAL TRIALS UPDATE

Tofersen (Biib067) Biogen; Adults with S0D1

The pharmaceutical company behind Tofersen has announced new data that shows earlier initiation of Tofersen slowed decline in clinical, respiratory and muscle function and quality of life. Biogen has expanded eligibility for its early access program to all eligible people with SOD1-MND to access Toferson outside of a clinical program and commercial setting. If you think you may be eligible for this investigational drug, please discuss with your medical specialist.

For more research news visit: mnd/org.nz/research

Our Support Advisors

We employ part-time MND support advisors around the country. If you live some distance from a support advisor, contact will mainly be by phone, email, and text, with occasional visits. We are not able to provide out-of-hours or emergency services.

Jo Kelly
Support Service Manager
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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.

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MND NEW ZEALAND FUNDERS

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

- Community Organisation Grants Scheme (COGS)
- Dragon Community Trust
- Guy Ansel Waddel Trust
- Higgins Bequest Trust
- L ion Foundation
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- Pub Charity
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- A & R Edgar South Canterbury Trust
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Bank: Westpac Banking Corporation

Account Number: 03 0539 0195083 000

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

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Upcoming Events

for more information email rob.bloch@mnd.org.nz
or give us a call at 09 624 2148

September 11th 2022

October 29th 2022

November 20th 2022

Interested in a Walk 2 D'Feet MND! event in your city?
Register your inerest at mnd.org.nz/get-involved/volunteer/

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