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mndnews

NEWSLETTER OF THE MOTOR NEURONE DISEASE ASSOCIATION OF NEW ZEALAND INC

www.mnd.org.nz

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Contents

mnd
New Zealand

Cuppa Tea for MND

MND Awareness Week, June 18 to 24

We're having a lovely cup of tea and would be delighted if you'd join us. During **MND Awareness Week (June 18 to 24)** we encourage you to organise a morning or afternoon tea at your workplace, school, club or home, to raise awareness of motor neurone disease and funds for our support service.

Our Support Team are at the core of our organisation, providing free support to people with MND all over New Zealand. They help build and maintain teams of health professionals around everyone with MND, and help the whanau surrounding people with MND work together as a team, so they can all have the best quality of life possible.

So please get your team together for a Cuppa Tea for MND in June. Go to **everydayhero.co.nz/event/tea4mnd** to donate or start fundraising.

Email fundraise@mnda.org.nz for more ideas and information

News from the Australasian MND Symposium

In March, MND New Zealand staff attended the first ever Australasian MND Symposium in Melbourne, organised by Fight MND.

For three full days, the Australasian MND Symposium brought together some of the world's best MND researchers in two conference streams: biomedical (for MND research) and clinical (for MND care). Members of our team all attended a mix of sessions.

We were really excited by the positivity of the researchers working in this field.

"I'm really optimistic for the future for the next five to 15 years," said Professor Paul Talman, director of the Australian MND Registry. "It *will* lead to a cure."

Professor Kevin Talbot, Head of Clinical Neurology at the University of Oxford, UK, told us that researchers are intensely and disproportionately interested in MND.

"There are more academic neurologists working on this in the UK than would be justified if you simply took the incidence of the disease."

"Researchers are intensely interested in MND, because it's an interesting problem," he said. "For lots of us, it's also a tractable problem – it's not impossible, it's just difficult."

Current thinking in research is that those with familial MND will eventually be treated with therapies targeting DNA, and those with sporadic MND will be treated with personalised combinations of precision medicines.

Increasingly, more specific sub-types and stages of MND will be defined using 'big data' to analyse progression patterns and personal genes.

Professor Don Cleveland, winner of the 2018 Breakthrough Prize in Life Science for his 'designer DNA' therapy (see page 14), pointed out that "4 to 5 million people now alive today will die from ALS". That gives researchers a sense of urgency – particularly as potential treatments appear increasingly achievable.

Top row: Kerry Walker (NZ MND Registry), Moira Young, Gilly Noon, Jayne McLean (NZ MND Research Network), Linda Oliver, Jacqui Drinkwater, Carol Matthews, Emma Scotter (MND Lab, Centre for Brain Research), Carl Sunderland. Bottom row: Annabel McAleer, Claire Reilly.

We are working to collate everything we have learned, to share with New Zealanders affected by MND and the health professionals who work with them.

We will make this information publicly available by early May at mnd.org.nz/research

The David Oliver Beacon Award goes to … **The Talklink Trust**

The David Oliver Beacon Award is our annual award to honour, acknowledge and celebrate those who work with people with MND. It is open to individuals, groups and services that provide a positive contribution, improvement or innovation in MND support or care.

We are delighted to announce the 2017 David Oliver Beacon Award winner is the TalkLink Trust.

TalkLink has been well respected in the MND community for many years for the understanding the therapists have of the needs of people with MND, and for their commitment to helping people with MND communicate using the most appropriate technology. TalkLink prides itself on ensuring that all its therapists understand the urgency for communication tools for people with MND and prioritise their MND clients. TalkLink advocates to the Ministry of Health on the importance of access to communication for those with MND. TalkLink therapists also get involved in our annual Walk 2 D'Feet MND.

Ann Smaill, the general manager of TalkLink, received the award at our AGM in October. She said: "We are very humbled by this award. It is really rewarding to see the difference providing communication options to people can make. For me, and I am sure I speak for many of the therapists at TalkLink, some of the most rewarding, challenging and emotional work we do, is when we work alongside people with MND. We are privileged to share their journey."

Nominations for the 2018 David Oliver Beacon Award are open.

This year's theme is 'Working as a Team'. We welcome nominations from people with MND, their carers and from healthcare professionals.

Click the black David Oliver Beacon Award box on mnd.org.nz to download the nomination form.

Nominations close 5pm, 21 June 2018.

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Medicinal cannabis for MND – an update

With increasing public interest in medicinal cannabis for pain management, and with the Misuse of Drugs (Medicinal Cannabis) Amendment Bill in Parliament at Select Committee, MND New Zealand wanted to be able to contribute to informed debate around the use of medicinal cannabis for management of the symptoms of MND.

Together with Multiple Sclerosis New Zealand, we commissioned a report, completed in December 2017: 'Review of Current Research Regarding the use of Medicinal Cannabis for MS and MND Symptom Management' (find the PDF link at mnd.org.nz/cannabis).

The report examines the risks and benefits of using medicinal cannabis, and reviews the current international recommendations for the safe use of medicinal cannabis.

The report found benefit in using cannabis for the treatment of several symptoms of MND: pain, spasticity, weight loss, and potential to slow disease progression.

It also found some risks: dependence, impairment due to THC intoxication, potential worsening of MND-related cognitive impairment, potential risk of mental illness, smoke inhalation, and potential contaminants.

We then chose to make a submission to the Select Committee currently considering the Misuse of Drugs (Medicinal Cannabis) Amendment Bill. The Bill proposes to make it legal for terminally ill people to possess and use cannabis. It also changes the classification of cannabidiol (CBD) and CBD products so they are no longer controlled drugs.

MND New Zealand does not promote a view either in favour or against the Misuse of Drugs (Medicinal Cannabis) Amendment Bill. However, we want to ensure that any rights that might be created by the Bill do not discriminate against people with MND.

We pointed out to the Select Committee that if people with MND use cannabis for relief from the symptoms of MND, many rely on a carer to procure and prepare their cannabis if they are physically unable to do so themselves. In its current wording, the Bill does not protect carers who procure, prepare or temporarily possess cannabis on behalf of a person with terminal illness. We believe this may discriminate against people with MND, and recommended that the Bill provide legal protection for such carers.

The secondary purpose of our submission was to share our report about the use of cannabis to treat symptoms of MND and MS, to inform the Committee's consideration of the proposed Bill. We also referred the Committee to 'Cannabis and its Use in Symptom Management of ALS/MND', a presentation from the International Symposium on MND/ALS in December 2017 (linked from mnd.org.nz/cannabis).

We also recommended that 'terminal illness', currently defined in the Bill as an illness from which a person can reasonably be expected to die within 12 months, instead be defined as an illness from which a person can reasonably be expected to die (with no time frame specified). We felt this would be fairer to people with MND who often experience uncomfortable symptoms for several years.

Finally, we recommended that Government provides funding for ongoing research into the use of cannabis to treat the symptoms of MND and other neuromuscular and neurodegenerative diseases. We believe it is important that further, well-designed scientific studies are conducted to investigate the effects, risks and benefits of cannabis on people living with MND, so we can empower patients to make informed decisions about their care.

Read our full submission to the Select Committee by clicking the link at mnd.org.nz/cannabis

End of Life Choice Bill – our submission

A Select Committee is currently considering the End of Life Choice Bill, a proposed Bill that would make it legal in New Zealand for people with terminal illness to request medical aid to hasten their death ('assisted dying').

MND New Zealand appreciates that many people in our community have strong views about assisted dying, both in favour and against. We choose to remain neutral 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.

However, it is important that MND New Zealand participates in the Select Committee process, to ensure that any rights that may be created by the End of Life Choice Bill do not discriminate against people with MND. In particular, we feel it is important that the word 'talk' used several times in the Bill be specifically defined to include users of assistive speech technology.

In March we made a submission to the Select Committee, which you can read at mnd.org.nz/EOLCsub.

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 must 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.

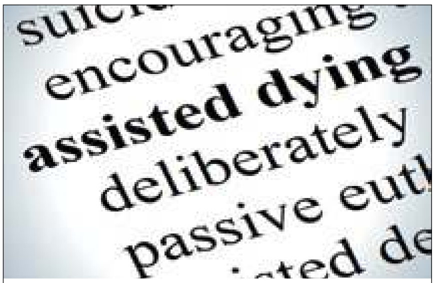
We were informed by the work of Rod Harris, the CEO of MND Victoria, Australia. MND Victoria worked hard to ensure the rights of those who cannot speak, swallow or self-administer drugs were protected by Victoria's new voluntary assisted dying legislation. This legislation was passed in November 2017 and comes into effect in mid-2019. (It will be restricted to people who have lived in Victoria for 12 months.)

Rod described the process to us as "one of the best opportunities to achieve a properly funded palliative care service for all who need and want it. We are seeing the recognition of that by the funding announcement regarding palliative care from Government."

In November 2017 an additional A$62 million was invested in palliative care funding, particularly to rural Victoria, as a result of the discussions around the assisted dying legislation in Victoria. From that five-year funding package, A$19 million will be spent in the current financial year, before the Voluntary Assisted Dying Act comes into effect.

MND New Zealand is 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. We welcome emails and letters telling us about your experiences with palliative care services in New Zealand.



Our recommendations to the Select Committee

1. We recommend that the words 'talk' and 'tell' be defined in the Bill to specifically include communication using assistive speech technology.
2. We recommend that any changes made to the wording of this Bill consider and continue to include people:
   - who are unable to communicate verbally, and/or
   - who receive nutrition and hydration by tube, and/or
   - who are unable to swallow, and/or
   - who have very limited mobility in their hands.
3. We recommend that Government funding for palliative care services is substantially increased. In particular, we recommend increasing funding to:
   - specialist palliative care outreach services to rural areas, and
   - respite beds in hospices (not private hospitals), and
   - inpatient services in small towns, and
   - overnight nursing care.

Living Giving

Bequests are a hugely appreciated, important part of keeping MND New Zealand's support service going. Some people prefer 'Living Giving' to leaving a bequest in their Will. A person considering making a bequest of $10,000 to MND New Zealand in their Will might choose to instead donate $2000 each year over a period of five years. They can then claim a tax rebate of $666 each year.

Of course we would be delighted if the donor then chose to also donate the annual tax rebate to us. Over a five-year period, this would compound in a similar way to compound interest, resulting in a total of $15,000 being donated to MND New Zealand from the original $10,000.

Comfort for grieving kids

Enzo was three when his grandmother died due to MND. Ever since, he has slept with his large Hope Puppy, which he has named Grandma.

"Sleeping with her every night makes me remember Grandma because she had MND. She was really soft," says Enzo, now aged six. "I miss Grandma. It makes me remember snuggling her in her wheelchair and laying back in her chair with her."

A soft toy can be a great source of comfort for a child who is grieving. Psychologists call this type of toy a 'transitional object', and their use can help a child feel stronger and more resilient.

An article in *Psychology Today* (tinyurl.com/transobj) describes a transitional object as providing "comfort, solace, predictability, and constancy – representational of a stable and predictable world". Interestingly, adults also form attachments to transitional objects that make us feel secure and connected (a wedding ring, for example).

Our large Hope Puppies are available for $20 or three for $55 (plus postage).
All the purchase price supports MND New Zealand.
To order email jenniferaknight@hotmail.com

Firefighters' extreme donation

We were impressed, delighted and a little bit afraid for the four members of the Palmerston North Fire Brigade who stepped forward last year and told us they'd like to walk 170 kilometres in full uniform, from Palmerston North to Wellington, to raise money for MND support and research.

Firefighters Chris Kennedy, Justin Storey, Dan Nesbit and Jeremy Dodge (supported by fellow firefighters Belinda Cadzow and Angela Pomana, and Dr Lynette Hodges from Massey University's sport and exercise programme) completed their ambitious Extreme Walk 2 D'Feet MND over three days, finishing at the Wellington Walk 2 D'Feet MND on November 12.

The extreme walkers wore full firefighting kit, which weighs around 25 kilograms, and endured agonisingly blistered feet.

Despite their pain, the team shook collection buckets as they passed through towns along the way, raising $7000 in cash donations. Many people who had lost loved ones to MND came out to support the team along the way, which was incredibly powerful and moving, said Dan Nesbit, motivating the firefighters to keep walking even as they completely lost the skin on their heels.

Including text and online donations, the Extreme Walk 2 D'Feet MND team raised $16,000 for MND New Zealand. They also received a lot of regional and national media coverage, which helped raise awareness of MND. We are enormously grateful for their efforts.

Lead walker Chris Kennedy presents a cheque for $16,000 to MND New Zealand's Beth Watson (right) and Annabel McAleer (left).

You raised ov

The Walk 2 D'Feet MND in November set a record for us, raising just over $300,000 for MND support and research. We are beyond thrilled at the growth of this event all over New Zealand, and the way it connects our MND community. Thank you for walking, fundraising and donating. See you next time – **Sunday 11 November**!

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▲ We loved seeing these children at the Christchurch Walk 2 D'Feet MND taking the 'blue' theme and running with it!

© BRIAN M HARMER

▲ Firefighters Chris Kennedy, Justin Storey, Dan Nesbit, Jeremy Dodge and Belinda Cadzow complete their epic 170km Extreme Walk 2 D'Feet MND, finishing at the Wellington Walk 2 D'Feet MND.

© JACS RUSH

▲ Although we sell event t-shirts every year, we are always delighted when groups of caring and creative friends take t-shirts into their own hands, like this group walking for Stephen at the Whanganui Walk 2 D'Feet MND.

Thanks to St John New Zealand

We're hugely grateful to St John New Zealand for providing their services to us at our Walk 2 D'Feet MND events all over New Zealand. St John is a charity too, so it's awesome that they support another charity by providing free services for our events!

ver $300,000!


© GAVIN JOHNSTON

▲ Our Auckland Walk 2 D'Feet MND was our best attended walk ever, with a sea of 1000 adults and more than 300 children walking together in a show of strength and solidarity for families affected by MND.


© ELTON MCALEER

▲ The weather was a delight in most locations (especially compared to last year!).


© ELTON MCALEER

◀ MND New Zealand Council member Greg Horton (see page 8) triumphantly crosses the finish line at the Auckland walk, after a determined effort to walk the entire circuit using only his beautifully carved tokotoko walking stick for support.

▼ Brent Thompson, inspiring builder of planes (see page 11), at the Christchurch Walk 2 D'Feet MND.


© SUE OXLEY

New faces at MND New Zealand

We are delighted that Carl Sunderland has been permanently appointed to the role of general manager at MND New Zealand. This is a full-time role, for the first time in our organisation's 30-year history. We are also pleased to welcome a new support team leader, administrator, and two new Council members to MND New Zealand.

Toni Foster

Support Team Leader

Toni joined us as support team leader in early April. Toni is a physiotherapist who has worked mainly with adult neurological clients for the past 26 years. She brings a huge amount of knowledge, expertise and ideas to our support service and the whole of MND New Zealand.

"Many of my previous roles involved providing education to and support for my clients and their families," she says. "I'm looking forward to the opportunity to assist people with MND and their families, and support people to understand more about their condition, the services available to them, and assist them in any way I can to enable them to have their best possible quality of life."

Toni has four teenage children (two girls and twin boys). She's a keen supporter of all four kids' hockey teams, and loves horse riding and camping with her family.

Toni will work 35 hours a week, Monday to Friday, in our National Office. She will lead our support team and support some people with MND in Auckland.

Hayley Watkinson

Office Administrator and Accounts

In February Hayley Watkinson joined our National Office team in Auckland and hit the ground running. Hayley's background is in hotel administration and management, and she has fantastic administrative, bookkeeping and customer service skills.

Hayley returned to Auckland after 13 years living in Wellington to take up this position and to live closer to her mum, who has MND. Hayley has a great deal of understanding and empathy for our community that will be an asset in this busy role.

Hayley works in the MND New Zealand office from 9am to 3.30pm weekdays. When she's not at work, she spends time with her husband and their two-year-old son.

Greg Horton

Council member

I am a family man and have been married to Shelley for 15 years. We have three children. I am 48. I was diagnosed with MND/PLS a little over two years ago, and it is an honour to contribute to the governance of the MND Association.

I hold degrees in Commerce and Law (Honours) from the University of Auckland. I am a founding partner of the law firm Harmos Horton Lusk, and have practised law for over 20 years in Auckland, Wellington and New York. Despite my condition, I am lucky to be able to still work full time.

I am a chartered member of the Institute of Directors, chair of New Zealand Funds Management and New Ground Capital, and a director of Fulton Hogan, Viaduct Harbour Holdings, Wairakei Pastoral and Team New Zealand.

Steve Green

Council member

I spent some time as full-time carer for my youngest brother Mark who had MND. This had a profound effect on my life. As Mark's brother I felt his struggle keenly, and at age 62 I bring to MND New Zealand my desire to "put back in" to this life I've been fortunate to have.

The highlight of my working life was being national sales manager for Sony Computer Entertainment and launching PlayStation. I am a painter and decorator by trade and this allowed me to travel and work throughout the world.

These days I run a small business and my spare time is taken up with acting and theatre. I have appeared in many shows and occasionally you may see me on *Shortland Street* or in a Netflix movie.

A Happy Announcement

Fundraising from the Walk 2 D'Feet MND has enabled us to employ an additional member for our MND Support Team. They will support people living with MND in the upper South Island. This will improve our overall capacity to support people with MND in the entire South Island and the lower North Island. The recruitment process is underway and we look forward to announcing our new staff member when appointed. We'd like to thank all our Walk 2 D'Feet MND fundraisers, walk organisers, volunteers and donors – we couldn't have done this without you!

A heartfelt thank you to our branches

The branches of MND New Zealand have been an important part of our organisation. In the early years, before we had a national office, they *were* the organisation. As our support service grew, branches responded by employing people. It was not until around 2006 that our support team was employed nationally.

Throughout this time, branches have found it challenging to find people with time to commit to long-term voluntary work. By 2017 there were only four regional branches left, and at least two were struggling to fill formal roles such as chair, treasurer and secretary.

This led National Council last year to ask our branch members for their input on the future role of branches in MND New Zealand. Their feedback was generally supportive of moving away from the formal branch structure. We were also aware that closing branches would save us significant accounting costs. So, in October, we made the decision to close the branches that no longer wished to operate as a branch with its various formal requirements.

Since then, we have been working with our dedicated branch members to create a less formal structure that better meets the time availability of our generous volunteers. Through the Walk 2 D'Feet MND we have learned that we can attract volunteers for short-term projects. We want to enable these wonderful volunteers to connect to and support their local MND community in other ways throughout the year, if they wish.

Our goal is to produce a flexible nationwide model so that anyone who wishes to be part of 'Team MND' can do so, in a way that suits them.

These flexible regional groups will be called MND Community Groups. We will work with walk organisers and current branch members to create some initial MND Community Groups. Together we will develop and refine some broad guidelines for future groups, while allowing groups to determine their own focus and activities.

We are aware that several informal support and fundraising groups already exist around the country, and we hope to bring these groups under the MND Community Group banner – so please get in touch if you belong to an existing group. We want to support your activities, connect groups to share great ideas, and make it easier for families newly affected by MND to make contact with local sources of social support.

Waikato branch Christmas function, 2013

Thank you to the branch members who have volunteered their time, thoughts and energy to this process, and for their contributions to their local MND communities over many years. Thank you to these volunteers, including **Elizabeth Murphy**, **Janet Hutchings**, **Lyn Hayson** and **Tanya Gilchrist** (Bay of Plenty branch); **Bruce Stokell**, **Kath McKay**, the late **Margaret McKay** and **Beth Watson** (Wellington branch); **Bronwyn Simons**, **Diane van Leeuwen**, **Hilary Weller**, **Nicole Hill** and **Jill Gimblett** (Canterbury/West Coast branch); and **Helen Palmer**, **Lesley Saville**, **Alice Robertson**, **Doug Farrow**, **Colleen Yorwarth** and **Sheryl Ker** (Waikato branch).

To those who have ended your volunteer service with us – thank you for all you have given over many years. To those who are staying involved, we are so pleased your commitment to making life better for people with MND will continue to inform our regional and national outlook and activities.

Over our organisation's history there have been many more dedicated people who have given months, years and even decades of voluntary service at local branch. We are sincerely grateful.

Join an MND Community Group

Would you like to be part of creating a new local MND Community Group? Do you already belong to an MND fundraising group, Walk 2 D'Feet committee, or local MND social/support group?

We ask that you please get in touch to help us establish MND Community Groups all over New Zealand. An MND Community Group could be a support group, a fundraising group, a Walk committee, or simply a few people who get together monthly over coffee. Each group can decide how often to meet and whether to meet in person or via email or social media, and can decide its own structure and focus.

These groups will be crucial in ensuring that MND New Zealand continues to have a strong regional presence, and hears about the concerns of families affected by MND all over the country. We believe everyone with MND must be able to access the same quality of support, equipment and palliative care, no matter where they live, and we will work with regional volunteers to identify and improve services that are falling short.

We ask anyone who wishes to form an MND Community Group to please get in touch. We are very excited about what this means for our community – we can never have enough good people as part of the team.

Please email Hayley at admin@mnda.org.nz, being sure to include your area and contact details.

Your tips and tricks

EAZYHOLD makes small rubber 'slings' which wrap around your fingers and can hold a pen, stylus, toothpick, or probably anything. Fantastic when you do not have the use of your fingers, or the fingers have no power.

Justin Toebes

I have recently obtained an **ERGOREST ARM SUPPORT**. The bottom of the device is clamped to my desk, and there is a swinging arm rest on which my lower arm is placed. With only a minimum amount of pressure I can swing my arm back and forth or side to side, and easily use a finger typing on my keyboard, and it also makes the use of the cursor easier.

Justin Toebes

None of the standard medications for saliva worked for me (eye drops, travel sickness patches, amitriptyline tablets), so my last resort was botox. This has been a success to a limited degree – I can tell when I am due for the next dose as the saliva increase is noticeable.

To absorb excess saliva, I tried tissues and gauze before I came upon eye pads, which are ideal. They are the size of the lens on your glasses and are the right size to just pop in your mouth. I probably go through about a dozen a day, which I keep in a bowl and boil them up and run them through the clothes dryer and reuse. I also sleep with one overnight, using two over an eight-hour period.

Cliff Bond

Please send us your tips, tricks and innovations that help ease life with MND.

Email comms@mnda.org.nz

I was equipped with an ankle brace and rubber band to make walking easier with foot drop. This band is connected to a loop sewn into the top of my shoe, around where the shoe laces start. If the foot is only partly paralysed, this may offer some help to lift the foot, avoiding trips.

As the paralysis progressed I found there was not sufficient lift being provided and the toe of the shoe would catch on the ground. I wear a metal leg brace so I experimented with attaching a bungy cord to the brace at knee height, running it down the inside trouser leg, and attaching it to the toe of the shoe. I drilled a small hole in the shoe sole, right at the toe end, to hook the bungy into (don't drill right into the shoe interior, it only needs just enough to attach to). The tension keeps it in place. It's a Heath Robinson job but it does the trick and does away with the ankle strap as well.

Cliff Bond

My brother has a mobility parking card for his car, but he has been harassed several times by members of the public for using the mobility car parks, as he looks young and normal. They have accused him of not being "disabled" (and how we wish this was true). I thought, if he had some leaflets about MND that he could give out when people fling open his car door and abuse him for parking in a mobility park, perhaps he could educate and raise public awareness about MND. Soon he will use a wheelchair and they will see his disability, but for now he is trying to live every moment and get out there. Thanks for listening.

Jane Seymour

We love this constructive, awareness-raising response to what is sadly a common experience for anyone with 'hidden' disability. We will happily supply multiple copies of our 'About MND' leaflet to anyone who would like to have MND information in their car for this purpose. Please contact our National Office at admin@mnda.org.nz or phone 09 624 2148, and let us know the address to post our 'About MND' leaflets.

Building a plane with MND

When aerobatics pilot Brent Thompson was diagnosed with MND he was part-way through a major project. The idea of leaving it unfinished was unthinkable, so he carried on – with a little help.

When Brent Thompson bought his aerobatic aircraft in 2010, he was running Thompson Aeronautical Ltd, a company that built wooden propellers for microlight and homebuilt aircraft around the world. He had developed a taste for aerobatics, and dreamed of owning a suitably capable aircraft. When Brent finally bought the Rans S-10 Sakota, a high-performance microlight, he started a major rebuild to make it his own.

By 2013, he had rebuilt and recovered the fuselage, and the wings were in the process of being rebuilt.

Then, in August 2013, came a diagnosis of motor neurone disease. Brent was aged just 35.

Aware that he would soon be unable to fly, that's what Brent turned his immediate focus towards. In 2014 he came second in the Flying NZ Nationals, and was selected for the New Zealand Wings aerobatics team.

Once the competitions were over, he turned his attention back to his plane. The to-do list was long: he wanted to upgrade the engine, build it a new cowling, modify the exhaust system, and finish the wings. It was a lot for anyone, let alone someone whose MND was beginning to affect every part of his body.

Friends began to help, turning up at the hangar at Rangiora Airfield to help complete the plane rebuild. Some people helped regularly for months at a time.

But Brent's biggest helper was his mum, Ann Thompson (pictured left). She had virtually no background knowledge or experience, but she was a willing helper and a fast learner.

As Brent's ability to do the work himself deteriorated, Anne's knowledge about aeronautical engineering slowly grew.

"Mum has just been amazing," Brent told the TV show *Seven Sharp* when they filmed his story in November 2017. "She's had to learn so many new skills. She's done fabric covering, rib stitching, metalwork, fibreglass repairs. She's learned to spray paint. There's really nothing she wouldn't take on."

While tasks were ticked off the to-do list, the time it took to complete them grew. Communication with computer-assisted speech was slow and frustrating, but in April 2017 the S-10 took its first test flight since the rebuild.

By January this year, the test flying was complete and signed off, and the aircraft is now up for sale, looking for a new owner who can fly her the way she's meant to be flown.

Life after diagnosis

David Seymour describes himself as an "MND battler". He writes about coming to terms with his diagnosis and how he makes the best of life with MND.

February 22, 2017. A day I will never forget. The brutal news that my diagnosis is motor neurone disease. A year has passed and still, now and again, I ask myself, 'Why me?' But most of the time, there are still things to do, places to go, and jokes to tell – along with a few beers to drink.

One of the ways I have navigated my way through my first year with MND is by setting short-term goals, and focusing on the good things and good times that were coming. I have no time to sit down and let it beat me just yet.

We had to move into our new home two days after my diagnosis, so the help of good friends and family was crucial to starting this new journey. We were also planning our trip to Beach Hop, a hot rod and rock 'n' roll festival at Whangamata, at the end of March. A week away with close family was in order.

As for work? I had some goals to achieve. I was selling real estate with LJ Hooker in Whangarei. I'm a goal setter, and my goals were close to completion. Along with all this, I was in the middle of organising the inaugural Rev Up hot rod show in Whangarei, which was happening late April.

By the end of April – with the house move, Beach Hop, Rev Up and my birthday behind me – it was time to work out what was ahead.

I aimed to achieve 10 more sales by the end of August, and agreed to work a few less hours. I would continue to go swimming on a regular basis with a good friend. Take a family trip to Fiji. Walk up Parahaki one more time. And the goal I most looked forward to: taking our Mustang to the National Mustang Convention in Invercargill in October. Before that, we wanted to drive up to Cape Reinga, so we could drive the country, top to bottom!

With no idea if I would still be walking by October, I said to my wife Rachael, "We're going regardless." As it turned out, I was still walking but no longer driving, so Rachael had to do it all – and she loved it! For 4500kms we saw some of the most beautiful country New Zealand has to offer. We had a barrel of fun travelling with close friends and made more friends along the way.

In September I'd made the tough decision to give up work. It took me a few weeks to get to grips with this, but throwing myself into other projects helped. I put my hand up to help organise the Whangarei Walk 2 D'Feet MND event in November. We thought we'd be able to raise $6000 or so, with maybe 100 walkers. Amazingly, with a bit of effort and huge support from our community, we ended up with over 500 walkers raising $22,000!

I also tackled the Whangarei District Council over their proposal to start charging for mobility parking. An article in the local rag got huge attention on social media and made quite a stir. I addressed a Council meeting, and at their next meeting Council agreed to not charge for mobility parking. A win for the little guys!

I volunteered to help ACT MP David Seymour promote awareness and seek support for his End of Life Choice Bill. I was one of 5 people who did a video regarding the Bill and had it heavily promoted on social media. I believe people should have the choice.

What's next? Another trip to Beach Hop 2018, and a road trip to the Waikato to visit another Mustang collection. In the meantime, I've started writing a book about selling and am mentoring several salespeople. My personal goal is celebrating my 55th birthday in style in April. I also walk my dogs down the drive (several hundred metres) most days. They need me!

I couldn't just sit back and let this MND beast get the better of me. That would be far too easy. Besides, I have far too many projects and goals to let that happen. I will keep going until I can't – not when someone tells me I can't, but when I just *can't* – and that's not yet.

New cars for Support Team

We are grateful for the support of Bay Trust, First Sovereign Trust Limited and ANZ Staff Foundation for granting us funds to purchase cars for two members of our support team.

Bay Trust and **First Sovereign Trust Limited** enabled Jacqui Drinkwater, our Support Team member in the Bay of Plenty, to join MND New Zealand with a new 2017 Mitsubishi Lancer.

The **ANZ Staff Foundation** enabled Linda Oliver, our Support Team member in Auckland, to replace her 2005 Mazda Demio with a zippy little 2018 Mitsubishi Mirage.

Members of our Support Team have very large regions to cover, and do a lot of driving to meet people with MND, their families/whanau, and health professionals face-to-face as often as they are reasonably able. Reliable, fuel-efficient cars are an essential working tool. We are very grateful to the funding bodies that make it possible for us to provide vehicles to our Support Team.

New MND InfoPack

When people newly diagnosed with MND register with the MND New Zealand support service, we give them a packet of information about motor neurone disease. It's common for people to have never heard of MND before their diagnosis, so this information is a crucial guide.

We are delighted that we have been able to update and redesign the content of this 'info pack' for 2018. For some time, we've been aware that the large amount of information we supplied could be overwhelming for some newly diagnosed people. We have replaced the previous nine brochures, all written over a decade ago, with a short booklet describing the 'need to know' facts of MND, including a guide to finding more detailed information online.

The creation of this booklet would not have been possible without the funds raised by the Walk 2 D'Feet MND. While it's exciting that 50% of this fundraising grows MND research in New Zealand, the 50% of funds raised for MND support is also absolutely crucial to our organisation achieving its aims.

Thank you to all of our Walk 2 D'Feet MND fundraisers for your contribution to updating this important resource for the newly diagnosed.

We would also like to thank MND Australia for generously allowing us to use their brochure as a base from which to build our own, and Lin Field, former MND New Zealand support team leader, for her work adapting the brochure to our client needs in New Zealand.

For a PDF of the new brochure email admin@mnda.org.nz, or ask your support team member for a printed copy.

JAMIEFARRANT / 123RF STOCK PHOTO

It's tax time

If you've donated more than $5 to MND New Zealand (or any other registered charity) this year, you're eligible for a tax rebate of 33% of your total donations.

We post or email tax receipts to all the generous people who donate to us via internet banking or cheque (as long as you've given us your contact details!).

A tax receipt is automatically sent via email when you donate via the Everyday Hero website (our preferred fundraising platform). At the time of the donation, you can also tick a box to have another receipt emailed to you at tax time. If you have ever created an account with Everyday Hero, you'll be able to access receipts for all your donations from the dashboard of your account.

If you're lucky enough to get a tax rebate from the IRD this year, please consider making a donation to MND New Zealand.

If you require a tax receipt for the 2017–2018 tax year, please get in touch with us at accounts@mnda.org.nz

Gene editing for familial MND

Scientists have proven it's possible to edit and silence disease-causing genes. Successful trials for other neurodegenerative diseases are giving MND researchers hope that gene editing to prevent familial MND from developing may prove successful, with clinical trials beginning this year.

There was great news for families carrying the gene for Huntington's disease in December 2017, with the announcement that a 'gene silencing' treatment for Huntington's has been proven safe in humans, with promising indications of effectiveness in the Phase 1 clinical trial.

This is also really promising news for families with the most common genetic causes of MND (SOD1 mutations or C9ORF72 gene expansions). The drug technology used for this Huntington's clinical trial was developed by Ionis Pharamceuticals, which is working with Roche and Biogen to develop similar treatments for MND.

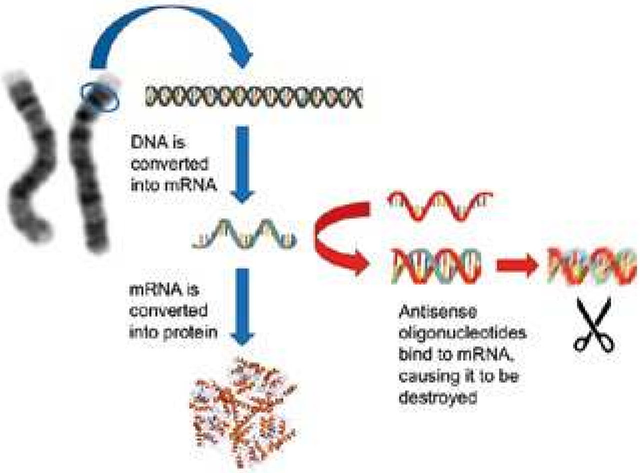
The treatments use 'antisense oligonucleotides' (ASOs), which are custom-built, chemically modified pieces of DNA that are injected into the spine with a lumbar puncture. The ASOs can then cross the blood-brain barrier, travelling into the brain to destroy the message that directs the production of the disease-causing proteins.

Mice with the C9ORF72 gene expansion associated with familial MND and frontotemporal dementia (FTD) eventually develop FTD-like behavioural abnormalities. In studies, a single ASO injection before onset of these abnormalities allows the mice to live without ever developing cognitive issues.

The first human clinical trials using ASOs for SOD1- and C9ORF72-related MND are taking place this year. The trial leader, Professor Don Cleveland of the Department of Cellular and Molecular Medicine, University of California San Diego, US, presented his research at the Australasian MND Symposium in March. He spoke about the difficulties in getting FDA approval for the trials, but is confident that if the Phase 1 trial for people with C9ORF72-related MND goes well in the coming months, it could be quickly followed by a Phase 2/3 trial.

Much work remains to be done, but many researchers are very excited about this therapy. The genetic fault in the C9ORF72 gene is found in approximately 40% of people with familial MND, and about 10% with seemingly sporadic MND. It was only discovered in 2011, so the development of a potential treatment has been remarkably quick. The ability to 'silence' this genetic fault could prevent hundreds of thousands of people from developing the disease.

Ionis has already had a massive success with an ASO for a childhood form of motor neuron disease, called spinal muscular atrophy (SMA). Children in the SMA clinical trial in 2016 did so well that the trial was halted early, so that every child receiving the placebo could instead receive the drug. Ionis' SMA drug, nusinersen (Spinraza™), was quickly approved for prescription in many countries, and is now being given to children with SMA around the world.



There was more good news for familial MND in January, when Pfizer paid US$12 million to Sangamo Therapeutics for a different potential gene therapy.

Sangamo's therapy uses 'zinc finger protein transcription factors' (ZFP TFs), which are proteins engineered to bind to a particular DNA sequence, and can maintain or turn off a gene's production. Sangamo and Pfizer plan to develop ZFP-TFs that can differentiate between the faulty C9ORF72 gene and a normal one, preventing only the mutated C9ORF72 gene from generating its faulty protein.

It's encouraging when a major pharmaceutical company sees a potential MND treatment as a good investment. The ongoing large-scale investment by Ionis, Roche and Pfizer in these gene therapies for MND gives us hope that treatments for familial MND will be developed in the coming years.

To allow New Zealanders with MND to access these therapies once they are clinically available, their genetic status must be known. Dr Emma Scotter at the Centre for Brain Research, University of Auckland, is planning a study testing people for both common and rare MND-causing genes. Dr Scotter's group have recently shown that MND is more common in New Zealand than in other countries, but it isn't clear whether our high rate is due to genetics. The planned study will answer this question while also paving the way for New Zealanders with MND to be connected to appropriate gene therapies. Recruitment for the study opens in late 2018.

Rates of MND in New Zealand – an update

> *The proportion of people in New Zealand who die from MND is higher than any other country we examined.*

The lifetime risk of developing MND is 1 in 300.

The number of people who get MND per year is 1 or 2 per 100,000 people.

These are numbers you have likely heard before, but they come from overseas studies and not from New Zealanders with MND. So how many New Zealanders really have MND and how many people can we expect to develop it over a given time frame?

We at the Centre for Brain Research used the cause of death listed on death certificates, compiled by Statistics Aotearoa, to answer the question of just how common MND is in New Zealand.


JESSIE CASSON

Dr Emma Scotter

We found that that the proportion of people in New Zealand who die from MND is higher than any other country we examined. While the average rate elsewhere is 1.67 deaths from MND per 100,000, New Zealand's rate is as high as 2.8 deaths from MND per 100,000. While the difference may not seem great, it means that our previous estimate of around 78 people lost to MND per year in our country should be revised to 131.

In Māori, the rate is about half that of the rest of the population, suggesting that Māori may have protective factors for MND – or that there are healthcare disparities that reduce the number of Māori with MND who are diagnosed appropriately.

MND is a disease seen more frequently in older people, so all of our calculations took aging into account.

Overall, we analysed data from 2264 people who had died from MND between 1992 and 2013. Our other key findings were that MND caused the deaths of 1.5 times more men than women, and that most people who died from MND were aged between 80 and 85 years.

We conducted this study as a foundation for our own research on changes in brain cells and brain tissue in MND, and to aid research by others around the country to whom we are connected through the NZ MND Research Network. Together we believe we can learn why people in New Zealand develop MND, help in the search towards therapies, and champion for people in New Zealand with MND to have access to such therapies.

Dr Emma Scotter, Head of Motor Neuron Disease Research Lab, Centre for Brain Research, University of Auckland

Reference. Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration journal, 2018; 1-9; Maize C. Cao, Andrew Chancellor, Alison Charleston, Mike Dragunow & Emma L. Scotter

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

MND Registry News

We are very pleased to report the new New Zealand MND Registry now has a total of 114 participants. We are most grateful to everyone who has enrolled and to MND New Zealand for all their support to make this happen.

In February, information about the Registry and enrolment forms were sent to all MND New Zealand clients, to introduce the Registry and explain its purpose.

If you had already enrolled, you may have received these forms again due to the privacy of your information within the Registry, so please excuse this double up.

Kerry Walker

Since it launched in May last year, the Registry has already facilitated our participants' enrolment into four research studies. These include a study into swallowing training at Canterbury University, a project investigating the use of brainwaves to control functions of a computer, and two online studies. We have more studies in the pipeline for this year.

In March, the Registry attended the Australasian MND Symposium in Melbourne to learn about research currently being run in Australia and what is coming up. We are now working to get a slice of the pie for NZ MND Registry participants.

If you are interested in enrolling in the Registry, or have any questions, please get in touch by email: mndregistry@adhb.govt.nz or phone: 0800 MND REGISTRY

NEW ZEALAND
MND
REGISTRY


CC0 PUBLIC DOMAIN

Tough to swallow

Research on therapy that may improve swallowing and quality of life for people with MND is underway at the University of Canterbury.

Following pilot research led by speech-language therapy researchers Paige Thomas, Emma Burnip and Professor Maggie-Lee Huckabee, a University of Canterbury study is now recruiting people with MND. This research will continue to build our knowledge regarding skill training for swallowing, and the potential for swallowing rehabilitation.

A reduction in swallowing safety can have major negative impacts on the life of a person with MND. It can affect a person's sense of self, ability to participate in family and social engagements, and ultimately lead to serious adverse events such as lung infections.

Until recently, little research had been done regarding rehabilitation of swallowing for people with MND. This stems from an outdated belief that exercise would have a negative impact on muscles. Recent literature shows this is not the case. The right therapy may be beneficial for delaying or reducing symptoms of swallowing disorders in people with MND.

How to participate

To participate in the study, you must have a diagnosis of MND and early indications of swallowing impairment. You must be able to attend assessment and therapy sessions in Christchurch. Among other things, assessment involves drinking a glass of water and eating a dry cracker, so you must be able to do this at the onset of therapy.

After an initial screening and assessment period, therapy will be provided over two weeks, for one hour per day, five days per week. This will be followed by two weeks of no therapy to determine whether any effects remain after the therapy stops.

Eligible participants will be reimbursed for travel costs with a petrol voucher.

Due to the limited number of possible participants in Chrstchurch, the study will also be recruiting participants in the US. Paige Thomas is currently working towards her PhD at Colombia University in New York.

If you are interested in participating, contact paige.thomas@pg.canterbury.ac.nz or register with the New Zealand MND Registry to be notified about this and other research participation opportunities (mnd.org.nz/registry)

Thank you, Walton Railton

MND New Zealand would like to acknowledge and thank Tauranga accounting firm Walton Railton for their support over the past decade.

Our close relationship with Walton Railton began thanks to our former life member and treasurer, Michelle Knox (pictured), who sadly died in 2016. Michelle was a chartered accountant and had been a director at Walton Railton. In September 2013 Michelle was diagnosed with MND. She continued to be involved with MND New Zealand during this tough time and we were grateful for the ongoing accounting service provided by her friends and colleagues at Walton Railton.

MND New Zealand has recently transferred our accounts to online accounting system Xero. We thank Walton Railton director Elizabeth Murphy and accounting manager Michelle Stimpson for supporting our move to this next phase. We've really valued the relationship and accounting support provided by the team at Walton Railton.

President's Piece

Tēnā koutou e hoa mā.

When I was recently emailed a scanned copy of our first newsletter, published in May 1985, I was reminded of how our Association (or the 'MND Society', as it was known then) was started. Although the driving forces were people with MND and their families, it was their friends, and friends of friends, who made it possible by contributing their energy and skills.

In this respect, very little has changed over 30+ years.

We are still a diverse group of people, united by our common determination to provide support for people with MND, to create public awareness of the disease and to contribute to research. And today we still rely on help from friends.

The success of our Walks 2 D'Feet MND exemplifies this: their success is due to the friends, and friends of friends, who come out to show their support. Our 2017 Walks really demonstrated the breadth of that support, with 17 communities holding an event. As an Association reliant on fundraising for our core income, we need all the friends we can get. A huge thank you to everyone who helped.

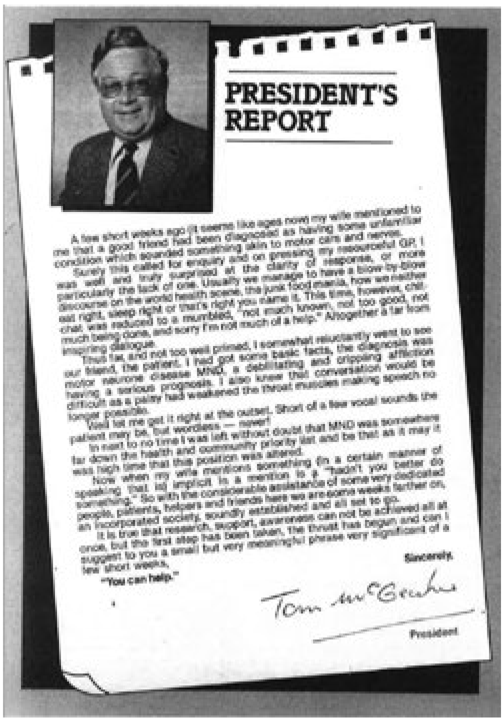
One exciting outcome from the 2017 Walks has been the decision to employ a second Support Worker in the South Island. It has long been our wish to extend our Support Service.

As Tom McGeachie, our first president, said: "It is true that research, support, awareness can not be achieved all at once but the first step has been taken."

I feel proud of the strides that we are making today.

I welcome new friends to the MND New Zealand senior leadership team too. I am delighted to welcome Carl Sunderland to the permanent role of General Manager. Carl won this restructured full-time position from a strong field. After working with Carl for six months in an acting part-time role, I am aware of the skills he brings and I look forward to further strides ahead for MND New Zealand. Carl has recently recruited Toni Foster as Support Team Leader and I welcome her too.

On Council I welcome Greg Horton and Steve Green. Greg has MND, is a partner in a law firm, and is a director on many Boards including Team New Zealand. He brings a wealth of skills to us. Steve has had a varied and successful career, having worked all over the world. He now runs his own business. He recently shared the care of his brother who died with MND.



PRESIDENT'S REPORT

"You can help."

Sincerely,

Tom McGeachie

President

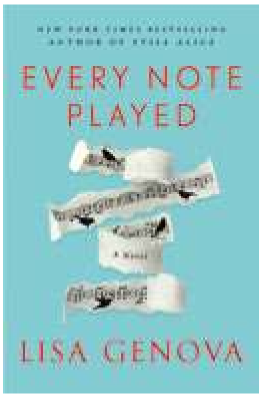
Not only do we as an Association rely on friends, but every family affected by MND needs the support of friends too – friends to help with tasks, friends to sit with you, friends to share your fears, friends to laugh with. Friendship is powerful. Has your family asked your friends for help recently? Have you offered to help your friends recently? To quote Tom McGeachie again, "You can help."

Nō reira, tēnā koutou, tēnā koutou, tēnā koutou katoa.

Beth W

Beth Watson

BOOK REVIEW



Neuroscientist Lisa Genova is the bestselling author of **Still Alice**, whose novels raise awareness of neurological diseases through engrossing and heartfelt storytelling, compelling characters, and the most interesting scientific details.

Her latest novel, **Every Note Played**, explores MND, telling the story of an acclaimed concert pianist, Richard, who is diagnosed with ALS at the height of his career.

Richard's biggest regret isn't just the loss of his ability to play, but also the loss of his wife and daughter, both of whom were driven away years earlier by his infidelities and single-minded career focus. In the time he has left, he needs to try to forgive and be forgiven by the people he loves most.

When Richard can no longer manage alone, his ex-wife Karina becomes his reluctant caretaker, and they try to reconcile their past. Genova creates a realistic depiction of MND, marriage and the process of dying in this compassionate exploration of regret, forgiveness, freedom, and what it means to be alive.

Carl's Corner

It certainly has been a hectic first six months for me at MND New Zealand, but what an awesome introduction to this fantastic organisation. I can now proudly call myself MND New Zealand General Manager, and am looking forward to the opportunities and challenges ahead.

Just a few of the highlights for me so far, and there have been far too many to list, have been attending the most successful Walk 2 D'Feet MND in Auckland (over 1300 people in one small New Lynn park), the appointment of two amazing new staff (Hayley, our new Office and Accounts Administrator, and Toni our new Support Team Leader), and the recent Australasian MND Symposium in Melbourne (which was so empowering for all who attended, with so much new and encouraging global knowledge on all things MND to bring back to New Zealand).

Your continued commitment to the annual Walk 2 D'Feet MND has blown me away. For such a small organisation, this is a prime example of how we fight well above our weight. It is only through your continued support and participation that we have been able to use the funds raised to grow our support service and to further develop our New Zealand MND Registry and Research Network.

However, there is so much more we need to do. We must keep growing the Walk 2 D'Feet MND as our major annual fundraiser, and I look forward to seeing even more people taking part this year on Remembrance Sunday, 11 November, in even more regions all over the country.

Over the past few months we have been meeting our commitment to advocate on behalf of the MND community through making submissions to Select Committees on the End of Life Choice Bill and Misuse of Drugs (Medicinal Cannabis) Amendment Bill. We look forward to hearing the decisions made by Government on these important issues.

We have also been working strategically on how we can all best work together to ensure we best represent and support New Zealand people with MND, their families and whanau.

As an organisation, it is imperative that the New Zealand MND community is central in all we do. Please see the box below for our 2018 priorities, set with this in focus.

We will continue to invest in and keep abreast of national and international MND research, but we are also firmly committed to helping people with MND access world-class support, care and representation. I look forward to continuing to achieve this together.

Take care of each other.

All the best,

Carl

Carl Sunderland
General Manager

Three priorities for early 2018

We have identified three priority initiatives for the first half of 2018 that you, our MND community, can assist us with.

1. As a small organisation, we put huge value on the many volunteers who work tirelessly on numerous regional projects. We have been working with our four regional branches to produce a more flexible nationwide model, so that anyone who wishes to be part of 'Team MND New Zealand' can do so, in any way they wish (see page 9). We ask that anyone who wishes to form an MND Community Group please get in touch.

2. Over the next two months we will conduct the 2018 MND Stakeholder Survey to ensure that we 'get it right' in developing our focus, strategies and commitments over the next five years. I ask you to please take the short time to participate in this online survey when we email you. It's a great opportunity to be part of our development.

3. Our Australian sister MND organisations often use the phrase, "Until there is a cure, there is care". I like that. This year, MND Awareness Week (18–24 June) will highlight our Support Service. This annual campaign week belongs to you and I urge you all to please get involved by getting your family, friends or colleagues together for a Cuppa Tea for MND.

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.

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Email: teamldr@mnda.org.nz

Gilly Noon
DHBs: Northland, Waitemata
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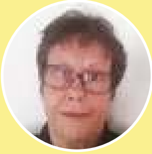
Email: northfieldwork@mnda.org.nz



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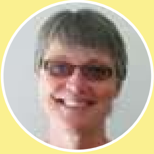

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Patron: The Hon. Ruth Dyson MP

Medical Patron: Professor Sir Richard Faull

Honorary Medical Advisor: Dr. Andrew Chancellor

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

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Treasurer: Lucy Haberfield
Councillors: Andrew Pardoe-Burnett, Fiona Hewerdine, Tony Treloar, Anna Chalmers, Greg Horton, Steve Green

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 post, 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.

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.

MND NEW ZEALAND FUNDERS

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

- Vasavour Charitable Trust
- Iris & Eric Nankivell Charitable Trust
- Louisa and Patrick Emmett Murphy Foundation
- Silicon Valley Community Foundation on behalf of Liquid Sky Vineyards Charitable Fund

Get your team together for a

Cuppa Tea for mnd

New Zealand

Join us for a cup of tea and raise money to support people with Motor Neurone Disease. **MND Global Awareness Day is June 21st** and people all around the country will be sharing a Cuppa Tea for MND.

MND Awareness Week
18th - 24th June, 2018

For more information email **fundraise@mnda.org.nz** or call **MND New Zealand on 09 624 2148.**

For information on MND and donations please visit www.mnd.org.nz