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mndnews

NEWSLETTER OF THE MOTOR NEURONE DISEASE ASSOCIATION OF NEW ZEALAND INC

www.mnd.org.nz



Cuppa Tea for MND

Join us for a cuppa tea and raise money to support people with Motor Neurone Disease.

MND
Awareness Week
17-23 June 2019



Supporting the motor neurone disease community



From the Chair & GM

It's been another busy 6 months at MND New Zealand which started with our AGM in Auckland. We thanked Andrew Pardoe-Burnett who stepped down from Council and welcomed Jodie O'Doherty. We also thanked Beth Watson who remains on Council but stepped down as President for her leadership over the last 6 years and a contribution that spans many more years. We were excited to present the 2018 David Beacon Oliver Award themed 'Working as a Team' to the MND Registry.

Sunday 11th November saw another fantastic turn out for the Walk 2 D'Feet MND in 18 locations all over New Zealand. We raised over \$220,000 for support and research, an amazing effort. A huge thank you to all our hard-working volunteers, our fundraisers and supporters, without whom this important flagship event could not happen. We look forward to this year's Walks on 10th November.

A huge amount of work has gone in behind the scenes to ensure that we get the best information possible out of the MND Community Survey. As reported in the last newsletter, we had a very high level of participation. Thank you to everyone who took part. It is greatly appreciated. We have contacted many people who asked us to get in touch with them directly and are sorry about the delay in releasing the overall findings, but we believed it was important to release the findings only when we had a clear idea of what we are planning to do about it.

It is important that we develop solutions together, so the whole team (staff and National Council) came together in Auckland on 1st March to go through the survey findings and

work on some priorities for the next 3 years. We value the feedback from our community, via the survey, as it helps shape our future direction. It was obvious from a very emotional start to the day how invested everyone in the team is in the organisation and the work we do. We want to use this passion and focus to strengthen our work moving forward. We generated many, many ideas, and identified several key priorities. These will shape our 2019–22 Strategic Plan. We hope to share the survey findings, together with our commitment to make positive changes, with you very soon.

Over the last few weeks we have successfully recruited and appointed a Support Team Member for the Upper South Island. This role will now be based in Nelson as well as working closely with the Canterbury DHB MND Clinical Nurse Specialist in Christchurch.

We are also proud to be co-funding a ground-breaking genetic screening study led by Dr Emma Scotter and Dr Richard Roxborough that's purpose is to understand the genetic cause of MND in New Zealanders. This study is due to start very soon and more details on the study and how to participate can be found on p17.

2019 is shaping up to be another big year for MND New Zealand and our community, we are fully committed to achieving more, and we will succeed if we continue to work together. He waka eke noa (A canoe which we are all in with no exception).

Kia kaha, Lucy & Carl

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mnd 
 New Zealand

A night to remember

New Council member Jodie O'Doherty fundraises for MND New Zealand.

On 3 November, I hosted an evening fundraising event in Wellington. Popular local singing group The BeatGirls was the main attraction for the evening. I enjoy running small events and am most comfortable raising funds this way.

I sold 130 tickets for \$50 per person which was great. Guests sang and danced the night away to their favourite tunes.

The event was BYO which made the organising side of things so much easier, as I didn't need to worry about a bar or licensing. I supplied cheese platters that were fully donated by Dunshea's Deli, Khandallah.

We had three live auctions thanks

to Myles Gazley from Gazley Mercedes Benz, Wellington and the Team at QT Hotel, Wellington. We also had a mirror photo booth thanks to MirrorMe Booth. With ticket sales, auctions, donations and small sales from the snack bar, we raised over \$6000.

I spoke about what MND is and how it affects those who have it, which is an important part of the event. It helps people to feel encouraged to donate and educates them about the disease. These events not only raise funds for MND New Zealand, they also raise awareness and community support. Another benefit from running events like this is that you

meet other people in the community who have also been affected by MND.

I am originally from Sydney but I have lived in Wellington with my husband and three young children for the past five years. Since my mum was diagnosed with MND, I have become more involved with MND New Zealand, arranging several events in Wellington. I am thrilled to be part of the National Council and hope to use my knack of developing partnerships and connecting people to further develop the organisation.

Jodie O'Doherty
MND Council Member



New Support Team Member



Hi everyone, my name is Elise and I feel privileged to be the new Support Team Member for the Nelson/Marlborough/

West Coast and Canterbury region.

My husband and I moved to Nelson about four and a half years ago and are just loving it here. For me it feels very much like 'coming home' as I was born in Takaka and spent many joyful summer holidays in the Nelson/Tasman region. Prior to moving to Nelson, I lived in Christchurch for nearly 38 years, the last 6 in lovely Lyttleton. With my, now grown up, children all living in Christchurch and

a new 'grandbaby' on the way, there will be an added bonus in regularly visiting Christchurch as part of my new role.

My work experience has been varied but I started as a speech and language therapist and special needs teacher. I then moved into health and social services as a health promoter, volunteer coordinator and manager for a range of large and small not-for-profits. My most recent experiences include working as a foundation skills tutor at Christchurch Men's prison and latterly as the Community Coordinator at Adult Learning Support Nelson where I was the first point of contact for adults wanting help with their reading, writing and maths skills.

I am passionate about NZ native flora

and fauna. My family know me as 'the crazy bird lady' and my husband Chris and I are currently working towards returning our steep 3000+ sq m section to native bush. Simultaneously we'll be trapping for rats, stoats and possums in the hope of providing a safe, bio diverse habitat for native birds spilling out from the fabulous Brook Waimarama Sanctuary. Apart from this my interests include pottery, interior design, and cycling whenever possible.

I really look forward to meeting and getting to know many of you in the near future and finding out how I can best be of help to you, your family/whanau and caregivers.

Support Team Member Elise Doyer



New Zealand Adventures in a V8 Mustang

David Seymour and his wife Rachel enjoy travelling the country in their 2015 Mustang. Diagnosed with MND in 2017, David continues to live life to the fullest. His adventures have taken him from the tip of the North Island to the bottom of the South. David talks to us about his travels.

Can you tell us about your Mustang?

Rachael and I bought our Mustang four years ago. It is the latest shape (2015) but is a left-hand drive model of which there are only about 10 in the country. What is there not to like? The 5.0L V8 and the comfort of modern motoring but in an all-time iconic American car. The colour is Deep Impact Blue and not that common.

When did you get into Mustangs?

Both of us have had an interest in cars, even long before we met each other. Rachael had always wanted a Mustang, so when the opportunity came around to own one, we took it. Over the years I have enjoyed a range of 'cool' cars. However, once we purchased 'JAC' (our Mustang) things got a whole lot more involved. Locally, we have an informal

group of Mustang owners, however, the formal club we belong to is the Auckland Mustang Owners Club. We get along to a few club outings now and then.

You said before that you and your wife have travelled from the tip of the North Island to the bottom of the South. Could you tell us about it and what did you pack to help you travel more comfortably?

Yes, we have. It was something I wanted to do as I've driven around the country a fair bit but never been the full length before. So how much better could it be than to do it in a Mustang? As a bonus, most of the trip was with a group of 16 or so other Mustang owners. We did the first leg to Cape Reinga with some friends. Then, we joined a group from Auckland to tour down south. We

were heading to the National Mustang Convention in Invercargill. This was in October 2017, over a two-week period to get there and back. Despite being a two-door sporty car, you can fit a fair bit in it including a fold-up wheelchair. Even though I was still walking at this point, the chair was a safety net in case I got tired or we had a lengthy distance to cover on foot (in my case in the chair). Of course, we had chilly bags and suitcases to fit in as well.

Most evenings, after being on the road for four to five hours, we gathered and had a few brews and nibbles, then would head down to a local eatery. This certainly was no race despite having fast cars in convoy; we would stop and take in the sights quite often.

In October 2018, we gathered the troops (12 Mustangs, most of which travelled to the deep south with us) and

hit the road again. This time we were heading to Napier for another Mustang convention. However, we took the far less travelled route around the East Cape.

We have also attended the Beach Hop event in Whangamata several times, and I went with a mate to Americarna in New Plymouth and hope to visit again this year.

Are there any fond memories about the trip that you'd like to share?

The good memories are just those of being with a group of very supportive like-minded people, having good laughs and plenty of high fives and hugs, along with enjoying a few drinks and many a good meal in their company. As a passenger, I really got to view and enjoy the country as we weaved our way around it. Probably the fondest memories of our travels to date is when we were up the top of East Cape and we all cruised alongside a beach at Te Araroa to admire our oldest pohutukawa tree. Next to the tree is a small rural school, and when the kids saw 12 Mustangs pulling over they just had to come and look. About 30 kids and their teachers and parents were in awe of this fine selection of cars. One of crew – Cameron – got out his bagpipes and played them a few tunes. Many of the kids had never heard the pipes before. The kids then, in return, did a haka for us. This stop, for us



and the school, was very cool and very special all round.

How was travelling for you?

I organised our 2018 trip. The key points for me at this point were accessibility and suitable bathrooms. Ground floor is essential unless the place has a lift. I called all the places we stayed to make sure these were booked correctly. We found a number of the Top Ten Holiday parks or similar are great value, and they cater for those in wheelchairs unlike a few of the older motels.

What would you say to someone who has MND and their partners, who are wanting to travel – especially the less adventurous types?

Do as much or as little as you feel comfortable with but do it sooner rather than later because we all know as time passes we are going to face more challenges with mobility. Call ahead and arrange disability units wherever possible. Don't be afraid to ask for help.

With our longer trips, we have had the good fortune to travel with a good group of people who were always checking on me and helping Rachael with luggage and the wheelchair.

Why is it important to get out and explore and continue being a part of clubs and organisations?



Social connection is important. Contact with other people helps keep me sane rather than being at home all the time. We have always been social people and so why stop. I only have MND; it's not contagious. We don't know how long we have before getting out and about is not going to be practical due to the MND issues.

We have always been keen to give back to the community where possible. It was a big part of our business strategies and success, plus we get a real buzz out of doing things within the community. When you get involved in things it's a way of having a positive vibe going on. The more the better!



Director of the Centre for Brain Research at the University of Auckland
Sir Richard Faull

MND New Zealand at Brain Day 2019

Over 150 people attended Brain Day in Auckland on Saturday 23 March. Presenters included leaders in the Neurology field, health care professionals, and community organizations.

MND New Zealand had a stand at the event to raise awareness of MND. Support Team Leader Toni Foster spoke with attendees and distributed the Facts about MND brochure to those who wanted more information.

An exciting interactive display area brought children of all ages over to look at how the brain works, and people filed in and out of the lecture rooms for various presentations.

Toni says 'It was a great day, which provided a good opportunity to talk with people who have been affected in some way by MND, and to health professionals working on this area.'



Share your story.

If you would like to share your story, poem or some great tips with us,
emailcomms@mnda.org.nz

Medicinal Cannabis Update

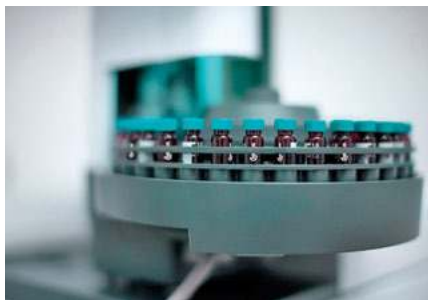
The Submission on The Misuse of Drugs (Medicinal Cannabis) Amendment Bill has been passed allowing for regulations to be written that will significantly improve patient access to locally-produced medicinal cannabis products. Additionally, while these changes are being made, people in palliative care can also access illicit cannabis without prosecution. This is a big win for people who are using cannabis to treat their symptoms and who have felt they needed to do so in the shadows for fear of legal action should they get caught.

MP Hon. David Clark says, "The creation of a statutory defence for people eligible to receive palliation allowing them to use illicit cannabis without fear of prosecution was a compassionate measure which recognised that it will take time for the development of regulations allowing for better access to legal and affordable cannabis products."

MND New Zealand submitted an amendment proposal which was included in the review. While MND New Zealand remains neutral on the topic of medicinal cannabis, it was in the interests of people living with MND and their carers that certain amendments be included to protect them legally prior to the bill passing into law.

So, what does that mean for you?

The bill removed the definition of 'terminally ill' as someone having 12



months to live and replaced it with more encompassing language to state people (no age restriction) who are needing medicinal and illicit cannabis for 'palliation'. 'Palliation' is defined as care which helps to make patients who have an incurable illness comfortable.

The bill also allows medical practitioners to determine how best to treat and prescribe relief to their patient.

However, in the 'possession and use clause' there is currently no reference to include carers and protection of carer rights, only for the person who is prescribed the medicine. David Clark says police use their discretion when it comes to personal possession.



Sativex, a medicinal cannabis mouth spray used by some patients with Multiple Sclerosis in New Zealand, can be applied for through their specialist. Sativex currently costs patients up to \$1200 per month. Parliament and the Ministry of Health are working with medicinal cannabis manufacturers like Helius NZ to widen the range and reduce costs.

Helius Therapeutics Executive Director Paul Manning says, "We have a large-scale, licensed facility in East Tamaki and we're preparing for rapid growth in this new industry. Our mission is to improve quality of life by producing high quality products, available to the local and international markets. By producing more and varied products, locally people living with chronic conditions will be able to readily access quality cannabis medicines, at a greatly reduced cost."

David says, "Ultimately, this legislation will greatly increase availability of quality medicinal cannabis products and will allow for their domestic manufacture. It will help ease their suffering by making a wider range of quality medicinal cannabis products available over time."

*If you would like to submit any comments to Hon David Clark: E: d.clark@ministers.govt.nz
P: +64 4 817 8709*

New MND online forum to replace KIWIIPALS

We are excited to launch our new MND New Zealand forum. The forum is an online community for people living with or affected by MND to share experiences and support one another.

This will replace the existing Facebook group KIWIIPALS and will be available on our website: mnd.org.nz

MND Community and Research Advisor Dr Claire Reilly lives with MND and has generously offered her time to moderate the KIWIIPALS group since 2014. Claire says, "KIWIIPALS was a great first step in providing people with MND and whanau with a place to connect with others in the same situation and provide each other with support."

"However, I always felt that we weren't reaching the vast majority of the MND community, and Facebook has quite a few limitations. I wanted a forum where people could benefit from the experiences of others without necessarily having to join.

The new forum will be available for all to view; if people want to join the conversation or comment, they will need to create a log-in. The forum has moderators from the MND New Zealand team to ensure safe rules are upheld to create a safe and supportive space for all members.

We ask our MND KIWIIPALS community to migrate over to the new

platform. The KIWIIPALS group will be closed by the end of April 2019.

Please note: The forum is not a substitute for professional advice. You should consult your doctor, or other relevant professional, before making any decisions that could affect you or others. This forum is open to anyone to read so please protect your privacy. We recommend creating a user name that's not your own name and only include information which can be made public. Remember that sharing your genetic information can have implications for you and your family members' privacy.

Any questions about the new forum please contact: Claire Reilly E: claire.reilly@mnd.org.nz



Whanau walk for MND

A true giver who has found joy in helping others in her whanau and wider community, Pauline Houia has found great care and support when she needs it most. Diagnosed with Motor Neurone Disease just last year, Pauline's whanau gathered to honour her by holding a walk in their community on 30th December 2018.

"Pauline has been an integral part of the Omaio community in Te Whanau a Apanui working with the kuia and koraua for many years. Not only has she been an exceptional wife and mother to her

tamariki, Pauline has been a big part of marae life serving her iwi and hapu," says her husband Danny.

Pauline was well known and loved by the young and old she's supported throughout the years.

As well as being a listening ear and giving wise counsel, Pauline has cooked, baked, served and washed up for her whanau. Pauline worked as a carer for Disabilities Resource Centre Trust for many years, assisting whanau who are unable to care for themselves.

To honour this hard working, caring

woman, the community in Te Whanau a Apanui arranged the walk in her honour. Those in Australia who know and love her arranged a fundraiser for her over the Tasman. Pauline had a motorised wheelchair but the road down to the community area was unsealed, rough and rocky. Nevertheless, she insisted on trundling down to join the whanau and she enjoyed every moment of the morning.

"This was indeed a fitting tribute to a remarkable woman. It is no wonder Pauline's whanau have come together for this awesome woman and surrounded her with the immense love and kindness that she has given to the whanau over the years," says Jane Kay, MND Support Team Member.

Pauline's diagnosis of MND in May 2018 came as a devastating blow to Pauline and her whanau. At her first meeting with the MND support team member, Pauline said that she wished other people with MND could be helped through her experience – ever the 'giver'.

Pauline thanks Seating to Go for the wheelchair and she thanks everyone for their support on this road of love, tears and anger. "May you find your peace when it comes," love, Pauline.

Pauline sadly passed away February 13, 2019. We thank Pauline's whanau for contributing to the article.

The TravelScoot – a mobile scooter solution

Greg Horton, MND New Zealand's Treasurer and Secretary, was diagnosed with MND in 2016. He has found a great way to keep his mobility when he is at work and travelling overseas.

As my mobility started to decline, my wife Shelley and I looked around for a



portable scooter – and, voilà! We came across the TravelScoot.

The TravelScoot is a lightweight compact electric mobility scooter. It fits easily in the boot of the car, in three pieces – the main scoot, battery and seat. The main body weighs about 12kg and is light enough for me to get in and out of the car, assemble or disassemble, giving me that all important independence. I ride it all around the Auckland CBD, and a key advantage is I can take it when I travel.

On planes, you can either ride it up to the door – and they will take it to the hold – or you can take a wheelchair at the airport and put the Scoot in its travel bag with your luggage. The battery goes with you in the plane, as carry-on luggage, and is accepted by airline authorities (with a

bit of documentation). My TravelScoot has been around NZ and as far away as Singapore and Botswana!

I bought my TravelScoot from <https://travelscootnz.co.nz/> which has a good deal of information. You can also buy them in some other shops where wheelchairs and scooters are sold.



Cuppa Tea for mnd

New Zealand



Join us for a cup of tea and raise money to support people with motor neurone disease.

**MND Awareness Week
June 17 – 23**

MND Awareness Week

What better way to show your support during MND Awareness Week this year than to host a Cuppa Tea for MND event? MND Awareness Week will be June 17–23.

Last year, 45 Cuppa Tea for MND events were held all over the country, including at the Beehive.

These special events are a great way for family, friends, colleagues and supporters to come together, share food and company, and raise awareness of motor neurone disease.

It is also a great way to honour those living with MND and commemorate loved ones lost to the disease, while raising vital funds to enable MND New Zealand to provide the best quality care and support to the motor neurone disease community.

MND New Zealand Fundraising Manager Kate Dalders says, “MND Awareness Week is an opportunity to raise awareness and educate people about motor neurone disease. Hosting a Cuppa Tea for MND not only raises awareness, but also raises vital funds which enable our Support Team Members to continue providing support to people with MND and their families nationwide.”

If tea isn't your thing, it's not a problem. As an alternative, why not host a sausage sizzle, gather at your local café, or host a high tea, lunch, or cheese and wine evening? As a host you can ask for donations which can be collected on the day, or set up an online fundraising page by visiting our website.



Support team members provide free, personalised support and advocacy for almost every person with motor neurone disease in New Zealand, from Stewart Island to Northland.

If you have any questions about MND Awareness Week, hosting or donations, contact Kate: kate.dalders@mnd.org.nz



You raised ov

Walk 2 D'Feet 2018

MND New Zealand was proud to hold its fourth annual Walk 2 D'Feet MND event series on Sunday 11 November, 2018. Beginning with just one Walk event, held in Christchurch in 2014, the event series has now grown and was held in 18 different locations across the length and breadth of New Zealand. Thousands turned out in support of their loved ones living with MND and to commemorate those they have lost.

All around New Zealand, adults, children and dogs dressed up in blue and white outfits and face paint and fundraised to continue nationwide support and advocacy for people living with MND and their carers. The Walks raised over \$200,000 in aid of MND New Zealand.

GM Carl Sunderland says, "The 18 Walks 2 D'Feet MND could not happen without our huge team of dedicated volunteers all over New Zealand who organise and run the events. MND New Zealand is extremely grateful for their hours and hours of hard work to ensure each walk is a success. Thank you to all of our MND volunteers."

These Walks are not just about the incredible amount of funds that are being raised for support and research in New Zealand, but also about generating a greater awareness of MND and seeing the impact of so many in the MND community coming together to show that we are united.

The New Zealand Walk 2 D'Feet MND will take place again in 2019 on Sunday 10 November.



Auckland – The sun shone on the country for Walk 2 D'Feet MND 2018

Tauranga Over 250 people in a sea of colours turned up to show their support for the sunny Sunday event. 60 dogs paraded in costume, and raffles and a silent auction, along with wheelchairs dressed up in blue and cheerleaders with pom poms, made the Walk 2 D'Feet MND in Tauranga a fantastic family friendly day.

More than just an annual Walk Leader for the past three years, Tanya Gilchrist has helped



© GRAHAM JONES

make Walk 2 D'Feet MND a community event. "I am passionate about MND. I started out not knowing how to organise an annual Walk, but we learned and with some support from the local Lions Club we could really organise the Walk effectively and build awareness in the Bay of Plenty region," she says.

Tanya's nana had MND and died in 1988. "I

remember how lonely it was; hardly anyone knew what it was or how to help. I want people to know they can get support, that we are here to help and for kids to also be supported after their parent dies," she says.

Tanya created an Education Fund specifically for the children. It is so important to support the children. A lot of

them are school age and when income reduces from the parent with MND, we want to make sure they can still attend school sports, after-school activities and class outings.

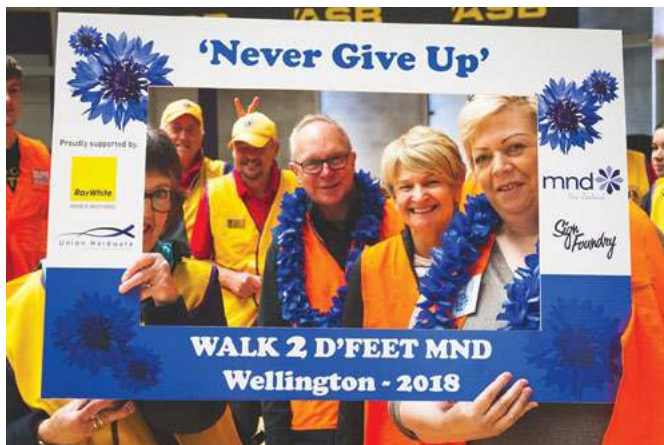
"Fundraising and the walk is about showing our love and support. We will show there can be joy through this and there can be a spark from the community where they can step up and make a difference," she says.

Tanya and co-organiser Richard Kluit encourage people to become Walk Leaders in their region. "Don't be scared that the commitment is too big. There are always people who are willing to help and will support your efforts; you only need to reach out."



Costumes galore in Wellington

Over \$220,000!



They never give up in Wellington



Chris Baird, Sarah Eddy, Carl Sunderland and Toni Foster

Former employer gets behind Chris Baird to help raise funds

A dedicated team member, Chris Baird spent 31 years working his way up to site manager through the meat and production manufacturer ANZCO Foods in Canterbury.

Diagnosed with MND late in 2017, Chris soon realised a lot of people did not know what the disease was or how it affected people. He was determined to promote awareness about MND and also wanted to take part in raising funds for the annual Walk 2 D'Feet MND fundraiser.

ANZCO Foods CEO Peter Conley and staff all got behind Chris. Peter helped to organise some amazing auction items including two Air New Zealand Mystery Trip giveaways, art, luxury household décor, food items and much more. The fundraising efforts of ANZCO Foods, friends and family resulted in more than \$60,000 of funds raised for MND New Zealand.

"Chris is an extremely well respected and highly valued member of our team. Since he was diagnosed with this terrible disease, as a company we've invested in supporting Chris's wish to raise money for research and increasing awareness of MND in general," says Peter.

Chris says, "I am humbled by the extreme generosity from my work colleagues, family and friends. It was amazing to see so many people support me and MND New Zealand. I was determined to raise funds for research and awareness about the disease because I didn't know what it was 12 months ago."



All dressed up in Christchurch



Face painting at Walk 2 D'Feet MND

Funded Family Care Update

A recent report surveying over 900 affected families and care organisations about the carer laws has been released with an overwhelming agreement for better pay, removal of the paid 40-hour-a-week cap and better rights for carers.

The unpaid work of carers has an annual economic value of more than \$7 billion NZD, making the Care Act review and amendment essential for carers to be recognised, paid and protected by law.

Background

The Funded Family Care policy was introduced in 2013 after successful court cases taken by some families who were not paid adequately for the care of their disabled family members.

This case highlighted the inequality of carers' pay, recognition for the value of their work and the ability to complain if they were not satisfied – and families demanded change.

In 2013, the then National-led government passed a law saying caregivers could not challenge the pay rates set by the Ministry, nor make complaints to the Human Rights Commission.

The Labour-led government has committed to review and amend the Act.

Disability Rights Commissioner Paula Torsoriero said it was great news. "It's discriminatory legislation that was passed into law in 2013 and it's a real opportunity to look at doing things quite differently and to afford the dignity that disabled people and their families deserve."

Survey Results

In summary, there was strong support to:

- Repeal Part 4A to allow paid carers to be family members, spouse and/or adult children. It also will repeal the clause preventing complaints from carers going to the Human Rights Commission and other language in the clause.
- Enable payment of spouses and partners of people eligible for Funded Family Care – a move towards a more inclusive payment scheme.



**Disability Rights Commissioner,
Paula Torsoriero**

- Receive equivalent pay to other care and support workers – fair pay for their work. It was agreed no one wanted to be paid 24/7, as the carers expressed they needed a break as well.
- Support for a simple process, with more choice and flexibility – there needs to be a more organised and

clear way people can apply to care for their loved one, not a one size fits all model.

- Change the terms of engagement employer status. There was consensus from those surveyed that most thought the disabled person with complex and high needs should not be expected to be the employer.
- Lower age restriction on payment for carer which is currently 18-years old. The survey shows an agreement with age 16 and over.

It is promising to see the current government willing to make the necessary changes to the Family Funded Care Act.

The Ministry of Health will take some time to review the results and make proposed amendments to the Act to incorporate what people have said in the survey and look at sustainable solutions.

Ministry and parliamentary members urge people to continue to engage with the process.

For more information on Funded Family Care please contact your MND Support Team Member.

"It's discriminatory legislation that was passed into law in 2013 and it's a real opportunity to look at doing things quite differently and to afford the dignity that disabled people and their families deserve." – PAULA TERSORIERO



End of Life Choice Bill Update

Having the right to choose assisted dying has become a global debate. Lobbying, submissions and protests have urged governments to look at current laws and work towards more compassionate policy around assisted dying and provisions to protect the most vulnerable.

Victoria, Australia made headlines in 2017 when it passed the Voluntary Assisted Dying Bill becoming the first state in Australia to pass this type of bill. The Australian Parliament spent 100 hours debating the bill which will come into effect in June 2019. This will mean Victorians who have lived a minimum of one year in the State and are terminally ill will have their case reviewed and can opt for assisted dying. A similar law was passed in Canada in June 2016.

New Zealand is now considering a law change with the End of Life Choice Bill, sometimes referred to as the 'Seymour Bill', passing its first reading on 13 December, 2017. The bill is currently being reviewed by the Justice Committee and is due to report back to the House of Representatives on 27 March, 2019.

Act MP David Seymour strongly supports the bill; he proposes limiting legalised assisted dying solely to people with a terminal illness and incorporate aspects of a palliative care bill drafted by National MP Maggie Barry. Some 37,000 submissions were made on the End of Life Choice Bill and the bill will need to allay concerns brought up in the submissions with a number of amendments still to be made.

David says, "We should have had an assisted dying bill 20 years ago. We give people more and more right to choose how they live, gradually empowering people, and this is one of the last areas in our lives where we do not have a choice on whether we live or die. As long as we are not hurting anyone else and having such a bill in place can alleviate a huge amount of suffering, then why would we not have one?"

While MND New Zealand's submission maintains a neutral position on the bill, it stresses the importance of ensuring that any rights created by the End of Life Choice Bill do not discriminate against people with MND and advocates for the increase of funding and improved access to palliative care.

MND New Zealand has also made

a request to change the terminology of 'talk' to 'communicate' in sections pertaining to someone telling a medical practitioner of their choice, and to include the words 'communication using assistive speech technology' to be inclusive of people who rely on this form of communication. At this stage the term 'talk' is still used on Clause 8 which outlines the various ways a person can ask for assisted dying from a medical practitioner.

MND New Zealand also recommends better palliative care for people in rural areas, more beds for respite hospices rather than private hospitals, inpatient services in small towns, and overnight nursing care.

When asked, David said, "This is a safety-first conservative bill. We will have in place the person needing to consent and two medical practitioners who would have to approve.

"There is a myth out there that palliative care and assisted dying are competing alternatives. Places like Europe with good palliative care does not change some terminally ill people still choosing assisted dying."



Act MP David Seymour

When asked about why he wanted to get the bill put into law he said, "I want to do work to help people. This is an obvious area of need that no one else is prepared to take on."

David speculates the bill will go to a vote in June and a result known by November this year.

If you want to get in touch with David Seymour
E: davidseymour.epsom@parliament.govt.nz
P: 09 522 7464

Care with Coins fundraiser

MND New Zealand proudly introduces 'Care with Coins'.

Collecting coins is an easy way to support MND New Zealand.

You could put a container in your office or on the counter of your local coffee bar. Ask us to send you a label to add to your container (the label is 21 cm long and 10 cm high).

Just add coins! When the container fills up, banking instructions are on the label to get those vital dollars put to good use funding support and research.

Please send us an email with your name and address and we'll get them out to you.

E: kate.dalders@mnd.org.nz P: 09 624 2148

Thank you for your support.



How can the MND Support Team help you?

Meeting the needs of people living with MND and their families and carers is a vital part of MND's mission. Our team of 8 MND support team members around New Zealand provide information, support and advocacy for clients, carers, whanau and the health professionals working with people with MND.

Support team leader Toni Foster shares on the diverse role of MND New Zealand Support Team.

Building relationships

For someone who is newly diagnosed with MND, we may be the first, second or third point of contact for this person or family member or we may become involved at a later stage. We feel privileged to be allowed to share this journey with the person with MND, their family and whanau, and to be invited into their lives. It is up to the person themselves to decide what this support looks like with regards to frequency and type of contact – face to face, email, text or phone call – and this may change throughout the journey. We are able to continue to provide support for family and whanau for as long as they would like us to be involved, and can help to link them with bereavement services.

The support team member is able to talk with people about support groups

Some people want to know everything about the disease and others do not wish to know much at all. We are sensitive to each person's needs; no-one has the same experience or the same needs.

We have written and online information and resources that we are able to share with clients, their family and whanau, and also information for health professionals. There is information on our MND New Zealand website and links to other helpful websites. Our aim is to provide people with information that will enable them to make informed decisions throughout the journey.

Advocacy

The support team are experienced professionals, with connections to multiple services which can help people at the various stages of MND, from



Toni Foster

“We want our clients, carers and their families to know we are just a phone call or email away.”

(where they are, when they meet and who attends them, e.g. people with MND, carers and the bereaved) so individuals can decide for themselves if this is something that they would like to be part of. Some people may prefer to meet with another person with MND on an individual basis, in which case the support team member may be able to facilitate contact with someone who is in a similar situation.

Support through empowerment

We want to empower our clients, family, carers and whanau with information which can help them navigate their way through the health care system and support them through their journey.

Each person comes to us with different needs, desires and wants.

diagnosis all the way to after-care for the families.

We are not part of the DHBs but work alongside each DHB and have built good working relationships with the DHB teams. We have knowledge of how the DHBs work and can help people to understand and navigate this, and who to contact with their queries.

We are also able to offer support with applications to the Lottery Commission and other agencies for equipment that is not available through Ministry of Health funding.

We can travel to you

We will always do our best to travel to clients, carers, and families. MND New Zealand support team members make personal contact and can help with any questions people may have.

Education

Some health care professionals might not have prior experience with a person living with MND. Support team members provide written resources, support via technology and can meet with health professionals to assist in providing the best possible care for their clients.

Many of our clients and/or their family/whanau ask what is happening with regards to research and any new trials emerging and ask to be kept in the loop with studies. Our website is regularly updated on current global MND research and news, and updates are posted on the MND Facebook page.

There is so much information out there regarding MND and, unfortunately, it is not necessarily all accurate. If you are looking online for information, a good starting point is the MND New Zealand website which has a large amount of accurate information and many links to other recommended organisations, agencies and resources.

We also want our clients, carers and their families to know we are just a phone call or email away.

You can contact your regional support worker – contact information is on page 19 of this newsletter.

Breakthrough trial results for copper-ATSM compound

Promising research results announced early this year from an Australian clinical trial using a compound called copper-ATSM show that the drug is safe and effective in the effort to defeat motor neurone disease.

It has taken the Melbourne-based research team 15 years of working with the compound to get to this stage of trialling the medication on 32 people living with MND. Phase 1 is now complete, and the drug has achieved a huge milestone in proving it is both safe and effective for the participants.

As this breakthrough in research has made headlines, we put together a Q & A with University of Melbourne neuroscientist Associate Professor Peter Crouch to help you get the most accurate information about the latest results and how this will affect the MND community.



Associate Professor Peter Crouch

What is copper-ATSM?

It is a compound comprised of copper and a special chemical scaffold that holds the copper in place. Significantly, when taken as an oral medication, the compound effectively reaches regions of the brain and spinal cord where it's needed to combat MND.

What can copper-ATSM do for people with MND?

It is intended that the drug will slow, and hopefully reverse, the effects of MND. It is not claiming to cure MND at this time. Extensive experiments conducted in research laboratories have proven copper-ATSM to be the most robust potential treatment for MND ever developed. It is hoped that these promising results from the laboratory translate into robust efficacy in the near future when copper-ATSM goes through the next round of clinical testing.

Is there a drug to cure MND on the market?

Not at this time. Additional clinical testing is still required before copper-

ATSM can be prescribed to people with MND.

Are there any medications available to help people living with MND?

Yes, there is one available here in New Zealand – Riluzole (Rilutek). However, it is said to help minimally with MND symptoms.

Other medications can be prescribed by a doctor to help with general muscle twitching and other symptoms related to MND and can be discussed with your Support Team Member.

What are the most recent results of the trial in Australia?

32 participants in Australia were given copper-ATSM as an oral medication and results from the trial have confirmed that copper-ATSM is safe to take as a treatment for MND, with minimal side effects. This is a critical milestone to reach in the drug development process because it means important criteria have been met and that the drug can now

move on to the second phase of clinical testing.

Some media reports have described a 70% improvement for patients taking copper-ATSM. University of Melbourne neuroscientist Associate Professor Peter Crouch says, "These are very exciting indications for copper-ATSM being an effective treatment for MND." But he also cautions that the primary objective for any phase 1 trial is to identify a safe dose to administer to patients. Positive outcomes from the next phase of clinical testing are needed to confirm the drug's therapeutic activity.

Where was the trial?

The trial was held in Sydney and Melbourne, Australia and took two years to complete.

Who participated in the trial?

32 people with clinically confirmed MND and with a time from diagnosis of not more than two years, were chosen to participate in Phase 1 of the trial.

What is next for the trial?

Phase 2 is intended to commence in the second half of 2019 and will involve approximately 80 MND patients. Full details of the phase 2 trial, including details of the participating countries and clinics, are yet to be confirmed. It is expected that the trial will be conducted in Melbourne and Sydney and it is not yet known if this will be extended to other cities or countries.

How long is phase 2 of the trial going to take?

The next phase of testing is likely to take another two to three years to complete. The goal is that with a larger number of people trialling the drug, and with the inclusion of a placebo group in the study, copper-ATSM will prove to offer very good results in slowing down the degenerative process of MND. For the full article visit: mnd.org.nz

NZ Registry receives 2018 Beacon Award

The annual David Oliver Beacon Award is open to individuals, groups and services that provide a positive contribution, improvement or innovation in MND support or care.

Each year the award has a different theme. In 2018 it was 'Working as a Team' and we are delighted to announce The New Zealand MND Registry team as our winner.

The MND Registry collects information about people in New Zealand with MND. It also aims to help the people

who enrol to participate in MND research studies and clinical trials as they become available. Collating data from each person means that we can help researchers to find potential participants for studies very quickly and efficiently. It helps us to become a more 'trial ready' country.

The New Zealand MND Registry team was launched in May 2017, just eight months after a Walk 2 D'Feet MND fundraiser helped raise the funds to establish the registry.

It was created in partnership between the Auckland District Health Board's consultant neurologist and neurogenetic researcher, Dr Richard Roxburgh, and MND New Zealand. The MND New Zealand registry team is made up of Dr Richard Roxburgh, Miriam Rodrigues and curator Kerry Walker.

Kerry accepted the award on behalf of the team at the AGM in October 2018, "We are honoured to receive this prestigious award and be acknowledged for our commitment to research and finding a cure for MND," she said.



Former MND New Zealand President Beth Watson & Kerry Walker

Prescribing of Rilutek

Riluzole is the only drug funded for the treatment of MND in New Zealand. Recently it has come to our attention that some of our clients have been prescribed the drug Riluzole (trade name "Rilutek") by their general practitioner. Under the Medicines Act 1981, Rilutek can only be prescribed by specialist physicians who care for patients with Motor Neurone Disease, neurologists and palliative care physicians. **This includes repeat prescriptions.** We are working with specialists to request this situation be reviewed. Until then you will need to talk to your specialist to ensure that you have the correct prescription, and an adequate supply of Rilutek if you are currently taking it. Your pharmacist should only dispense Rilutek if it has been prescribed by a specialist physician who cares for people with Motor Neurone Disease.

Please talk to your Support Team Member if you have any questions or require further information or email claire.reilly@mnd.org.nz

Join the MND Registry

If you haven't already, please consider joining the New Zealand Motor Neurone Disease Registry.

The Registry was established in 2017 with the aim of helping people in New Zealand with MND to participate in clinical trials and research about MND.

The MND Registry is a confidential database where researchers can find people who may be interested and are eligible to participate in clinical studies or trials. Because MND is not common, and New Zealand is only small, finding enough participants for a study about MND can be difficult. Without a registry to gather details in one place, finding enough patients for a meaningful study can be a barrier to research.

Internationally, the number of new treatments being researched has

grown exponentially in the last few years, but none of these have been available to New Zealanders. The first thing we can do to help change that is to be 'trial ready'. That means grouping everyone who is interested in participating in research into one place and having data available at a moment's notice.

Anyone who has been diagnosed with MND, or has a genetic form of motor neurone disease in their family, is eligible to register. Once you decide to participate, we will collect your contact and demographic information, information about your clinical condition, and results from any genetic testing you have had.

I will then contact you if there is any research or study available that you would be eligible for. You can say yes or no to any of these opportunities as you wish, and I will never give out your contact details to any other

party. The information you give us, and your medical information, is stored securely at Auckland DHB, where the Registry is run from. Anonymous data is also stored in an online database maintained by the Australian Motor Neurone Disease Registry. This data will be used to give us a picture of what MND looks like in New Zealand.

Your local Support Team Member can help you with consent forms to participate, or you can find them online at <https://mnd.org.nz/registry/>. Alternatively, please feel free to contact me on email mndregistry@adhb.govt.nz or phone 0800 MND REG or 027 561 7332. I am happy to answer any questions you might have about the Registry or participating.

Kerry Walker
NZ MND Registry Curator

Participants needed in new genetic study

MND New Zealand proudly helps fund vital research at the Centre for Brain Research at the University of Auckland and supports the latest genetics study.

Dr. Emma Scotter (Centre for Brain Research, University of Auckland), Dr. Richard Roxburgh (Neurogenetics Clinic, Auckland City Hospital), and collaborators are now recruiting for a study of the genetics of Motor Neurone Disease in New Zealand. Dr. Scotter says, "We invite people with MND (familial or sporadic, total 300 people) and people without MND (total 30 people) to participate."

The purpose of the study is to understand the genetic causes of MND in New Zealanders. In addition, the study aims to test how certain MND gene mutations affect human cells.

What samples and information would I need to give?

We need 2–3 tubes of blood for the testing. We invite control participants and 30 people with familial MND to give a small biopsy of arm skin tissue.

Your personal and clinical information will be collected when you register with the MND Registry. This is a necessary and required part of the genetics study.

Where will my DNA go?

The DNA itself will go the University of Queensland and to Canterbury Health

Laboratories, Christchurch, NZ. You can decide whether you want to share your gene code information with other researchers internationally too. In this case, your name would not be shared, just your anonymous gene code.

What will I learn?

If you have a gene change that definitely caused your MND, you will have the option to learn this result. You also have the option NOT to learn your result. We expect that about 15% of all participants with MND or 70% of those with familial MND will have a gene code change that definitely caused their MND.

If we don't find good evidence that a gene code change caused your MND, we will still give you information about the overall results of the study.

Is it better to know if I have a gene change that caused my MND or not?

Knowing that you have a gene code change that causes MND can be empowering, and



therapies are being developed for some genetic forms of MND, so knowing you have genetic MND may allow you to access these therapies in future.

However, knowing you have a genetic form of MND may affect your insurance, and will have important implications for your family. These issues will be discussed fully during the study consent process.

Please do not hesitate to contact us for further information: emma.scotter@auckland.ac.nz.



Dr. Emma Scotter



Dr. Richard Roxburgh

Nominate a health care professional or team!

The David Oliver Beacon Award is open for 2019 submissions. This year's theme is: **Acknowledging an individual or team making a difference on the journey of people or families living with motor neurone disease.**

Dr David Oliver, internationally acclaimed physician who has dedicated much of his life to enhancing the quality of life of people with MND through his practice, his writing and his teaching, generously agreed to his name to be associated with this award.

You may have a neurologist who

has been supportive and caring when making your diagnosis, offering you helpful information or a referral. Perhaps your GP, nurse or local health care team is taking some extra time or interest in helping you and/or your family along the way? Or the Hospice team has gone the extra mile to make sure you and your family are well supported and cared for and this has made all the difference.

It could be an innovation within the science or health care community which is making a real difference for people with MND. Maybe you want to nominate

your team or have someone nominate you for all the positive work you are doing for people living with MND – we encourage you to do so.

If someone comes to mind, then don't be shy, nominate them. You can renominate each year. Submissions close on June 21, 2019.

Nomination guidelines, evaluation criteria and further information about this award are available on the MND NZ website: www.mnd.org.nz

National Council Update



“After my father passed away from MND, I see each day as a gift.”

New Chair Lucy Haberfield

I've been asked to write a bio and my tendency is to tell you about my degrees and my corporate experience, but it probably doesn't really give you a sense of why I'm involved.

In 1994, my father told us he had MND. He was 54. I remember it vividly because it was the day my youngest son was born when I heard the news.

When he received his diagnosis, my father's initial reaction was to second guess the diagnosis and then to seek out any and every possible treatment. He was determined to work for as long as he

could and had a never-give-up attitude.

I learned the value of hard work from my father who was a Dutch immigrant to New Zealand. We worked alongside him on the farm for many years milking cows, chipping thistles, feeding out and all the other chores that go with rural life. My father's real passion was being a salesman. He became New Zealand's top tractor salesman in the 1970s, and he was also one of Dallas Motors' top salesmen. I am also proud he was able to see me become an educated woman in my field.

After my father passed away from MND, I see each day as a gift.

I look forward to giving something back to honour my father's memory and a desire to be a role model to my family. Being Chair is a great opportunity to do just that and help others who are affected by MND.

Council member Jodie O'Doherty

I have been involved in fundraising and helping charities since I was a child. By the time I was 20, I was organising gala balls to raise money for various causes. Before I had children I was working in business processes and later as an Executive Assistant. These roles have taught me that I love coming up with new ideas, I can make anything happen. I have an eye for finding a more streamlined approach to any task or process. Since



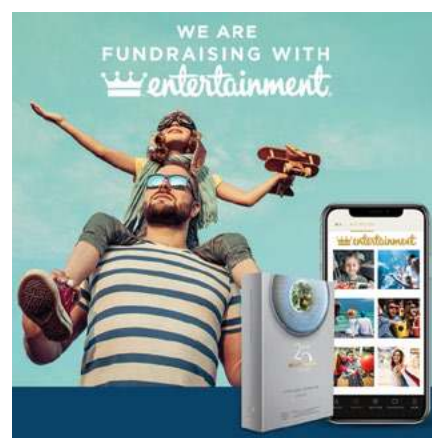
my mum was diagnosed with MND, I have become more involved with MND New Zealand, arranging several events in Wellington. I am thrilled to be part of the Council and hope to use my knack of developing partnerships and connecting people to further develop the organisation. Originally from Sydney, I have lived in Wellington with my husband and three young children for five years.

The Grocery Charity Ball



We are pleased to announce MND New Zealand will be The Grocery

Charity Ball 2019 event beneficiary. The Grocery Charity Ball has proudly directed over \$3million to charitable trusts throughout New Zealand since it began in 2004. Funds raised from this event will help MND New Zealand to provide the best quality care and support to the motor neurone disease community. MND New Zealand is seeking a number of high value items to be auctioned at the event which will be held in Auckland during September. If you or someone you know may be able to help by donating a service, package, experience or product to the auction, please get in touch with MND New Zealand Fundraising Manager, Kate Dalders. **E: kate.dalders@mnd.org.nz; P: 027 206 9606**



Entertainment Digital and Book Memberships

are now available to purchase. Enjoy 2-for-1 and up to 50% off offers, and deals for travel, hotel accommodation, family activities and much more. To purchase your Entertainment Membership simply fill out the form or go to our website merchandise tab to find out more. 20% of each sale will be donated to MND New Zealand. www.mnd.org.nz/merchandise

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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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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NATIONAL COUNCIL

Chairperson: Lucy Haberfield
Vice-chair: Anna Chalmers
Treasurer: Greg Horton
Members: Fiona Hewerdine, Tony Treloar, Steve Green, Beth Watson, Jodie O'Doherty

PLEASE CONTACT US

- If you have any suggestions for inclusion in the next newsletter
- If your address has changed
- If you would prefer to receive MND News by email or post only, or no longer wish to receive MND News.

Our thanks go to minimum graphics for design and layout of MND News and to Stewart Motorsport for sponsoring the printing.

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.



Lottery Grants Board
FUNDS FOR YOUR COMMUNITY

ANZ Staff Foundation

Eastern & Central
COMMUNITY TRUST



COGS
Community Organization
Grants Scheme

Four Winds
FOUNDATION LIMITED
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THE LION FOUNDATION
Here for good

MACARTHUR TRUST



MINISTRY OF HEALTH
MANATU HAUORA

FOUNDATION NORTH
Te Kaitiaki Take Kōwhiri o Tāmaki o Tei Tokerau

New Zealand Post

- Iris & Eric Nankivell Charitable Trust
- Louisa and Patrick Emmett Murphy Foundation
- The Guy Anson Waddell Charitable Trust
- W Duncan Bickley Charitable Trust
- F H Muter and the E M Pharazyn Trust
- Phillip Verry Charitable Foundation
- B W & S W Picot Charitable Trust
- Page Trust
- Sir John Logan Campbell Residuary Estate
- Trust Waikato



Get Involved – Save the Date

17–23 June: MND Awareness Week

Cuppa Tea for MND

We invite you to organise a morning or afternoon tea at your workplace, school, club or home to raise awareness and funds.

MND Awareness Collections

Could you help collect at a local shopping centre or supermarket for MND New Zealand to raise further awareness and funding during MND Awareness Week? We need volunteers to help by organising, coordinating or manning a collection for a few hours in your local area.

Sunday 10 November – Walk 2 D'Feet MND

Walk 2 D'Feet MND events are all volunteer led and organised. Walk 2 D'Feet MND events are a great way to give back to your local community and raise vital funds to support people living with motor neurone disease. Could you volunteer this year as part of your local walk volunteer group, or organise a new walk location?

For more details or to show your interest in any of the above opportunities, please contact Kate Dalders, Fundraising Manager.
E: kate.dalders@mnd.org.nz; T: 09 624 2148

Ongoing – Care with Coins

Do you know of a local shop, café or another business that would be willing to place a collection box on their counter? Care with Coins labels can be added to a container and placed at point of sale. Volunteer to place, collect and bank funds raised through Care with Coins.

Cuppa Tea
for mnd
New Zealand



Join us for a cup of tea and raise money to support people with motor neurone disease.

**MND Awareness Week
June 17 – 23**