ISSN 2357-173X SPRING 2018

mndnews

NEWSLETTER OF THE MOTOR NEURONE DISEASE ASSOCIATION OF NEW ZEALAND INC

www.mnd.org.nz

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mnd New Zealand

The power of connection

Walk 2 D'Feet MND, Sunday 11 November

Our annual Walk 2 D'Feet MND is being held nationwide for the fourth time on **Sunday 11 November**. Please join us by registering today at **www.mndwalk.org.nz**

As you know, MND can be very isolating. The Walk 2 D'Feet MND events powerfully show people they aren't alone. People from all walks of life find strength together, united by their experiences with MND. By walking we also create hope for others, by fundraising for research. Fundraising from the Walk 2 D'Feet MND in the past has led to the establishment of the New Zealand MND Registry, the New Zealand MND Research Network, and a report on the use of medicinal cannabis for people with MND.

We hope that you will join us to walk and fundraise this year. If everyone who walks fundraises $100, together we will raise over half a million dollars!

***Register today at* www.mndwalk.org.nz**

Tattoo for you?


DESIGNED BY TOM TOM, SUNSETTATTOO.CO.NZ

Cornflowers are the international symbol for the resilience shown by those affected by MND. In April, we asked our Facebook community if anyone had a cornflower tattoo – and we were astonished by the response! At least ten people who follow our Facebook page (www.facebook.com/mndanz) have a cornflower tattoo to commemorate the person with MND they love, and many more were planning to get one.

Sisters Paige and Taylah West have matching tattoos to show their admiration for their dad who has MND (pictured right). Noelene Paikea has a cornflower and ta-moko tattoo. The design was commissioned by her husband, who had MND, and who sat with Noelene while the tattoo was being done. She added the dates after he passed (pictured far right).

This inspired us to have a temporary tattoo designed for this year's Walk 2 D'Feet MND. The cornflower tattoo design (pictured left) was generously donated to us by Tom Tom of Sunset Tattoo (www.sunsettattoo.co.nz), one of Auckland's most in-demand tattoo artists.

Buy your temporary cornflower tattoo from your local Walk 2 D'Feet MND on Sunday 11 November for a gold coin donation. Register at www.mndwalk.org.nz. We can't wait to see photos of your temporary tattoos at the walk!

Email photos of your cornflower tattoos (temporary or permanent!) to comms@mnda.org.nz


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Share your story

Do you have a story to share about your experiences with MND?

We invite you to help raise awareness about MND and its impact on New Zealanders by sharing your story when the time feels right.

Your story may assist us in various ways. It could help us write more powerful funding applications, help us advocate for the rights of people living with MND, help us raise public awareness of MND, and help other people with MND and their families know they are not alone in their experiences.

To read others' MND stories, go to www.mnd.org.nz/yourstories. To share your personal experience of living with MND or loving someone with MND, go to www.mnd.org.nz/share or email comms@mnda.org.nz

New books!

We have four new publications that contain helpful, practical information for people with MND and those who support them.

- **Living with MND: Aspects of care** provides an overview of MND and symptom management, aimed at people with MND, their family and friends.
- **Living with MND: Day-to-day** provides strategies for living at home with MND, more in-depth information and day-to-day tips for people with MND, their family and friends.
- **Aspects of Care: For home and community care teams** is aimed at home and community carers assisting someone with MND.
- **Aspects of Care: For staff of residential care facilities** is aimed at staff of rest homes who care for someone with MND.

Find the Aspects of Care publications in the 'Support For Carers and Family' section of our website (www.mnd.org.nz/for-carers), under 'Helpful Publications'. These books can be downloaded as PDFs but cannot be printed. We have applied for grants for printing these books and will have copies with the Support Team as soon as funding comes through.

Bless ewe, Smedley Station shearers

We were blown away when three farmers from Smedley Station in Hawkes Bay told us they were planning to shear sheep for 24 hours straight, to raise money for MND New Zealand and the Hawkes Bay Rescue Helicopter.

We were even more blown away when the fundraising result came in – the 24-hour shear-a-thon raised a grand total of $16,760 for MND New Zealand and the same for the Rescue Helicopter. Talk about raising the baa!

The three farmers (who don't even consider themselves shearers) deserved every donation that came their way. Working for 24 hours straight, Rob Evans (Smedley Station manager), who recently lost his best mate to MND, shore 687 sheep, Shane Bouskill (fencer general) shore 666, and Ricky Bullock (block manager) shore 555.

Meanwhile, more helpers sheared a further 1917 sheep, making a total of 3820 sheep shorn. The Onga-Tiko Rugby Club manned the BBQ for 24 hours to keep everyone well-fuelled.

If you've never tried shearing a sheep, it's hard to comprehend what a massive effort this is. One sheep weighs as much as an adult woman. A study from the University of Southern Australia in 2000 found that sheep shearing is tougher on the human body than any other work that has been measured.

We would like to extend a huge thank you to Rob and Jenn, Shane and Joelene, Ricky and Leigh, and the Cadets and helpers that volunteered their time. You efforts are awe-inspiring!

Funding changes are coming

The Ministry of Health (MoH) is transforming its disability support system nationwide. Its aim is to ensure that people with disabilities and their families have greater choice and control in their lives by enabling them to be in charge of the funds allocated for their equipment.

In 2011 a group from the disability sector proposed reforms they called 'Enabling Good Lives' to the government. Ministers agreed change was needed, which lead to a team, including people with disabilities, designing a new system that was trialled in Christchurch and Waikato.

A new 'transformation system' has now been developed to completely change the existing disability support system. The new system includes a new funding model, which will give people with disability the opportunity to manage their own support funding. It also allows people the option to employ their own support workers directly, use a flexible contract with a support provider, or ask MoH to manage the contract.

The new system will be implemented in the MidCentral area (Palmerston North, Horowhenua, Manawatu, Otaki, Tararua) from 1 October with a 'try, learn and refine' approach. Decisions on the final model and expansion across the country will happen in 2020.

Useful links

www.enablinggoodlives.co.nz/system-transformation

tinyurl.com/mohtransform

www.youtube.com/enablinggoodlives

New faces at MND New Zealand

We are pleased to introduce two new support team members, filling the roles vacated recently by Jacqui and Gilly. We also welcome a new fundraising manager, as Claire Reilly moves to a community development role.

Sally King

Sally joins MND New Zealand after 15 years as a family coordinator for the Wilson Home Trust, supporting families who have a child with a disability. More recently, she spent 18 months as a grants administrator for the Children's Autism Foundation.

For fun and relaxation, Sally says she reads, walks, meditates, does yoga, and makes things with textiles and vegetable dyeing. "When the pots aren't used for dyeing, I love a nice meal and a glass of wine," she says. "Our family has been touched by disability, accident, injury, child death, MND and lots of love and kindness. I have learnt the value of care and support for the whole family. When there is a baton to pass, there is always someone to pick it up. I truly appreciate it when I am invited to walk alongside folk for a while. Whakawhetai ki a koe."

Sally is joining the MND New Zealand Support Team, supporting the Northland and Waitemata (north and west Auckland) communities.

Jane Kay

Jane is from South Africa where she worked as a special needs teacher for many years. She emigrated to New Zealand in 2006 with her younger daughter and was employed by Alzheimer's Waikato as an educator. Having had hands-on experience with family members with dementia, she was well equipped for this role and served as manager of Alzheimer's Waikato for a time. In 2017, Jane joined Hamilton Age Concern as part of the Elder Abuse Response team.

She has since shifted to Whakatane to be closer to all her New Zealand family who reside in the Bay of Plenty. She has a daughter, son-in-law and two gorgeous little grandsons in England, and a daughter in Whakatane. Jane is an animal lover, an avid reader and she enjoys walking and dancing.

She is looking forward to her role with MND New Zealand's Support Team in the BOP, Lakes, Tairawhiti and Hawkes Bay areas.

Kate Dalders

For the first time, MND New Zealand has a full-time Fundraising Manager, Kate Dalders. Kate is originally from the UK and has previously worked for British charities including Cancer Research UK, The Brain Tumour Charity and The Donna Louise Children's Hospice. She has been in New Zealand for about 15 months, previously working for the Child Cancer Foundation.

Kate then kindly worked with us as a volunteer until her work visa was renewed in September.

Kate will be very busy with the Walk 2 D'Feet MND for the next few months, then looks forward to developing new fundraising strategies and opportunities.

Kate says, "A lot of the charities I've worked for have been health support organisations. I love seeing the immediate impact of fundraising on support services, alongside the long-term changes that can be made through funding research. I'm looking forward to being part of this for MND New Zealand."

Kate will be based at National Office in Auckland, from Monday to Friday.

Walk 2 D'Feet MND – officially excellent

Congratulations to Claire Reilly and our volunteer Walk 2 D'Feet MND organisers, whose hard work has been recognised by the Fundraising Institute of New Zealand. We were delighted to win a Certificate of Merit for 'Excellence in Fundraising Events' at the FINZ Awards in May.

The judges said some lovely words about the award-winning 2017 Walk 2 D'Feet MND: "Not every charity is easy to raise funds for. This charity is such an example. This was an impressive extension of this national event, undertaken with few available resources. With steady growth in numbers attending, the event captured the heart of participants and attracted significant pro bono support. The event was also well organised with an extensive toolkit to assist event participant organisers."

©FERN MCAULEY

Capture a moment in time

Photographer Fern McAuley took this photograph of her grandmother, May Jenkins, on her last birthday before she died due to MND. It's a photo that is treasured by Fern and her family – and Fern wants to photograph others with MND, so their families can have their own cherished memento.

With support from her sponsors Olympus and Momento Pro, Fern hopes to provide each family with a print, and to compile the images into a book that would raise funds for MND support and research.

Fern says: "My nana is gone, I can't photograph her ever again, but I can photograph others, I can listen to and share their stories. I believe this project will make a difference."

Fern is able to travel throughout Southland, Otago and potentially Canterbury. Eventually she hopes to be able to travel nationwide.

If you have MND and wish to be photographed for this project, please email Fern McAulay, fernmcaulay.photography@gmail.com

Your Health Passport

A Health Passport is a booklet you can carry with you when attending hospitals, respite care or other providers of health and disability services. A Health Passport contains information about how you want people to communicate with you and support you.

You can get a Health Passport from your MND support team member, who can also assist you in filling it in if needed. Or you can download one from the Health and Disability Commission website (www.hdc.org.nz/disability/health-passport).

How to get the best out of your Health Passport:

- Complete it as soon as you receive it (don't wait till you have to visit a hospital)
- Remember to take it with you every time you visit a hospital
- Inform reception staff that you have a Health Passport when you go to a hospital
- Keep your Health Passport close to your bed when in hospital, and remind staff who work with you to read it

© MATT MCKONE

Summer holidays and MND – it can be done!

Holidays can be an essential way to recharge your batteries, particularly in times of stress or illness. Getting away from your normal environment and routines can really lift flagging spirits. It is possible to travel and have holidays with MND, with a bit of extra research and preparation

Being outside in New Zealand's beautiful natural environment is good for everyone. Spending time in nature is associated with lower blood pressure, lower rates of depression, and better mood. It's ideal for someone coping with the stress of a life-limiting condition such as MND – but the limited mobility that comes with MND can make accessing nature difficult.

When Merle Bradley was diagnosed with MND in 2014, she was determined to keep enjoying the outdoors – and she wanted to make it easier for others with MND to do the same. In March 2016, Merle volunteered to help the Department of Conservation and the Halberg Disability Sport Foundation undertake a wheelchair accessibility trial on the Abel Tasman Coast Track. The trial lasted three days and Merle and her family and friends covered 30km, testing three different off-road wheelchairs.

The trial gave the Department of Conservation (DOC) a greater understanding of the requirements of people who have limited mobility, and DOC has since changed its website so people can filter tracks that may be suitable for a wheelchair user (there are 50).

Halberg Disability Sport Foundation, Be Accessible and DOC are now developing Accessibel, a new app and website that contains accessibility information about New Zealand tracks, waterways and cycle ways.

DOC says that people with disabilities, with support, are known to have reached Mt Everest Base Camp and the summit of Mt Kilamanjaro, which inspires them to continue to work to make New Zealand's great outdoors increasingly accessible.

Merle's inspiration, enthusiasm and passion during the accessibility trial created lasting memories for the DOC and Halberg staff involved. Merle's contribution now drives their joint work to have more New Zealanders accessing our beautiful country.

Merle also worked with New Zealand inventor and engineer Peter Thompson to test and promote his ViMo wheelchair, designed for rough and uneven surfaces.

> *"I had been a fairly regular tramper, heading out about twice a year. I thought my tramping days were over, but the trial has given me confidence that I was able to get out on tracks."* – MERLE BRADLEY

She advocated for the Hokitika Lions and Rotary clubs to buy two ViMo chairs for the Hokitika i-Site, to be hired out to people wanting to explore the West Coast's accessible tracks.

Following her Abel Tasman Coast Track trial, Hokitika-based Merle completed most of the West Coast Wilderness Trail, the Mananui track, the Hokitika Gorge and sections of the Punakaiki Pancake Rocks. "I had been a fairly regular tramper, heading out about twice a year. I thought my tramping days were over, but the trial has given me confidence that I was able to get out on tracks," she said.

"I hope the West Coast will become a destination for people who want to have a great time and enjoy the benefits of being in the outdoors. I want as many people as possible to come to Hokitika and hire a ViMo wheelchair for $20 per day and enjoy the many accessible tracks Hokitika has to offer."

Sadly, Merle Bradly died due to MND in July 2018. We are very grateful for her work helping people with limited mobility enjoy New Zealand's outdoors.

Beach wheelchairs

Wheelchair users – did you know that wheelchair conversion kits are available that allow your wheelchair to work on sand? Beachwheels New Zealand (www.beachwheels.co.nz) sell wheelchair conversion kits that replace the back

Accessible accommodation

Many holiday choices can be made accessible with forward planning. Start with an idea of the destination and price range that appeals to you, then you can begin looking for accessible accommodation and activities to suit your needs.

Be Accessible (www.beaccessible.org.nz/find), Oyster Accessible Travel (www.oysternz.co.nz) and Access for All (www.access4all.co.nz) are online resources that can help you find accessible hotels all over New Zealand, plus accessible activities.

As these websites are for anyone with mild to major accessibility needs, we encourage you to click right through to the most detailed level of information available. Remember, 'accessible' can encompass non-mobility-related difficulties, such as visual impairment, so you'll need to check suitability for your particular needs.

For self-contained accommodation, Bachcare (www.bachcare.co.nz) lets you filter your search for holiday accommodation by disabled access. However, you will need to carefully check the photos and ask detailed questions to ensure a house is suitable for you.

You could also contact a disability travel operator like Ability Adventures (www.abilityadventures.co.nz) to organise your trip for you.

If you have problems walking, or are in a wheelchair, it's best to telephone ahead to find out what accessible facilities are available at the attractions you may visit. Be very specific about what your needs are. "Accessible" means different things to different people, so you will need to ask if there are ramps, hand rails next to the toilet, etc.

The bathroom of one of 6 accessible rooms at the Quality Hotel, Wellington (www.cqwellington.com)

wheels of your wheelchair with large 'balloon' wheels that work on sand and other difficult terrain. They are not cheap ($399) but if you're living in or visiting Auckland you can also rent the wheels from Beachwheels directly, 300m from Long Bay, North Shore.

Air travel

When flying in New Zealand, we have found Air New Zealand to be generally well prepared for passengers with limited mobility. Make sure you email Special Assistance (specialassistance@airnewzealand.co.nz) to let them know your needs.

All Air New Zealand aircraft are equipped with a special torso harness to provide additional support to those with torso weakness in the aircraft seat. You need to request this at the booking stage and on board the aircraft.

Some people with MND will need to confirm availability of the Eagle 2 Hoist. The airline has one available for Airbus A320 aircraft at Auckland, Wellington, Christchurch and Dunedin airports. The Eagle 2 Hoist is a clever piece of equipment that hoists a person up from their wheelchair, parked on the airbridge beside the entrance to the plane, and rolls you into the plane and down the aisle, then lowers you into your seat, and vice versa upon arrival.

You may also need to request a sling in size large, medium or small, or see if a special fitting for your usual hoist sling (if any) is required. You should also confirm the availability of two staff trained in the use of the hoist and sling.

If travelling internationally, you will also need to check with Special Assistance at Air New Zealand whether your destination airports have the Eagle 2 Hoist. In Europe, UK and the US, International airports are required by law to have available an "airport assistance" service – which involves two people who will physically lift the passenger from their wheelchair to their seat.

Read Air New Zealand's full guidance for passengers who use wheelchairs here: www.airnewzealand.co.nz/special-assistance-service-people-flying-with-wheelchairs

Our appreciation to Justin Toebes, who sadly died in August, for his input into this article.

Long distance travel

When considering long distance travel, it is essential that you contact the airline or holiday company before booking, to discuss your requirements and explore any limitations on the service they can offer. Be aware that for safety reasons, an airline may ask that a carer travels with you.

If you use a PEG, you'll need to check the airline will allow your supplies and food on board. If you're using NIV, check with the airline about a power supply and battery back-up.

Once you have made your booking, confirm your needs in writing. It's helpful to include a completed copy of ABTA's Checklist for Disabled and Less Mobile Passengers, to ensure that they have an exact record of your needs (www.abta.com/tips-and-advice/accessible-travel). Add this to a file of paperwork to take with you, along with copies of clinic letters, confirmation of diagnosis, and a list of medications.

You should re-confirm your needs again with the airline at least 48 hours before departure to ensure something has been put in place for you, especially if you are planning on taking your own wheelchair. Pre-notification is vital because without it you have no legal guarantee that you'll get the assistance you need on your journey.

If you are able to walk, we recommend requesting an aisle seat to make moving around the plane easier. Use the airport wheelchairs provided, even if you don't usually need one, because there are long distances between arrival and departure gates in some airports. In-flight, get up and move often, and move your feet and ankles often while seated to reduce the risk of DVT.

Having a 'worst case plan' can help you feel confident, such as what you'll do if flights are delayed, or you need to see a doctor while you are away. Get in touch with the local MND Association at your destination if you are not quite sure of what is available, before you leave home.

In-flight tips

- Wear compression stockings
- Drink plenty of water
- Take essential medications in your hand luggage (in case the luggage goes to Honolulu and you go to Sydney)

Travel insurance

We recommend people with MND use an insurance broker to find travel insurance when travelling overseas. This will give you access to more insurance options than you're likely to find yourself with a Google search. Brokers approach different insurance providers on your behalf, and are paid on commission from

USEFUL WEBSITES

Be Accessible **www.beaccessible.org.nz/find**

Access for All **www.access4all.co.nz**

Oyster Accessible Travel **www.oysternz.co.nz**

Ability Adventures **www.abilityadventures.co.nz**

Air New Zealand guidance for wheelchair users **www.airnewzealand.co.nz/special-assistance-service-people-flying-with-wheelchairs**

ABTA's Checklist for Disabled and Less Mobile Passengers **www.abta.com/tips-and-advice/accessible-travel** the insurance company (so their service is free for you to use).

A travel insurance broker will take some time to get to know your individual circumstances, as each situation is unique. Unfortunately, not everyone can be insured. Whether you are approved for travel insurance can depend on several factors, including how long you've had MND and your destination. Australian travel is more easily insured than travel in the US!

See your doctor

Try to get an appointment with your neurologist or respiratory consultant before you wish to travel, and before making any payment towards your journey or holiday. You may find it reassuring to see your doctor again nearer to the date of your travel, especially if your condition has changed. Ask for practical advice about any medical issues that may affect you when travelling, such as:

- how to manage your wider symptoms while you are away
- how to reduce the risk of a blood clot, known as deep vein thrombosis or DVT, if you are travelling by air
- what medication to carry in case you become ill, such as emergency antibiotics to take at the first sign of a chest infection (you'll also need to check that you will be able carry the prescribed medications into the countries you are visiting)

Solo travel

A personal story

This report comes from an experienced traveller who has been affected by MND for a number of years, yet has travelled solo, with his motorised wheelchair from the UK to Japan, North America, Europe and Australasia.

Travelling alone, while having advanced MND, and flying long distances is perfectly possible given a bit of thought and preplanning. Obviously, it would be a great help if someone can travel with you from door-to-door, but we don't often have the resources to finance an ideal situation.

You should declare your personal circumstances with your chosen airline at the time of booking to ensure that there are no unexpected barriers to a successful journey. Many airlines are unwilling to accept solo passengers who are unable to fasten their own seatbelt, leave their seat or evacuate an aircraft unaided, and may insist that such passengers are accompanied by someone who can help them. Similar restrictions may apply for passengers who need help with breathing, feeding, using the toilet or medication.

© MANUEL FABA ORTEGA / 123RF STOCK IMAGE

Someone who hasn't developed bulbar symptoms has a great advantage over those who have, they can ask for help and directions. Those who have speech problems might need to prepare some anticipatory cards in advance of their journey and carry a means of communication.

For any independent travel the journey breaks down into either three or four components:

- Getting from home to the airport, complete with luggage
- Making the flight itself
- Transfers, if the flight is not direct
- Getting from the airport to the final destination.

Friends or family can deal with the home end of the journey and likewise, the people you are visiting or holidaying with can deal with the other end of the journey. The tricky bit could be the actual flights and transfers in between.

With a bit of preplanning and consultation, airlines are actually very helpful for those who are disabled and they will be able to facilitate transfers, including handling the luggage. Normally you should give the airline as much notice of this need as you can, and can ask for pre-booked assistance to be listed on the ticket or itinerary. You should contact the airline at the airport 48 hours prior to departure to ensure something has been put in place for you.

The one thing that absolutely no airline will entertain is helping someone in the toilet. They will help someone to get from the seat to the toilet and back, but that will be it. If the person is unable to use his or her hands and arms to undo zips or buttons, they will have to resort to one or two possibilities.

In some ways, the simplest solution is to wear a heavy duty adult nappy or incontinence pants for the entire journey, despite the potential discomfort. This may be unappealing but it could work, especially if the person is careful to cleanse their bowels before setting out on the journey. The person would then not have to leave their seat at all except to change planes. Many people with MND have done this successfully.

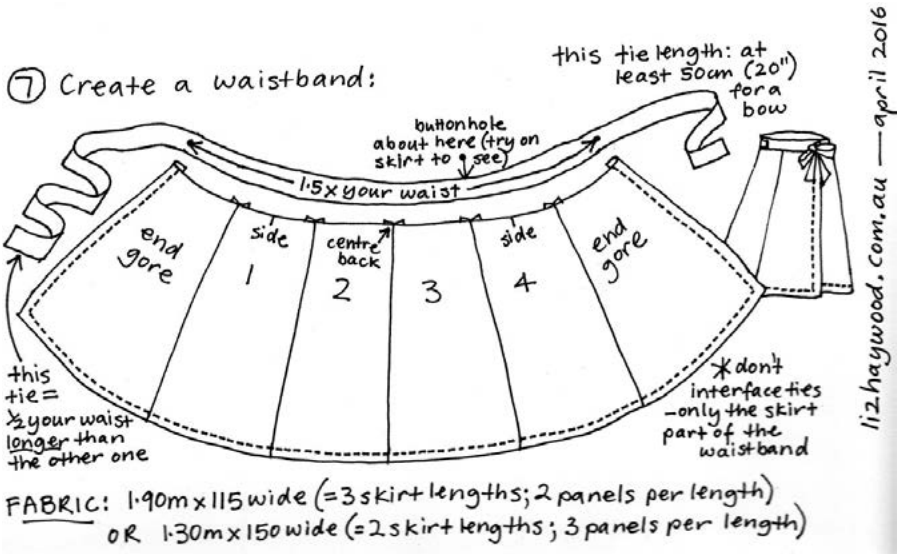
Another alternative is to wear what is called in the US a "Texas catheter": an externally fitted catheter which drains into a bag fitted on the inside of the thighs or calves. The downside is, of course, that until you reach your final destination you can't defecate and can only urinate, and people need to know you are wearing it if they are helping you to move. (So much for dignity!)

In-flight meals do not have to be an issue; adjacent passengers are often willing to help. This is where having adequate speech or an alternative communication strategy is pretty much essential. People, however willing, can be, understandably, a bit reluctant if they don't clearly understand what they are helping with.

A well-known Dutch gentleman, Jan, used to come to international MND meetings, travelling on his own. He couldn't speak at all but he could write copious notes in very good English so he didn't have an issue with asking for such help.

As for personal care and support when abroad: Contact a suitable agency at your destination, with the help of the local MND Association, and hire an aid to help with the personal things, morning and night. Australia, Canada and the US are quite well set up with this sort of thing, especially in the major cities. This strategy could be a very practical solution for a solo MND traveller, although there would inevitably be costs involved.

Your tips and tricks

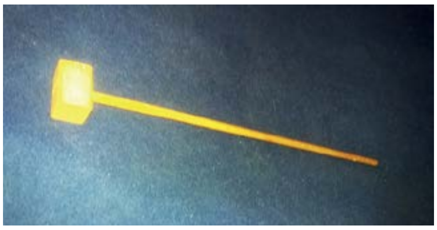


◀ David Seymour uses a bin attached to his walker to get jobs done around home, from helping build a gabion basket fence to talking out the rubbish and recycling.

David Seymour

▼ David Cook has created a few independent living inventions, including this "mini reacher" that lives beside the arm rest of his wheelchair. He uses it many times a day to push buttons on lifts and pedestrian crossings, turn light switches on or off, to scratch his head (and dog's belly!), push up his glasses, pull objects closer toward him, raise the rubbish bin lid, and to train his dog to pick up things for him.

David Cook



◀ Wrap-around skirts and neckerchiefs make life a little easier for my sister and her carers. I simply use a wrap-around skirt pattern and velcro at the two cross-over points at the waist.

To make a neckerchief I fold a square scarf diagonally to form a triangle and cut a pattern. I line the front part of the triangle with parka material (eg ripstop nylon) to make them a little moisture-proof.

Zena Smith

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

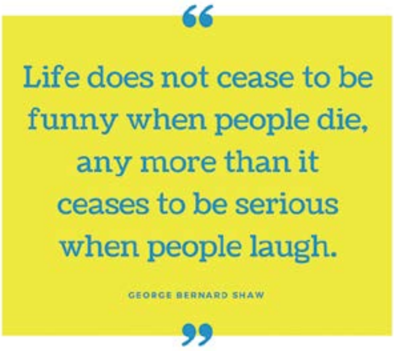
Email comms@mnda.org.nz

▲ This 'Uri Geller' magic on usual spoons has helped Peter in Tauranga maintain self-feeding. A family member who makes jewellery heated and bent the spoons. Peter can drape his fingers over the spoon without needing to use a fine pincer grip.

How to host a comedy fundraiser

On the 27th and 28th of July, Silvia Hodel and a friend ran a comedy weekend in Marlborough that raised nearly $13,000 for MND New Zealand and the Graeme Dingle Foundation. Silvia explains how they did it

My sister had been running comedy fundraisers for years, and they were always such a fun night with so many laughs – everyone always left happy. To me, a comedy night seemed fitting for a MND fundraiser. My sister was diagnosed with MND in 2016, aged just 40. MND is so horrible, debilitating and so very sad, I felt a comedy night was a good idea for lifting spirits and bringing some joy.


“Life does not cease to be funny when people die, any more than it ceases to be serious when people laugh.”

GEORGE BERNARD SHAW

I used the comedian contacts that my sister had, and I am happy to pass these on to anyone who would like to organise a comedy night (email admin@mnda.org.nz). I sorted a venue – or in this case, two venues – and set to work sourcing auction items and raffle items. I used the contacts I already had, and then I called and emailed other businesses asking for a donation and telling them what the money raised would be used for.

A few months out, it was time to release ticket sales. We did this through Eventbrite (www.eventbrite.co.nz). Then it was all about advertising the event through a Facebook page, posters, an interview with the local newspaper, and emailing everyone and every local business we could. We also did a ticket giveaway on The Hits radio station to the person who told the best joke.

After the event, we made sure we let everyone know how much was raised. Then we sent thank you cards to everyone who helped and the people who donated prizes, with a small message to let them know how thankful we were.

Silvia’s top tips

- Keep it simple, especially for your first event. We served platters of food, each item donated from a different local business, which took a lot of organising and time. Next time, I’ll keep the food very simple!
- It’s easier to organise one large event rather than two smaller ones.
- Don’t price people out of the event. Choose a target market and have your venue and prices aimed at this. We held two events; one venue was cheaper and in a less affluent area. Next time, I’d lower the prices for the event at the cheaper venue.
- Make sure you put the ticket purchase link on the posters and every email you send.
- Support your sponsors! Businesses hope for some good publicity in return for their sponsorship or donation, so mention them whenever you can, give them shout-outs on social media, and have their branding at the event and on posters and flyers.
- Donations and sponsorship is a numbers game: if you ask 100 business, you might get support from 20. Remember, businesses get hammered for donations all the time, so reply with a thank you even if they have said no!

Rally your support crew

When people in your life say, “Let me know how I can help”, it’s not always easy to know what to say, or when to ask for help. A new Kiwi website, Support Crew (www.supportcrew.co.nz), aims to make it easy to ask for help – whether it’s practical, emotional, social or financial.

You can create a private page for yourself or someone else, and invite the friends, family, colleagues and people in your community that you want on your journey with you. There are templates that assist you to ask for the help that you specifically need – without feeling uncomfortable. You can request help with meals, companionship and any other help you need.

It’s a great idea that will hopefully make it easier for more Kiwis going through tough times to ask for the help they need without embarrassment. Let us know if you sign up!

MND Awareness

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For international MND Awareness Month in June this year, we encouraged people to have a Cuppa Tea for MND. Thank you so much to everyone who held events, and all those who attended or donated.

Over 45 morning and afternoon teas were held all over the country – including in the Beehive! The campaign also raised over $27,000.

Event attendee Tania Balzat, who took the beautiful photos of the Birkdale Bubbly High Tea you see on this page, described the Cuppa Tea event she attended as "cathartic for all who are involved in running in these types of fundraisers. Friends and family feel that there is something they can tangibly do to show their support."

We were pleased to shine a media spotlight on MND during MND Awareness Month. Awareness matters to us, because as a newly diagnosed person, sharing your MND diagnosis is difficult – and it's much worse when you have to repeatedly explain the effects of MND to loved ones. Greater public awareness of MND lessens this burden.

Thanks to our creative agency Hound & Steed (www.houndandsteed.co.nz) for their generous pro bono work creating a video interview with Graeme Smith, who lives with MND in Christchurch (watch it at www.youtu.be/mAhoAfJParM).

Month – thank you!

We also alerted media to research published in January 2018 by the Centre for Brain Research (CBR) at the University of Auckland. Dr Emma Scotter, head of the MND Lab at the CBR, and her team had uncovered a surprisingly high mortality rate due to MND, showing that New Zealanders have the highest known rate of MND of any country in the world.

There was considerable interest in the story, with coverage by One News, the Sunday Star-Times, the New Zealand Herald and The Project on TV3. In total, these stories were seen approximately 2.5 million times.

We are very grateful to Graeme Smith, Kirsty Gerlach and Greg Horton for so generously sharing insight into their lives with MND during Awareness Month, and to Emma Scotter, for taking media interviews while on holiday.

If you would like to help raise awareness by sharing your experience of living with MND, please email comms@mnda.org.nz

The original Cuppa Tea

Jenny Brunton has been hosting fundraising afternoon and morning teas for MND New Zealand at Uraidla, her Doll and Teddy Bear Museum in Christchurch, for a couple of years. Jenny and her helpers host people from rest homes, community groups and Aged Concern for a small donation. In total, Jenny has raised over $6000 for MND New Zealand. Thank you, Jenny!

What is CRISPR?

CRISPR is a tool for gene editing, discovered just five years ago and now being used in labs all over the world in plants and animals. Progress towards using CRISPR to treat human diseases is moving fast. Human trials have already taken place in China, and 18 cancer patients are being recruited for a trial in the US.

CRISPR stands for Clustered Regularly Interspaced Short Palindromic Repeat. It's a pattern of genetic sequences in DNA that can be cut, replaced or edited by a special cutting protein. The most commonly used cutting protein is called Cas9, so when you hear or read about CRISPR, it's short for CRISPR-Cas9.

Gene editing within a living cell

A technique called CRISPR-Cas9 is one method of what is called genome editing, allowing scientists to precisely repair or modify genes in the quest for new ways to treat or prevent inherited diseases.

Guide RNA
Scientists customize RNA molecules to guide an enzyme named Cas9 to the correct spot.

Cas9
The enzyme precisely cuts DNA like scissors. The cell repairs itself or a new piece of DNA can be inserted.

© UNIVERSITY OF CALIFORNIA, BERKELEY

At least two biotech companies are trying use CRISPR to equip the body to fight MND: Locana and CRISPR Therapeutics.

CRISPR Therapeutics is collaborating with researchers at the University of Florida to test CRISPR strategies for familial MND, by deleting repeat gene expansions in DNA or blocking their transcription. "This could achieve a long-term solution to C9orf72 repeat toxicity." says Chad Cowan of Harvard Medical School, a co-founder of CRISPR Therapeutics. C9orf72 is the most common genetic cause of MND, accounting for 40% of familial MND.

Gene Yeo, cofounder of Locana and professor of cellular and molecular medicine at the University of California San Diego, is using CRISPR to target RNA, which transfers the genetic information stored in DNA, and can build up and make aberrant proteins that cause disease. Yeo and his team have modified Cas9 to leave DNA alone and instead bind to and remove problematic RNA. Yeo envisions that RNA-targeted Cas9 could find and destroy any repeat transcripts, such as those in the C9orf72 gene that can cause MND.

Editing RNA has several benefits over editing DNA: it eliminates much of the risk of altering DNA imprecisely, or with unexpected or undesired side-effects; and it opens up potential to recover function in almost any kind of cell.

Companies developing CRISPR technology have seen their shares skyrocket over the past year, and the global market for shares in these companies is predicted to reach US$10 billion by 2025. All that investment is great news for getting therapies to patients. The field is probably 5 to 10 years away from having CRISPR therapies for various diseases approved, say those working in the field. We hope MND treatments will be among those.

For more information, see tinyurl.com/crisprc9

Kiwi company develops blink-control tech

Thought-Wired is an Auckland-based company that is developing technology to allow people with MND to control a computer by blinking and thinking.

Last year 8 New Zealanders with MND were able to take part in a trial of this technology. The participants were all registered with the New Zealand MND Registry (www.mnd.org.nz/registry), which Thought-Wired approached to help them carry out their study.

In September 2017, Thought-Wired ran a month-long study in collaboration with 8 individuals (four male, four female, aged from 50 to 76) who had various types and stages of MND. Participants learned to use a communication app, where they could navigate to a specific word on the screen using blinking. Part of the research also included assessing whether participants could use their brain activity alone as a computer access method.

All participants could use the technology after the first training session, and were able to select the correct word with 100% accuracy. Participants could successfully use their brain activity as another computer control, but it was not as reliable as blinking and people found it tiring. However, the results showed the Thought-Wired team should continue researching the feasibility and accuracy of this option.

After this study, Thought-Wired hired two designers to help them transform the research prototype into a functional, commercial product called Nous. It is now available from www.getnous.app.

Australasian MND Symposium – our summary

Possibility of gene therapy

- Aim to cancel out effect of harmful mutation
- Four methods
  - RNA ablation (si or miRNA and RISC)
  - Immune reduction of protein
  - Transcriptional interference with small molecules
  - Gene editing (CRISPR/Cas9)

> *"It's a very exciting time to be involved in MND research. There's a lot of hope and positivity."*
>
> PROFESSOR MATTHEW KIERNAN, BUSHELL CHAIR OF NEUROLOGY, SYDNEY MEDICAL SCHOOL

The first Australasian MND Symposium, held in March 2018, was an in-depth, technical, fascinating glimpse into current MND research from all over the world.

We learned there are more therapeutic approaches being developed for MND than ever before, increasing the likelihood that new therapies will become available that provide a meaningful impact on the lives of people with MND. Several drug development avenues are being explored, and any one could have a big impact.

The current thinking is that, in future, those with familial MND are likely to be treated with DNA therapies such as CRISPR (see page 14) and antisense oligonucleotides (ASOs). Clinical trials have begun this year that use ASOs to treat the two most common genetic forms of MND (SOD1 and C9orf72). Researchers at the Symposium seemed extremely optimistic that successful treatments for these familial forms of MND may be found within the next 5 to 15 years.

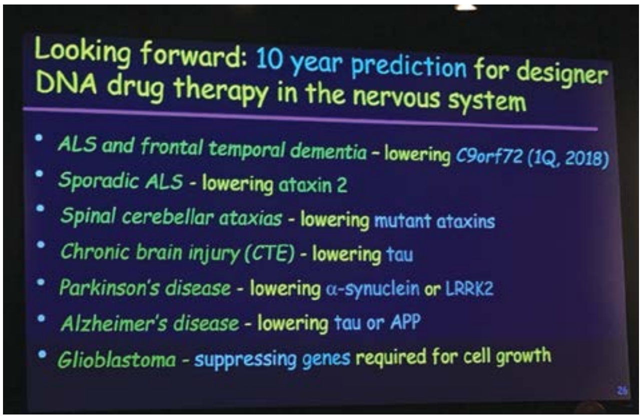
Researchers expect sporadic MND to continue to be separated into more specific sub-types, allowing people with sporadic MND to eventually be treated with very personalised medicines (an approach known as 'precision medicine').

There was a lot of discussion about why clinical trials for MND treatments have not been more successful. Frustratingly, 18 clinical trials have failed in the last decade. Researchers now understand they need to select more homogeneous groups of people for clinical trials, who share similar genetic factors, environmental factors, progression rates and patterns. And researchers are urgently working to identify biomarkers (eg in blood or urine) that reflect the underlying biology of MND, to ensure clinical trials can better measure their effectiveness.

MND is extremely complex but many researchers said they were more optimistic than they'd ever been. There has been an exponential increase in our knowledge of the basic mechanisms of MND, and knowledge is increasing at an extraordinary rate, especially in the last 2 or 3 years.

Professor Robert Henderson, University of Queensland, simply explained a current theory of the mechanisms of MND: "Whatever causes MND results in misfolded proteins, which triggers an immune response, which causes inflammation, which causes damage to functional cells. This cell stress leads to motor neuron death, which leads to motor function loss."

▶



Looking forward: 10 year prediction for designer DNA drug therapy in the nervous system

- ALS and frontal temporal dementia - lowering C9orf72 (1Q, 2018)
- Sporadic ALS - lowering ataxin 2
- Spinal cerebellar ataxias - lowering mutant ataxins
- Chronic brain injury (CTE) - lowering tau
- Parkinson's disease - lowering α-synuclein or LRRK2
- Alzheimer's disease - lowering tau or APP
- Glioblastoma - suppressing genes required for cell growth

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▶ Progress is also being made towards finding the cause of MND. We now know of 25 risk genes for MND, each of which increases a person's risk of developing MND by 5% to 10%. At the current rate of discovery, in four years we will have found 50 risk genes. These genetic discoveries give us a better idea of the pathways that should be targeted by drugs, including common pathways between genetic and sporadic MND.

Developing MND is now thought to be a multistep process where genetic risk and environmental factors accumulate over time until a threshold of disease is reached. Six of these steps are required for MND to develop (fewer for familial MND).

We have an incomplete understanding of these steps and how they cascade, because it's much harder to identify environmental risk factors than to find genetic risks. Environmental risk factors that many, but not all studies have agreed on are: smoking, trauma (eg broken bone, surgery), diesel fumes, exercise, being a war veteran.

> *"I'm really optimistic for the future for the next 5 to 15 years. It will lead to a cure."*
>
> PROF PAUL TALMAN, DIRECTOR,
> AUSTRALIAN MND REGISTRY

There was also some valuable research into MND care reported at the symposium.

Multidisciplinary teams (MDTs) are seen as one of the biggest advances in recent years. Research shows that people receiving coordinated care through MDTs live on average a year longer. "MDT clinics are the biggest advance in the treatment of MND," said Professor Jeremy Shefner of the Barrow Neurological Institute in the US.

Evidence also suggests that survival and quality of life is improved by early intervention with non-invasive ventilation. There is also increasing evidence that palliative care, when integrated into a multidisciplinary approach to care, leads to improved symptoms and quality of life in people with MND and their families.

For more in-depth information about current research towards a cure and understanding the causes of MND, see Research Resources at www.mnd.org.nz/research/research-resources

MND Research Network Update

On 30 and 31 August, 28 speakers and their audience gathered in glorious sunny Queenstown to participate in the Rare Genetic Diseases of the Brain Symposium, initiated by the New Zealand MND Research Network. This inaugural symposium was a break-out meeting that was part of the much larger Queenstown Research Week.

We were privileged to have people from the Neurological Foundation, PHARMAC, research scientists from Paris, London, Australia and New Zealand speak. We had sessions on molecular mechanisms, research resources, gene hunting, emerging therapies and an amazing key note speaker, Professor Chris Shaw from Kings College in London, to close the two days.

The MND Research Network goal of kanohi ki te kanohi/face-to-face contact of researchers in the field of MND research was met by this fantastic opportunity. We believe the conversations that started will lead to progress in MND research.

The New Zealand MND Research Network is funded by Walk 2 D'Feet MND donations. Thank you to fundraisers and donors, past and present!

Have you completed the ALS Quest?

ALS Quest is an online questionnaire run by Sydney University, looking at the possible causes of MND. People from all over the world are participating. There is a goal for 200 New Zealanders with MND to complete the questionnaire, and a further 200 healthy controls. This will give the data the statistical power to be useful for New Zealand.

So far, **44 people** from New Zealand have completed the questionnaire.

Anyone over 18 is eligible to participate – those with MND and those without. Every response helps international research into important areas, such as links between environmental toxins and MND.

The questionnaire takes about an hour, and can be done in multiple sessions. (If using an iPad or iPhone, change the Safari settings to 'Accept all cookies' before starting.) No personally identifiable information is requested, so your privacy is assured.

To fill out your questionnaire, please visit www.alsquest.org

President's Piece

The book launch of Ask Me About Merle in Hokitika was a fitting tribute to Merle Bradley

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Tēnā koutou katoa, ngā mihi nui ki a koutou.

More than 30 years ago, our Association formed to support people with motor neurone disease and connect them and their family and friends to others. This has been achieved in various ways over the years.

Our recent closing of the branches is part of this natural change. The success of our Walks 2 D'Feet MND and our Cuppa Tea for MND show our community is active and engaged in a different way. We extend a sincere thanks to those people with MND who have shared their stories to grow these events and public understanding of MND.

It is exciting that we have recently gone out to you, our community, to ask for your ideas and suggestions to guide us as we plan the future of MND New Zealand. With your input into our MND Community Survey I am confident that MND New Zealand will continue to provide meaningful and valued support.

I am heartened by the increasing public awareness of motor neurone disease. The Catholic Women's League of New Zealand has chosen MND New Zealand as its charity this year, and I was privileged to address their conference in July. In early August I was in Hokitika attending the launch of Merle Bradley's book (see below; Merle's effervescent presence was very much a part of the book launch). In mid-August I spoke at the Kapiti Rotary Club's meeting.

In late August I presented at the Rare Brain Diseases conference in Queenstown. I look forward to seeing our New Zealand motor neurone disease research community grow, and I thank Dr Emma Scotter for her leadership in this space.

As an aside, MND is not a rare disease by incidence (how often it occurs). It is the third most common neurological disease after Alzheimer's and Parkinson's. However, as people with MND often have a short life expectancy it is rare by prevalence (how many people there are in the community with the disease at any time).

It is with some sadness, but mostly excitement and great optimism, that I advise that this will be my last newsletter piece. After 11 years on Council, with 6 of those as President, I am stepping down at the AGM in October. I will continue on Council for another year. I am delighted that Lucy Haberfield, our current Treasurer/Secretary, has put herself forward for President. Council whole-heartedly endorses Lucy's nomination.

It has been a privilege and a pleasure to work with and for people with motor neurone disease. I have met many unforgettable people who have helped me grow and learn. I have been challenged and supported, saddened and gladdened. I tried to listen well. We have taken long strides together to grow our Association. I thank you for your work and your support.

Nā tō rourou, nā taku rourou, ka ora ai te iwi. (With your food basket and my food basket the people will thrive.) I am confident that the Association has an exciting future.

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

Beth Watson

BOOK REVIEW

Ask Me About Merle

Merle Bradley, the organiser of the Hokitika Walk 2 D'Feet MND in 2016 and 2017, wrote a memoir before she died due to MND in July. **Ask Me About Merle** is the story of Merle's life, from her childhood in South Africa, through her married life in Hokitika ("I started looking for a husband. I wanted to find a husband who had a foreign passport, clean nails and was a non-smoker"), to her later years living with MND. It is peppered with her tips for loving life.

The foreword by Yvonne Simpson, QSM, says: "Merle Bradley was a woman of vitality and a keen organiser. She was renowned for… encouraging and cajoling others to join her mission to be bright, fun-loving and sometimes outlandish… I am reminded by Merle to be upfront and ask; to think on the bright side; to live fully for now and have fun."

To order email president@mnda.org.nz ($31 including postage, all profits go to MND New Zealand)

Carl's Corner

My first 12 months as General Manager of MND New Zealand have flown by, and what a huge amount has happened over the last year. My main focus was putting foundations in place that will ensure a sustainable future for the organisation for many years to come.

In the last newsletter (Autumn 2018) I highlighted three priorities for early 2018. The 2018 MND Awareness Week in June was a great success, raising over $27,000 mainly thorough our inaugural Cuppa Tea for MND events. We also received great media coverage including a feature on TV3's The Project. A huge thank you to everyone who took part. We hope to build on this next year.

The MND Community Survey was sent out in August to over 4000 people with five versions available. A survey of this size was a first for MND New Zealand. It asked questions covering our five key purpose areas (information, support, advocacy, awareness and research) as well as questions on fundraising and general demographics. We had a fantastic response. Thank you to everyone who completed it.

The results will be available in October and will be used to help shape our strategic direction over the next five years. As the only organisation that represents and supports people with MND, their families and whanau in New Zealand, we want to ensure we are doing the best job possible. Only through your feedback can we get a better understanding of what we are doing well, what needs improvement, and what else we could or should be doing. (See below for further details on the survey.)

With the closure of our four remaining branches earlier in the year, development has continued on a flexible nationwide model to enable our community in all regions to meet, support each other, participate in events, and create fundraising activities. We have seen the creation of several new peer support groups and this year we have 18 Walk 2 D'Feet MND volunteer committees, which is outstanding. We will use the survey results to better understand what is required in each region, then continue with this community development over the next few months.

We sadly said goodbye to staff members Gilly Noon, Jacqui Drinkwater and Julie Hooper (all Support Team members), and most recently to Annabel McAleer (Communications Manager). A huge thank you to you all for your hard work and dedication, and all the best with your new endeavours.

Claire Reilly has left her role of Fundraising Development Manager, where she made an incredible impact on MND New Zealand by developing the Walks 2 D'Feet MND into our main income source. We look forward to Claire continuing to contribute to the growth of MND New Zealand in a new role working with our community.

We welcomed Sally King and Jane Kay (Support Team members), and Kate Dalders (Fundraising Manager) to the MND New Zealand team. I welcome you to the team and look forward to working with you and getting to know you better.

Finally, I want to thank all our supporters large and small. Without you we could not continue to support Kiwis and their families living with MND, we could not support health professionals, we could not advocate on your behalf, we could not raise awareness and distribute information, we could not encourage research, and we could not effectively fundraise the 92% of our operating expenses currently not funded by the NZ Government. We ask for your continued support and I look forward to working together for many years to come.

I hope to see you all at the Walk 2 D'Feet MND on Sunday 11 November!

Great work team, keep it up.

All the best,

Carl

Carl Sunderland
General Manager

The 2018 MND Community Survey

The survey opened on 15 August and closed on 10 September. **4687** people were directly invited to participate via email or by post. Five surveys were created, with people selecting the survey most appropriate to them:

1. Survey for people living with MND – 187 responses (a fantastic 70% response rate, thank you!)
2. Survey for people currently caring for someone living with MND – 190 responses
3. Survey for people who had previously cared for someone living with MND – 320 responses
4. Survey for healthcare professionals – 219 responses (42% response rate)
5. Survey for supporters (fundraisers, volunteers, donors etc) – 356 responses

The full survey results and report will be shared in October 2018 via the MND New Zealand website and social media, and work will start on 2019–2024 Strategic Plan in late 2018. The plan will coincide with the financial year and start from 1 July 2019.

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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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

Register to Walk

Please join us to Walk 2 D'Feet MND on **Sunday 11 November**. Buying your ticket early from **www.mndwalk.org.nz** helps our volunteer walk organisers plan their events, reduces queues and stress on the day, saves us admin costs, and saves you $5!

Don't wait to see what the weather is like on the day. We know that people with MND face huge challenges every single day – so we can endure a little rain or wind to show our support!

Walks are being held in 18 locations this year: Whangarei, Auckland, Hamilton, Bay of Plenty, Hawkes Bay, Taupo, New Plymouth, Whanganui, Palmerston North, Kapiti Coast, Wellington, Nelson, Blenheim, West Coast, Christchurch, Balclutha, Dunedin, and Invercargill.

Go to www.mndwalk.org.nz to buy your ticket – today!

Join the MND Registry

The New Zealand MND Registry connects people living with MND to researchers. If you have MND, we encourage you to enrol in the MND Registry. It doesn't matter if you are old or young, newly diagnosed or not, born in NZ or not... we want to enrol people of all ethnicities, from Cape Reinga to Stewart Island.

There are currently 145 people enrolled in the Registry. We aim to capture information about every single person with MND in New Zealand.

If one of your family members has had a positive genetic test for MND or frontotemporal dementia, you can join the Registry even if you have no symptoms of MND and have not had a genetic test yourself.

If you have questions, contact the Registry Curator, Kerry Walker: email MNDRegistry@adhb.govt.nz or phone 0800 MND REG (0800 663 734).
See www.mnd.org.nz/registry for more information and the enrolment forms