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NEWSLETTER OF THE MOTOR NEURONE DISEASE ASSOCIATION OF NEW ZEALAND INC

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Join the Walk 2 D'Feet MND

Please join us at our Walk 2 D'Feet MND on **SUNDAY 12 NOVEMBER**. The Walk 2 D'Feet MND is our annual fundraiser, being held in 18 towns and cities all over New Zealand this year.

Previous years' Walk 2 D'Feet MND events have been a huge success, with enthusiastic participation from our passionate and growing community of people who have loved someone with MND, current and past (Continued on page 2)

This year's Walk 2 D'Feet MND events are being held in: Auckland, Balclutha, Bay of Plenty, Blenheim, Christchurch, Dunedin, Hamilton, Hawkes Bay, Invercargill, Nelson, New Plymouth, Rangiora, Taupo, Wairarapa, Wellington, Whanganui, Whangarei

Motor Neurone Disease (MND) causes the muscles that enable us to move, speak, swallow and breathe to gradually stop working. MND New Zealand works with people living with MND to enable them to have the best quality of life possible. We provide support, information and advocacy to people with MND, their whanau and health professionals.



Queen's honour for Claire Reilly

The healing power of even the most microscopic exchange with someone who knows in a flash precisely what you're talking about because she experienced that thing too cannot be overestimated.

CHERYL STRAYED

(Continued from page 1) caregivers, and those now living with MND themselves.

MND can be very isolating for people with MND and their carers. 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 to find a cure.

As in previous years, half of the money we raise will be used to foster MND research in New Zealand. The remaining funds are a major contributor to the donation and grant income that we depend upon to continue our vital free Support Service.

Thank you so much for being part of Walk 2 D'Feet MND 2017.

Go to mnda.org.nz/walk to find your local walk, buy a ticket and t-shirt, and sign up as a fundraiser.

We were absolutely delighted when MND New Zealand's very own fundraising development manager Claire Reilly was honoured with a Queen's Service Medal for services to motor neurone disease in this year's Queen's Birthday Honours.

Claire is an amazing powerhouse of determination, driven by her passion that people with MND deserve being cared about. Her determination has given hope to many hundreds of people either living with MND, or who have lost someone they loved to MND.

This hope has been created both through raising funds to go to research into MND, but even more importantly the hope that comes from being part of a visible group, reducing the sense of isolation people with MND and their carers can have.

Through the Walks 2 D'Feet MND, Claire is giving hundreds of people a chance to 'fight back' at MND by participating in these walks and fundraising for research. She is also building an MND community in New Zealand, helping hard-working carers and grieving families find comfort and support.

Claire has empowered and assisted several other people who have MND to organise Walks 2 D'Feet MND in their own communities, giving them an opportunity for leadership and achievement that improves their quality of life.

Claire sets an example of living with a terminal disease that is inspiring, positive and motivating for others

with life-limiting conditions.

In particular, Claire shows people with MND that despite their enormous challenges and limitations, it's possible to keep achieving and contributing positively to society. This has inspired many other people with MND to stay busy, active and connected to their communities.

Claire's research advocacy has also had a significant outcome. She encouraged MND New Zealand to extend its vision beyond support to people living with MND, to actively supporting research in New Zealand. Because of Claire, significant progress is being made to encourage more MND research in New Zealand.

In August, Claire attended the investiture ceremony at Government House in Wellington, with her family and MND New Zealand President, Beth Watson.

"It was an amazing and very humbling experience," says Claire. "I was very pleased that Beth could attend with me, as the success of the Walk 2 D'Feet MND and awareness campaigns have very much been a team effort."

"I felt very privileged to be among such a fine group of New Zealanders who have given so much to their country. Dame Patsy summed it up perfectly with a quote from President Nelson Mandela, who said, 'What counts in life is not the mere fact that we have lived. It is what difference we have made to the lives of others that will determine the significance of the life we lead.'"

Announcing the MND Research Network

We are thrilled to announce that the website of the New Zealand MND Research Network (www.mndresearch.auckland.ac.nz) will be launched on November 1st 2017.

The Research Network website's purpose is to provide a central location informing others of all MND-related research in New Zealand. At launch, it will profile six research groups currently doing work that impacts on MND. Over time, more researchers will be added to the website.

Dr Emma Scotter, who has a passion for MND research, has led the establishment of the network.

After a four-year fellowship in the UK, where she investigated misfolded proteins in MND at King's College London, Dr Scotter returned to Auckland in 2014 to head up the Motor Neuron Disease Lab at the Centre for Brain Research at the University of Auckland. She immediately saw a need to link New Zealand

MND researchers together, having seen in the UK the way that research networks could accelerate and broaden research in the topic of focus.

The New Zealand MND Research Network will facilitate the interaction between MND biomedical and clinical researchers, allied health professionals and other researchers who will have an impact on MND in New Zealand. It is anticipated that this increased interaction will also encourage new MND research.

Jayne McLean is the manager of the New Zealand MND Research Network. She has a science, IT and communications background, giving her the unique skill set required to take the research network concept and work to make it a reality.

"It is really exciting to see what Kiwi researchers are doing in the specific area of MND," she says. "There's also a great deal of research occurring in other fields, such as assistive technology, which will also make a positive difference to people who have MND."

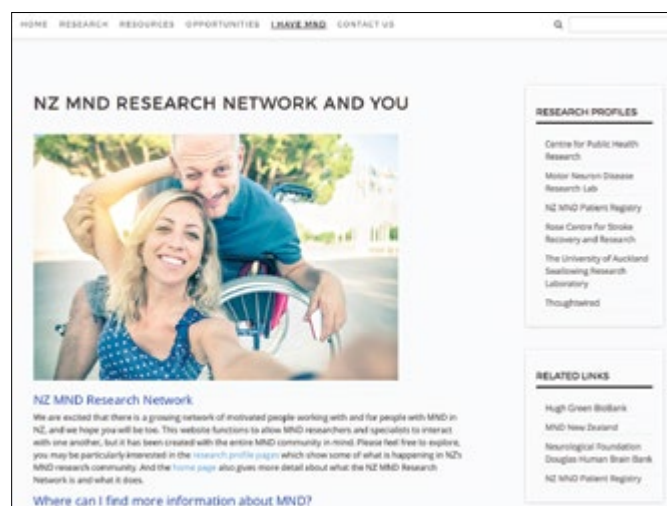
Dr Scotter says she is delighted that so much progress has been made towards creating a more connected MND research community in New Zealand. "I look forward to seeing more Kiwi researchers recruited to the study of MND, and to working together to accelerate MND research progress in New Zealand."

The New Zealand MND Research Network has been funded by a grant from research funds raised by the Walk 2 D'Feet MND in 2015 and 2016. Dr Scotter was recently awarded a Rutherford Discovery Fellowship to further support her vision of growing a national Motor Neuron Disease Research programme.



Dr Emma Scotter

JESSIE CASSON



Support Team changes

Our MND Support Team fulfills a critical role, as the only service that offers support to people with MND from diagnosis to death. We are pleased to welcome two new members to our Support Team: Jacqui Drinkwater, based in the Bay of Plenty, and Carol Matthews, based in the Waikato. You can read more about Jacqui and Carol on page 6.

In late May, Support Worker Graham Jones resigned after eight years of service to people with MND. Graham was based in the Bay of Plenty but, like all our Support Staff, he covered a much broader area.

In September Support Team leader Lin Field finished her time with us after eight years in our support service. Lin is a speech-language therapist with an encyclopedic knowledge of MND, and the health professionals and agencies who can help people with MND all over New Zealand. She has been an invaluable source of support, information and wisdom, not only to people with MND and their whanau, but to all our Support Team members and wider staff.

Finally, we are tremendously sad to let you know that Lynne Neshausen, a valued member of our Support Team who retired due to ill health early this year, passed away in July.



Lin Field with new acting national manager Carl Sunderland

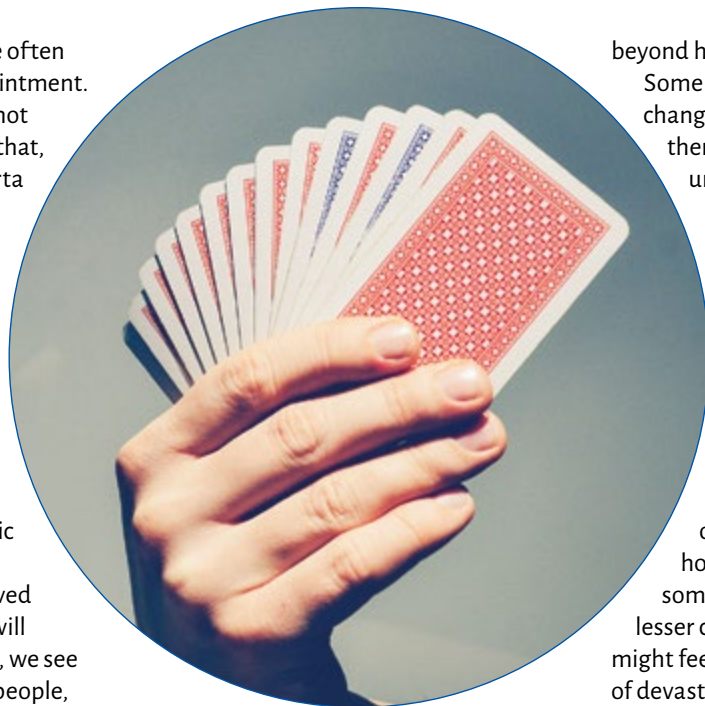
Play your cards right

Life isn't fair. That's what we are often told, so we can suck up disappointment. Does it help? Not really. Fate is not even-handed, and we all know that, but somehow we still kinda, sorta expect that it totally should be. That if we are good people, keep our nose clean and our room tidy, life will treat us fairly. And most of the time it does.

Until it doesn't. Unfair things happen every day. Occasionally, we can take a (secretish) smirk of glee when there appears to be some karmic retribution being handed out from on high. "He totally deserved it. You reap what you sow," we will say. However, much of the time, we see bad things happening to good people, ourselves included, and we rail against the injustice and unfairness of it all. "How could that happen? She doesn't deserve that at all. It's so unfair."

All of a sudden (and usually just when you think your ducks are nicely in a row) life can end up looking spectacularly sideways from what you had intended. The rug is pulled out from beneath you; the future you had planned did not include the loss that has blindsided you. Cue grief, pain and shock. Life, for sure, ain't fair.

Events so catastrophic can happen that life will never be the same again, and we will never be the same again.



Part of our soul will be forever be marked and our future will not roll out as we envisaged. It should not be like this, we say. This should never have happened. I should not have to go through this. I should not have to suffer this. I don't deserve it. It's so unfair.

And it is.

However – disputing fairness holds us in the trauma. It keeps us tethered to the pain. We cannot rebuild the different life that is waiting for us when we hold so tight to what was.

Releasing the future we saw for ourselves, that is no longer on the table, is

beyond hard – but it is the way forward. Some losses are so great you cannot change them. You can only transcend them. Releasing the grip on the unfairness of it all will help.

One of my favourite authors, Cheryl Strayed, makes this point: "You don't have a right to the cards you believe you should have been dealt. You have an obligation to play the hell out of the ones you're holding."

And so it is. Whatever we have lost, our treasured pair of aces we thought we would hold until the end, we still do have some cards left. They may be way lesser cards. The roof over our heads might feel like a five of clubs in the wake of devastating grief, but it is still a card of value.

In the worst of times we can overlook the lesser cards in our hand – the supportive friends, absorbing hobby, incredible doctor, amazing financial plan, loving spouse, helpful daughter. But they are what we have left.

And so we can only play on with what we have. Playing harder, smarter, looking at the cards we still hold and those that might make their way into our hand in the next deal. Life isn't fair. It's what you do to transcend unfair that counts.

Louise Thompson

Sign up for a free e-book and meditation audio at louisethompson.com/start-here



HOUND & STEED CREATIVE AGENCY

We are proud to have sponsored all the creative needs of MND New Zealand over the past two years and we look forward to working with the great team of passionate people who work tirelessly to make a difference.



DANIELLE DOOLEY

Cornflower Dogs for Christmas

The 2018 Cornflower Dogs 15-month calendar by Danielle Dooley will make a great Christmas present!

Danielle Dooley, a young painter living and working in Auckland, has painstakingly painted 16 gorgeous pups crowned with cornflowers – the international symbol of hope for MND.

Calendars are \$25 each (plus \$3 postage), or \$100 for five (plus \$6.50 postage). Every dollar is being donated to MND New Zealand, to help fund research and support. Fifteen

sponsors helped cover the cost of printing the calendars, and Danielle donated all her time.

Danielle completed a Bachelor of Design and Visual Arts, majoring in painting, at Unitec in 2014. Her uncle is currently living with MND.

To order, email shereee@booksaredone.onmicrosoft.com with your name, delivery address, and phone number. Danielle Dooley paints private commissions; email danielledooley93@gmail.com

Have you completed the ALS Quest?

ALS Quest is an online questionnaire run by a researcher at Sydney University, looking at the possible causes of MND.

People from all over the world have filled out the questionnaire, which is allowing collaborative international research into important areas, such as links between environmental toxins and MND.

So far, 26 people from New Zealand have completed the questionnaire.

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.

Anyone aged 18 or over is eligible to fill out the questionnaire – those with MND and those without. Every response counts.

Filling out the questionnaire takes about an hour, and it can be done in multiple sessions. (Some problems with the 'save and continue' feature have been

reported with the Safari web browser on iPads and iPhones. This can be fixed by changing the Safari settings to 'Accept all cookies' before starting the survey.)

No personally identifiable information is requested, so your privacy is assured.

This is a painless, easy way to participate in MND research and we recommend that you participate.

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

New faces at MND New Zealand

The past two years have been a time of growth and change for MND New Zealand. Our priority will always be our support service, but following 2014's global 'Ice Bucket Challenge', we have also recognised and risen to the need to foster the

development of research in New Zealand. The nationwide Walk 2 D'Feet MND events in 2015 and 2016 were tremendously successful, both for their fundraising achievements and for the way they have connected and empowered families affected



Carl Sunderland
Acting National Manager,
MND New Zealand

In September, we welcomed Carl Sunderland as the acting national manager for MND Zealand.

Carl has been in the not-for-profit sector for 12 years. His most recent role was interim manager at Carers NZ, and before that was general manager of Coeliac NZ. He has developed several New Zealand charities, including co-founding KidsCan, which provides food, clothing and health items to Kiwi children in need.

An ex-police officer and teacher, Carl gets satisfaction from making a positive difference to people's lives. Originally from England, he's been living in New Zealand for 18 years. He lives on the North Shore with his partner and 16-year-old son, and loves the beach and playing rugby.

Carl works 24 hours per week, with four days in our National Office in Royal Oak, and some hours remotely. He has an Honours degree in Psychology, a PGDip in Business and an NZ Cert in Fundraising.

Part of Carl's role with us will be to scope the permanent leadership position for MND New Zealand. We believe this will likely be a full-time position, to increase our capacity and assure our future sustainability, while fully developing our cornerstone service, the national MND Support Team.



Jacqui Drinkwater
MND Support Team, Tauranga based

Jacqui Drinkwater joined our MND Support Team in August, based in Tauranga and working across the DHB areas of Bay of Plenty, Lakes, Hawkes Bay and Tairāwhiti.

Jacqui is a registered nurse who trained at Auckland's Unitec. Her calm and unflappable nature found her at home in acute and emergency nursing for many years. A recent role as a practice nurse in a rural medical centre motivated her move to work in the community.

As a student nurse in the '90s, Jacqui cared for a gentleman with MND in the weekends. "I developed a great relationship with him and his family," she says. "Although there were challenges, it was a very special time and I have very fond memories of everyone involved, hence my interest in MND."

Jacqui lives in Mount Maunganui, where she enjoys the beach with her husband and two primary school aged children.

She's enjoying her new role with MND New Zealand. "Everyone has been so friendly and welcoming. I feel it's a real privilege to come into people's homes and share their personal stories of how life is for them and their families. Luckily I enjoy driving!"



Carol Matthews
MND Support Team, Hamilton based

Carol Matthews joined our MND Support Team in August, based in Hamilton and working across the DHB areas of Waikato, Taranaki and Whanganui.

Carol's background is in nursing, a career she began in England in 1975. After moving to New Zealand in 1989, she has worked as a nurse in intensive care, coronary care and neonatal intensive care. For the past 12 years Carol has been with Hospice in Tauranga, mainly as a community nurse and educator. It was here that she developed a special interest in MND, and has very fond memories of supporting people with MND over her years with Hospice.

Carol says she's enjoying her new role with MND New Zealand, particularly meeting and building relationships with families and health professionals, and the challenge of learning different support systems.

Carol has three adult sons and a beautiful two-year-old granddaughter. She finds strength in her Christian faith and enjoys travel, reading, music, walking, movies and writing poetry.

by MND. Half of the funds raised by the walks are to be used to foster MND research in New Zealand, and in 2017 we have been excited to make the first grants from these funds.

We are pleased to welcome several new staff members and the recipients of Walk 2 D'Feet MND grants to our MND New Zealand community, who we introduce to you below.



Noelann Davies
Grants Administrator,
MND New Zealand

Noelann started with MND New Zealand in April as a part-time grants administrator, working 12 hours a week, which she juggles with contracting roles in the corporate world.

Her job starts with lots of research, to make sure our grant applications qualify under the terms of a fund, and determine who we approach. "There's a lot of reading involved!" she says. Noelann then makes submissions and applications to the various trusts and organisations that have the ability to provide us with funding.

There's a lot of form-filling involved. "It's mostly online these days," she explains, and just as you might think, that part of the job can be frustrating!

About one in every three or four grant applications are successful, because the demand for grant funding hugely exceeds supply. "The declines are disappointing, but when you have a grant application funded it feels fantastic!"

Noelann lives with her husband and their adult daughter and son. Her first grandchild is due at Christmas time, and will be joining the extended family at their busy Auckland home.



Kerry Walker
Curator, New Zealand MND Registry

The New Zealand MND Registry was launched in May, to connect people with MND to researchers and facilitate the growth of the MND research field in New Zealand.

As the Registry Curator, Kerry enrolls participants, gathers and records clinical data, ensures the regulatory requirements for the study are maintained, and connects with MND researchers. Because the Registry is just starting out, this means being proactive to create research opportunities for New Zealanders.

"If you have MND, please consider joining the MND Registry," says Kerry. "I'd love to answer your questions, so do get in touch."

Kerry comes from a science background, and worked in lab research for several years before moving onto clinical trials. Most recently she coordinated a national epidemiological study. Kerry has fabulous insight as to how research works at many different levels.

Kerry is originally from Taranaki, and now lives in Auckland with her husband and 2-year-old daughter.

The Registry is funded by MND New Zealand from funds raised for research by the Walk 2 D'Feet MND events in 2015 and 2016.

You can contact Kerry on 0800 MND REG (0800 663 734) or at mndregistry@adhb.govt.nz



Jayne McLean
Manager, NZ MND Research Network

The New Zealand MND Research Network launches on November 1st, to connect researchers all over the country whose work impacts on MND. Jayne has been working to develop the network and create the website, www.mndresearch.auckland.ac.nz (see page 3).

Jayne has a background in microbiology, and previously worked as a genetic counsellor. Her last role with the Muscular Dystrophy Association has given her a wide knowledge of neuromuscular conditions and experience communicating scientific information in language that is easier to understand.

"I love helping people," she says. "Being part of the NZ MND Research Network is amazing because, although I am not in the lab with the test tubes, I really feel like I am making a contribution towards scientific advancement in the MND field."

Jayne has a large blended family with five children, a labrador, a cat, chickens, and fortunately a very supportive partner, Calum. Jayne's work with the Research Network, based at the Centre for Brain Research, adds another 8 hours of work to her busy week. Jayne's role has been funded for one year through funds that were raised for research by the Walk 2 D'Feet MND events in 2015 and 2016.

Swishes come true for MND New Zealand



The Wellington Saints basketball team wore a specially created purple uniform featuring our cornflower logo in May, to raise awareness of MND and honour longtime Saints chair Justin Toebes. Justin has been involved with the Saints for 25 years, and has been living with MND since December 2012.

The uniforms were later auctioned on Trade Me, and combined with donations taken on the night, a total of \$8000 was donated to MND New Zealand.

Fran Scholey, general manager of the Saints, says the team was honoured to be able to raise funds and awareness for MND.

“Our hearts go out to all of those individuals affected and their families. We hope that turning our uniform purple and displaying the MND New Zealand logo brought much-needed awareness and that the small amount that we were able to raise is able to bring some sort of relief to those individuals and their families.”

Justin Toebes told the *Dominion Post*, “One of the joys of my life is basketball and especially the Saints.... It’s a team that has always cared for what it wants to achieve, but also cared for the people in it.”

Justin has been living with MND for four-and-a-half years. “I wasn’t expecting this long,” he says. Fortunately he is still able to attend Saints home games in his electric wheelchair.

Thank you to Eden Park and Doddie Weir

At the third All Blacks v Lions test on 8 July, Eden Park hosted a dinner for its members with a special guest speaker, Doddie Weir.

Doddie is a former international rugby player for Scotland and British and Irish Lions, who was diagnosed with MND this year aged just 46.

Eden Park’s GM Commercial Nick Sautner says, “Doddie mixed and mingled amongst our members and entertained everyone with stories of his early playing career and family life, leaving the crowd in hysterics. Very few of those present were aware of Doddie’s illness.”

At the end of the evening, the crowd was made aware of Doddie’s MND diagnosis and Eden Park donated two All Blacks jerseys which were auctioned off, raising \$14,000 for MND New Zealand.

“We were more than happy to support such a worthy cause and would like to thank our members for their generosity,” says Sautner.

MND New Zealand is tremendously grateful to Doddie and his family for helping to raise awareness of MND at such a difficult time, and we are thankful to the team at Eden Park who initiated the event.



Nick Sautner (Eden Park GM Commercial), Grant Diggie (former National Manager, MND NZ), Lian Tetley (Eden Park Membership Manager), Annabel McAleer (MND NZ Communications Manager), and Guy Ngata (Eden Park CEO).



The definition of brave

According to the Oxford dictionary, the definition of brave is: “Ready to face and endure danger or pain; showing courage.” People have told me I’m brave, but I don’t think anyone is ‘ready’ to face what a MND diagnosis brings with it.

There have been times where I have been anything but courageous, but somewhere along the line, my husband Tony and I decided we didn’t want to spend what time I had left in sobbing, gibbering messes on the lounge floor.

I try to make a joke of things anytime

I can, because there will be times when I just can’t. But that sense of humour that used to get me in trouble at school now serves me well.

I also decided to grab onto the things I enjoy, like science fiction, and shed the things I don’t, like housework – we now have a cleaner!

One of those things is kiting. As work-from-home geeks, my husband and I need something to get us out of the house. For the last few years that’s being dragged around by big kites on beaches. Like kite-surfing – but we do it on land.

It’s very zen, zooming along the beach with only the sound of the wind, the sand two inches from your backside (and no – there are no brakes). But

it can be a challenge wrestling what is the equivalent of a sail around in blustery conditions.

I’ve reconciled myself to no longer having the strength to tackle these adrenalin-pumping conditions, although it took me a few “kite-mares” to admit it. But I still buggy if conditions are a little gentler. I’ve had to adapt my style, and I now use more of my body strength rather than my arms.

I don’t go very fast – but I’m still out there. And if I can’t do it, there is the tow bar Tony made, so he can tow me around in his buggy. He does all the work, I just sit back and enjoy.

I guess I’m lucky in that I have a stubborn streak, a fine sense of the ridiculous, and a husband who is very inventive in helping me adapt.

Getting on with this ‘new normal’, as I see it, is to not to mourn the things I can no longer do, like making jewellery, but to make the most of what I can do. And if I can give the fingers to the MND monster, all the better.

Sandra Newton



Edaravone approved to treat MND in the US

What does this mean for people with MND in New Zealand?



WIKIMEDIA COMMONS

On Friday 5 May, the US Food and Drug Administration (the FDA, the organisation that approves medication in America according to its safety and effectiveness) announced its approval of the drug 'edaravone' for the treatment of MND.

This is exciting news. Edaravone is the first MND medication to be approved by the FDA in 22 years, since riluzole (Rilutek) in 1995.

Edaravone (known by the brand name Radicava in the US, and Radicut in Japan and South Korea) **is not yet available on prescription in New Zealand.** MND New Zealand will keep you informed about further developments and what they may mean for people with MND in New Zealand. This is what we know so far.

What is edaravone?

Edaravone is an antioxidant drug that protects nerve cells by mopping up 'free radicals' in the body. Our cells usually have effective ways of dealing with free radicals, but these become less efficient with age. When neurones are damaged, as happens with neurodegenerative diseases, then more free radicals are produced and the body becomes less effective at eliminating them.

Edaravone is administered via intravenous infusion by a health care professional. It is administered with an initial treatment cycle of daily dosing for 14 days, followed by a 14-day drug-free period. Subsequent treatment cycles consist of dosing on 10 of 14 days, followed by 14 days drug-free. It takes 60 minutes to receive each 60 mg dose.

A company called Treeway is currently developing an oral preparation of the drug.

How effective is edaravone?

Some clinical trials have shown that edaravone can slow the progression of MND in some people, potentially helping preserve function for longer. It appears to work in a sub-set of people and may be effective only for those at the early stages of the disease (eg those who are able to eat a meal, move alone and do not need assistance in everyday life).

MND will continue to progress even if taking both riluzole and edaravone. These medications can both be seen as potentially slowing the progression of MND and lengthening lifespan slightly.

The evidence for edaravone's efficacy is so far fairly modest. A Phase 3 clinical trial ran for six months with 137 participants in Japan. At Week 24, participants receiving edaravone showed less deterioration on a clinical assessment of daily functioning compared to those receiving a placebo. Riluzole was also

being taken by 90% of participants during the trial. The complete results of the study have not yet been published in a scientific journal.

MND New Zealand's medical advisor, neurologist Dr Andrew Chancellor, says that new therapies for MND are very welcome, but may not be an improvement over existing medication (riluzole) or therapies. He points out that coordinated medical care from multidisciplinary teams is known to improve survival in MND, as does non-invasive ventilation. "These are probably better than these drug therapies," he says.

These medications can both be seen as potentially slowing the progression of MND and lengthening lifespan slightly.

Access to edaravone in New Zealand

At this time, edaravone is only approved for use in Japan, South Korea and the US.

If a medicine is not approved by Medsafe, a person can go to a doctor and request them to make an application to supply it under section 29 of the Medicines Act 1981. To our knowledge, this is untested for edaravone in New Zealand. It should be noted that this process can be challenging and expensive. The estimated annual cost of edaravone in the US is US\$146,000 and in Japan US\$26,000.

People with MND have attempted to access edaravone in Japan. A representative of the Japan ALS Association has provided a FAQ document (linked from www.mnda.org.nz/edaravone-fda/) that explains how international patients may access Radicut in Japan. This process can be challenging and expensive. It also requires the cooperation of a local medical professional to administer the drug and monitor the patient.

Working towards making edaravone available in New Zealand

As the national representative of all New Zealanders who are impacted by MND, MND New Zealand is committed to advocating for medications approved by major international regulatory bodies for the treatment of MND to be made available to people living with MND in New Zealand.

Mitsubishi-Tanabe does not yet have plans to introduce edaravone to New Zealand, which is initiated by applying for Medsafe approval.

If eventually approved by Medsafe,

an application will then need to be made to Pharmac, which decides whether medications receive government funding based on their cost-effectiveness and a number of other factors. If a drug is not funded by Pharmac, it must be paid for privately.

Based on our experience with other MND treatments, edaravone is unlikely to be available and funded in New Zealand in the near future.

To understand the time frame that could be involved, we can look back to the process that riluzole went through in New Zealand following its approval by the FDA in 1995. Avantis (now Sanofi) applied for riluzole to be approved by Medsafe in 1995. It was approved by Medsafe for prescribing in New Zealand in 2007 at a cost to each patient of \$827/month. Riluzole has been funded by Pharmac since 2013, following a long campaign from MND New Zealand.

Dr Chancellor points out that if other *highly effective* drugs are developed for MND, these would be prioritised for people with MND.

As we learn more about the developments of the drug we will keep everyone updated.



NORWOOD (CHARITY) CC BY-SA 3.0

Ask The Experts

This year's International Symposium on ALS/MND is being held in Boston in the United States, from 8-10 December.

The 2017 International Symposium is the 28th of these annual events, organised by the MND Association of England, Wales and Northern Ireland, in cooperation with the International Alliance of ALS/MND Associations.

The International Symposium is the largest medical and scientific conference on MND. It brings together leading international researchers as well as allied health professionals, who present they year's key innovations in both biomedical science, and in the care of people affected by MND.

With so many active MND researchers under the same roof, it's no surprise that the 'Ask The Experts' session is popular worldwide.

Anyone, anywhere can watch the session, which will be live-streamed through a website link. At that link, while you are watching, you can ask the experts questions by typing into a dialogue box.

In New Zealand time, this year's Ask the Experts session will be held on **Thursday 7 December, from 7:30am to 9:30am.**

We will let you know when the live-streaming link is available, by posting it on our Facebook page: www.facebook.com/mndanz

Rallying for the cause

After Hawke's Bay rally driver Malcolm Stewart died due to MND in 2009, his wife Sue Stewart decided to keep a car on the rally circuit in his memory. She also made the brave and generous decision to use the car as an opportunity to raise awareness of MND, and raise money to support MND New Zealand and the Neurological Foundation.

The rally car, an Audi S2 coupe Quattro, has been racing with its striking blue and pink livery since 2010. Sue brought together Malcolm's service crew, co-driver Mike Fletcher and former adversary Ray Wilson to compete in rallies all over New Zealand.

Ray, a full-time rally car mechanic, was a long-time rival of Malcolm's – "but also a long-time friend," says Sue. "He's a safe driver too."

Entering classic and historic car categories, the crew now travel the country to spread their message. Winning isn't really their goal, says Ray. "The main reason I'm doing it is for the cause."



Ray and Malcolm raced in the same rallies throughout the 1970s and '80s. At the time, many believed Malcolm could have made a career out of rally driving, but his farm near Dannevirke was always his first priority.

Rally driving was a close second however, and Malcolm remains in the history books as the most prolific competitor of Rally New Zealand, having raced 29 times in the 39 years the event has been run. When aged 62, he was due to celebrate his

30th start at the 2008 Rally New Zealand, but had to withdraw his entry due to symptoms of MND, which he was diagnosed with shortly afterwards.

His 36-year rally career came to a close with his last race in May 2008. By July he was diagnosed with MND. The following year he died at 63.

Sue Stewart funds the MND New Zealand / Neurological Foundation rally car project out of her own pocket, and has been a wonderful supporter of MND New Zealand for the past eight years. Stewart Motorsport very generously covers the cost of printing this newsletter.

We are tremendously grateful for the ongoing support of Sue, Ray and the team at Stewart Motorsport.



Include a Charity

MND New Zealand is pleased to have become a member of Include a Charity, a not-for-profit organisation that aims to make it the norm for New Zealanders to leave a bequest to charity in their Will.

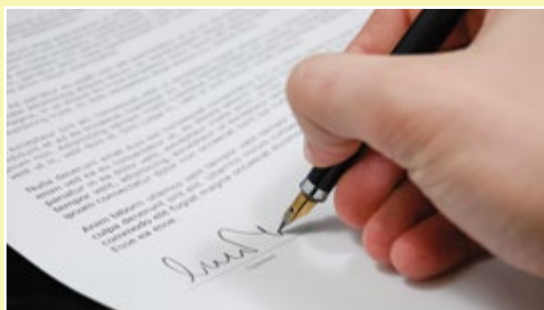
A bequest is a gift left in a will. Many people don't realise that you don't have to be rich or famous to make a bequest! The truth is that most bequests are made by ordinary, hardworking people who want to make a positive difference after they're gone.

We're often not able to give as generously during our lives as we might like to. Leaving a bequest –

after we have provided for our family, of course – is a great way to support the vital work of charities we've always wanted to help.

We understand that leaving a gift in your Will is a big decision, and we are interested to know if you have thought about leaving a lasting legacy to help us ensure that New Zealanders with MND get the support they need in future.

Please take a look at the Include a Charity website for further



information and help on leaving a bequest (includeacharity.org.nz). If you have any questions or would like a confidential chat, please contact national manager Carl Sunderland on 09 624 2148 or email mgr@mnda.org.nz.

How Hospice helps

Sue and Jim's story

About three years ago I began to notice some subtle changes in my husband. His ability to cope in different situations had changed and he had lost interest in activities he'd always enjoyed. Having been married to Jim for nearly 50 years, I knew his personality traits very well. But he looked fine, and when I expressed my concerns, he kept assuring me nothing was wrong and he could see no reason to visit our GP.

It wasn't long before Jim's physical symptoms began to worsen. He started to experience shortness of breath and fatigue. Having a history of asthma, out came the Ventolin inhalers. It was early 2015 when Jim finally admitted something was wrong. His breathing was so laboured that we were sent straight up to the hospital.

Life as we knew it changed irreversibly on 22 April 2015. That was the day the specialist at Rotorua Hospital gave my husband a diagnosis of motor neurone disease. In addition to the MND, Jim was one of the unfortunate ones who also present with frontal temporal dementia (FTD), which explained the subtle personality changes.

It was a very long, silent drive back to Taupō that afternoon as we both tried to come to terms with this devastating news. One of the hardest things that needed to be done was to tell our two children. I sat at the computer that evening with tears streaming down my face, still in a state of shock.

We soon made contact with the MND New Zealand Support Worker, Graham. He came to our home and facilitated a family meeting. His honesty and expert knowledge gave all of us a very clear picture of what could be in store for Jim and our family.

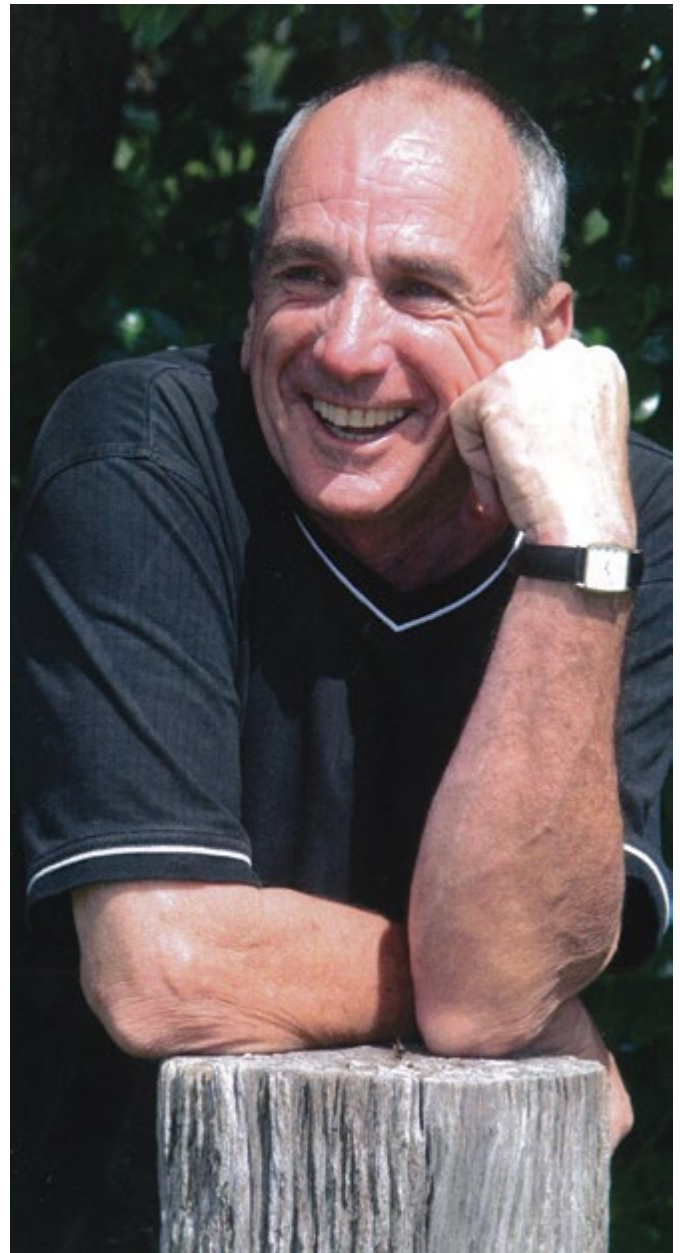
Jim then expressed a wish to relocate, to be closer to family. The Taupō house was sold, and back we came to Palmerston North.

Saying goodbye to our supportive team of medical specialists was hard, but we were fortunate that Mike Yee, our Palmerston North GP, connected us to Arohanui Hospice and their amazingly dedicated staff. They arranged a home visit to assess Jim's needs and facilitate a care plan. We were then assigned a Palliative Care Coordinator (a specialist registered nurse) and a social worker.

By this time the effects of the disease were impacting more seriously on Jim's day-to-day living. Jim was very brave in the face of this debilitating disease, but it was heartbreaking to watch my husband struggling to breathe and beginning to lose grip in his hands. He had always appreciated good food, but this simple pleasure was also denied of him.

Jim loved his home and family, and wanted to live the time he had left at home, with the people he loved and trusted most. Being able to keep him at home was crucial to me, as it was the only wish he had expressed. But as his main caregiver I had major feelings of inadequacy from time to time, and doubted my ability to care for Jim right to the end. Thank God for Arohanui Hospice, there for us 24/7. I have no doubt that Hospice support empowered me to be able to look after my husband to the very end.

Jim died peacefully at home on 22 June 2016 in my arms after 50 years of marriage. Our journey from diagnosis to Jim's



death was 14 months. His death came with relief in knowing his suffering had ended, but an immense sadness that his life ended at only 68 years old.

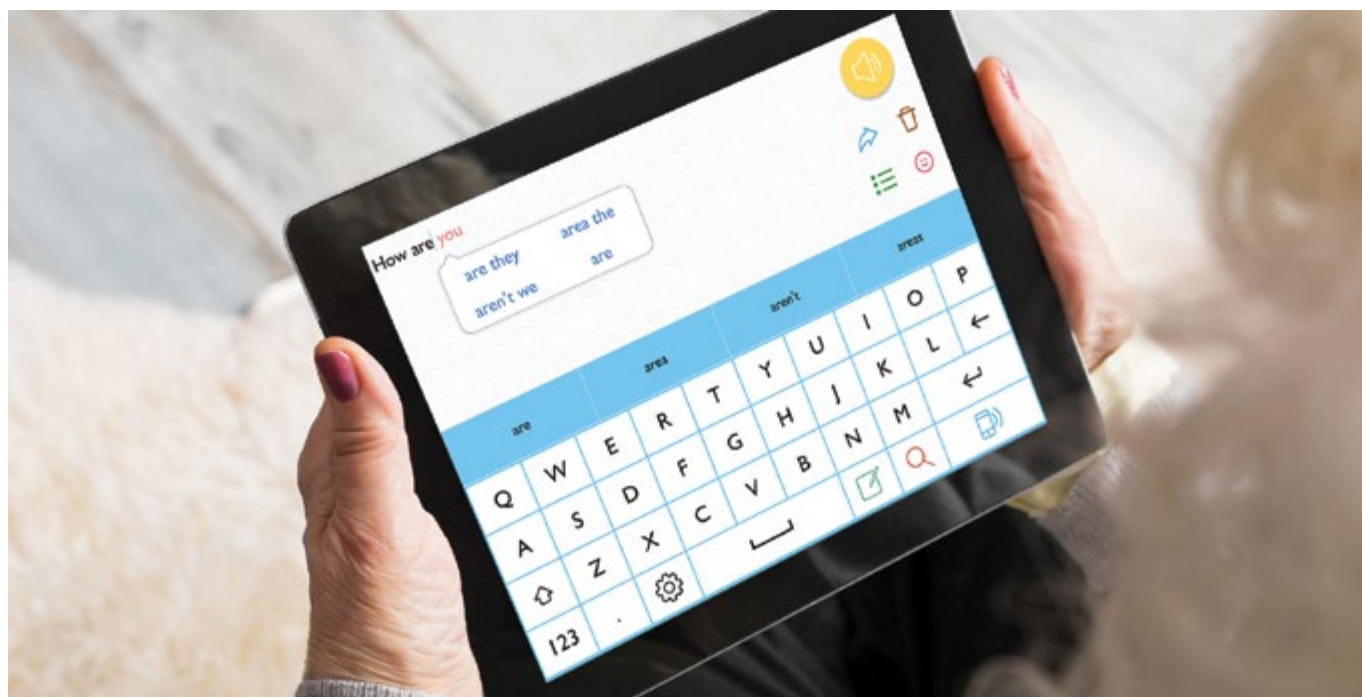
I will be eternally grateful to the Arohanui Hospice team for enabling me and my family to support Jim to the end. I must also mention the role of the MND Support Team, who work so hard to support and advocate for people living with this disease. A special thanks to Reima Casey and Graham Jones.

I encourage you to continue supporting both of these organisations, so they have the funds they need to ensure they can continue to offer such great support to all those who need it.

Sue Lashbrooke

Story supplied by Arohanui Hospice, www.arohanuihospice.org.nz

TalkLink's Guide to Voice Banking



THERAPY BOX

Our voices are important to our identity and relationships. Often, as a result of MND, the ability to communicate via speech is affected. For some people this results in the complete loss of speech. For others, speech is still the main way they communicate, but it can be difficult to understand, especially for unfamiliar communication partners.

The TalkLink Trust supports people to access communication devices that 'do the talking for us'. These help people with MND continue to communicate, and maintain their ability to control and participate in important aspects of life.

Up until recently, anyone using a speech-generating device (SGD) to help them communicate has had to use a voice that sounded American or British.

Now, advances in voice banking have allowed people to record their own voices to create an individualised synthetic voice for use in a SGD.

TalkLink Trust therapists are keen to support people to take advantage of this new technology.

What is the difference between voice banking and phrase banking?

Phrase banking is the recording of whole words or phrases, using your own voice. Many communication apps allow for the addition of frequently used phrases in order to speed up communication. Recorded speech can be added to these programmed phrases. Phrase banking is limited to the phrases programmed

and does not allow spontaneous speech generation.

Voice banking involves recording a sample of a person's speech and creating a synthesised voice similar to the original recorded voice. This voice can then be set as the 'in-built' voice within a SGD. Any message typed into the device can be spoken with the synthesised voice.

Creating a synthesised voice using ModelTalker

The ModelTalker System (www.modeltalker.org) is a speech synthesis software package developed by the Nemours Speech Research Laboratory. It is designed to benefit people who are losing or who have already lost their ability to speak.

Kiwi voices project

TalkLink is working with some University of Canterbury speech-language therapy students on a project to create New Zealand-sounding voices using ModelTalker. This range of 'generic' Kiwi voices will be available to people who are not in the position to create their own voice.

Female, male, young and old voice donors have recorded approximately 1600 phrases each, and additional

New Zealand-specific words (such as *kia ora*, *kai* and *Whakatane*) using the ModelTalker voice banking system. The final voices will have distinctly Kiwi flavours and be available for use on selected devices in early 2018.

Future projects include looking at the option of creating a Te Reo Māori voice.

My voice banking experience

Four years ago I was diagnosed with MND. When someone suggested that I record my voice, I contacted my hospital and was put in touch with a very helpful speech-language therapist named Julia.

Julia explained the procedure to record my own voice. She was very patient with me, and we recorded lots of phrases. It wasn't as easy as I thought it would be. Talking into a microphone takes a bit of getting

used to. I now have a recording of my own voice that can be loaded on to most devices, if or when I am not able to speak.

I strongly advise anyone with MND to record their voice in the early stages of the disease. If it is not recorded, you will have to use a foreign voice.

My advice to anyone unfortunate to get MND is do not delay in getting help. It is out there – just ask.

Joe Potroz

ModelTalker can be used to create a synthetic voice from voice banked phrases, using the person's own voice as the basis for the synthetic voice. It is important to note that while this will sound similar to the person's real voice, it is not an exact replica. It is still recommended to phrase bank important personal phrases through more traditional methods.

To hear a ModelTalker synthesised voice created by a TalkLink client please see youtu.be/hBo79VATDqC.

What is involved?

In order to create a synthesised voice, approximately 1600 phrases are recorded by the user over a period of several weeks. This generally occurs in the person's own home following training and instruction from a TalkLink speech-language therapist. Starting this process while speech is relatively unimpaired is preferred, but not essential.

Voice banking for ModelTalker is a lengthy process requiring a significant commitment from the person recording his or her speech.

There is a cost for a ModelTalker voice, but only when it is successfully completed. TalkLink would apply for funding for the voice at the same time as requesting funding for the SGD. In order to support more people to access voice banking technology, TalkLink is currently fundraising to purchase a number of laptop computers and high-

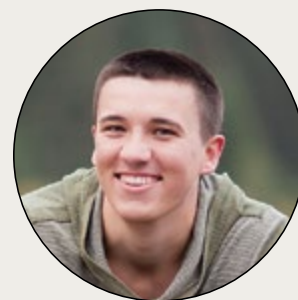
quality headsets that we can loan to people wishing to voice bank.

What you will need

- A laptop or computer running Windows 7 or above with very quiet fans. Noisy fans interfere with the recordings and make them unusable.
- A broadband internet connection.
- A high-quality USB headset.
- A suitable environment to record in. TalkLink Tech Support can work with the person to help set this up. A suitable environment is one that has minimal echo, is small, has minimal background noise and lots of soft furnishings. A walk-in wardrobe is a great possibility. The room should be cool in temperature to stop the computer's fans running at high speed and generating lots of noise. Fluorescent lighting which operates at 60Hz should be avoided as this create a buzz which is picked up on the recording.
- The environment must also be comfortable and be able to access the internet as it will be necessary to spend a lot of time here!

TalkLink therapists provide ongoing support to meet changing communication needs. TalkLink has offices throughout New Zealand and can be contacted at 0800 TALKLINK (0800 825 554). Further information is available from www.talklink.org.nz

RESEARCHER PROFILE



Andrew Siemens

Research Technician, Scotter Lab

As a research technician for the Scotter Lab in the Centre for Brain Research, at the University of Auckland, Andrew investigates the role of inflammatory cytokines and the blood brain barrier on motor neurone disease. He works with human brain cells grown from people with sporadic or C9ORF72-linked MND.

Funds raised for research by the Walk 2 D'Feet MND were used to employ Andrew for three months from February this year. Funding from Rutherford Discovery and Marsden FastStart grants have enabled his ongoing employment since May.

Andrew was born in the United States, where he completed a Bachelor of Science in Biology and graduated Summa Cum Laude (with highest honour) from the University of Oregon with an A+ grade point average.

In December 2016, he moved to New Zealand with his wife to study and work at the University of Auckland. He loves exploring the natural beauty of New Zealand, and has completed the Tongariro Crossing, explored Mount Cook National Park, and observed the Milky Way from Lake Tekapo.

In autumn 2018, Andrew will return to the US to attend medical school and pursue a career as a physician. "While conducting MND research, I have learned to appreciate the impact of collaborating with peers both domestic and abroad," he says. "As a result, I will continue to emphasise collaboration throughout my career."

Digging deep for MND once again



My husband Roy had always wanted to walk the Milford Track. Sadly, he was diagnosed with MND before he had the chance to fulfill this dream. Caring for Roy was challenging – especially as he was also affected by frontal temporal dementia – but it was rewarding too. A wonderful support team of family and friends made this time so precious, and many happy memories were made.

To mark the second anniversary of Roy passing away, in April this year I embarked on another challenging but rewarding mission.

With my sister Yvonne Horgan, who flew out from London to join me, I walked the 53.5km of the Milford Track, through two glacial valleys and over the McKinnon Pass, down through the rainforest to finish at Milford Sound.

The walk started easily, with an hour on a boat across Lake Te Anau, then an easy walk through beech forest. On day 2 it began to rain. This is normal for Fiordland, where 15 days without rain is considered a drought and the waterfalls dry up. We walked 16.5km to the next hut, through forest, open prairie, and several scrambles over dry(ish) watercourses. We were toggged up in full waterproofs, over us and the packs, looking like a pair of hunchbacks.

Uphill was hard, and we'd have been lost without our walking sticks. We weren't the oldest by any means at 60 and 65, but it had been a number of

years since either of us trekked any great distance.

The huts on the four-day walk are basic, with bunks in mixed dormitories (these sound a bit like a frog pond, with snoring in different keys!) and a communal kitchen. You must walk carrying your cooking and eating utensils, food and bedding, head-torch, emergency equipment and clothing.

Day 3 was only 14km – but it was up and over McKinnon Pass. On fine days the views are spectacular, but for us, the low cloud, constant rain and heavy wind meant an increased chill factor. The track zig-zagged up out of alpine forest to the top at 1154 metres, and a welcome break for flasks of hot soup and a chance to wring out socks and stretch backs.

Uphill was tough, but going down was much, much worse. Cold windy rain, a very narrow path of loose stones, and a sheer drop needed careful watching. Water finds the easiest course downward, which is often the track itself. We struggled back down into rainforest, past some magnificent waterfalls and rapids to arrive last, and seriously sore, at Dumpling Hut.

Much like the journey of people dealing with MND, there were several points along this stretch where we really had to dig deep for the resources to keep going.

Day 4 started with blistered feet, sore ankles and knees, and various muscles

letting us know they were unaccustomed to such abuse. While the next 18km were relatively flat compared to the previous day, every downward step jarred our knees and every loose rock hurt our feet. However, we managed it.

We were ever so grateful to see the shelters at the aptly named Sandfly Point, and the boat waiting to take us to Milford Sound.

The walk was tough, but the scenery was magnificent. Just as when Roy was living with MND, I was so grateful to the friends and family, and some complete strangers, who supported us. Many made a

contribution to the MND Associations in both New Zealand and the UK.

MND is a cruel killer, and anything we can do to further research into a cure and to help Associations work with affected families, is worth every effort. I am so happy to have reached my fundraising goal.

Although I wish MND had never touched my life, I'm grateful for the resilience and resources I have developed, that continue to help me conquer other challenges.

Viv Adams



President's Piece



Kia ora koutou,

After our long, wet winter it is a joy to see the sun and be moving into summer with its promise of kinder weather.

Elsewhere in the newsletter our many happenings have been reported on. I think you will agree with me that MND is finally getting more recognition with the general public – something I find tremendously heartening, as for too long it has stood in the shadows of other diseases. People living with MND and their families have to be brave and resourceful every day, and I like seeing their stories shared and inspiring others in the community.

Dr Claire Reilly received a QSM in the Queen's Birthday Honours this year. She told me that she accepted the honour to show her respect for all the MND community. Congratulations, Claire.

This newsletter celebrates others who work to raise awareness and much-needed funds for MND in New Zealand:

MND is finally getting more recognition with the general public – something I find tremendously heartening, as for too long it has stood in the shadows of other diseases. People living with MND and their families have to be brave and resourceful every day, and I like seeing their stories shared and inspiring others in the community.

Sue Stewart in motorsport; Danielle Dooley who painstakingly hand-painted our fundraising calendar; the generous Eden Park rugby and Wellington Saints basketball communities.

Awareness and support is indeed growing and your MND New Zealand Council has seen the need to make sure our Association has the resources and structure to lever off this and grow its support service, increase its advocacy, and ensure our modest contributions to research really help make a difference.

It was with sadness that we farewelled Grant Diggle, our national manager of four years. He had been a stable presence for us. We thank him sincerely for his contributions in that time. Grant was not in a position to work the extra hours that our growth brings.

Gwynyth Carr resigned at the same time. Gwynyth has been the glue in national office through eight years and several changes of manager, and everyone appreciated her willing and helpful approach. Lin Field, our Support Team leader, who has also been with MND New Zealand for eight years, also chose to resign after Grant left. During

her time with us, Lin has developed and grown the support service, and underpinned it with sound policies and guidelines. Until this year she also took responsibility for the newsletter, where she did a great job.

Change has taken its toll on our Council too with the retirement of two of our executive team: secretary Bruce Stokell, who held that position for 10 years, and vice-president Richard Ryan. We will miss their considered input.

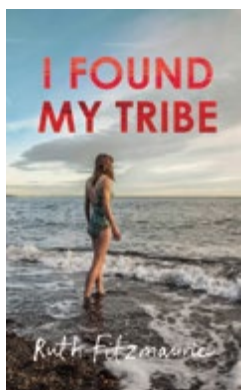
Change is challenging but offers exciting opportunities too. We welcome Carl Sunderland as our acting national manager to help us develop a sustainable framework to take us forward. I look forward to working with him to extend and broaden the services MND New Zealand offers its people with MND and their families, whanau and the health professionals who work with them.

Mā te wā,

A handwritten signature in black ink, appearing to read 'Beth Watson'.

Beth Watson

BOOK REVIEW



Ruth Fitzmaurice was 32 when her husband was diagnosed with MND in 2008. Already parents of three, the couple went on to have twins, and Ruth began to write about their life – and she swam.

Almost every day since, Ruth has swum in the sea with the 'Tragic Wives' Swimming Club', as they jokingly call themselves – a group of women who swim to cope with the extreme challenges life has put in their way. On nights with a full moon, they swim naked.

I Found My Tribe (Chatto & Windus, 2017) describes the healing power of the natural world, and shows the rewards of loving and living as fully as we can. Ruth also writes about her marriage, and the feelings of loneliness that can occur as a consequence of communication limitations caused by MND.

I Found My Tribe is being made into a movie.

Ruth's husband, film director Simon Fitzmaurice, is also an author. *It's Not Dark Yet* (Hachette Books, 2014) is his autobiography of life with MND.

Carl's Corner



I'm very excited to be joining MND New Zealand at this positive time of development and change. I'm passionate about working in the not-for-profit sector, and I particularly relish the opportunity to support this fantastic organisation through this period of growth.

Although I've only been in the national manager's role a short time, I can see that MND New Zealand is staffed and governed by deeply caring people who truly believe in our core purpose – to work with people with MND to enable them to have the best possible quality of life.

The reason I've grounded my career in the not-for-profit sector for the past 12 years is that I too need my work to be purposeful, and although it sounds cheesy, I feel driven to make a positive impact on people's lives. Having been a police officer, a teacher, and the founder of several New Zealand charities, I have the front-line experience and the empathy necessary to make a difference in organisations wanting to make a difference.

In my most recent role as interim manager at Carers NZ, I developed a real understanding of the importance of a holistic support network. I'm very keen to assist MND New Zealand to continue to grow our support for the amazing whanau and family carers supporting their loved ones with MND.

Before that as general manager at Coeliac NZ, I worked hard to create a strong and stable leading national organisation after

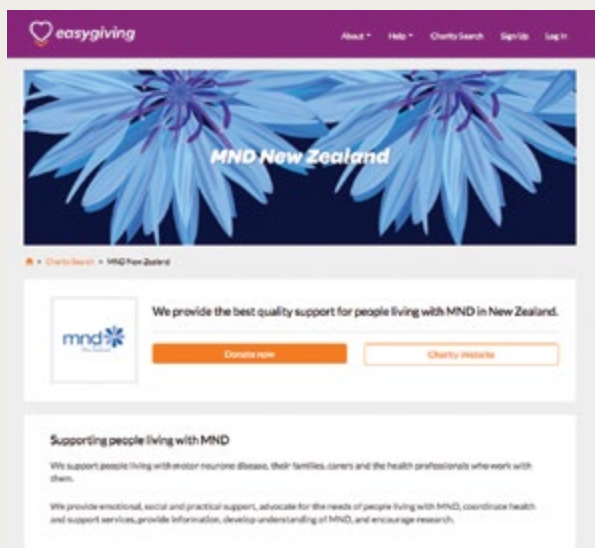
a long period of instability. I established sustainable policies and procedures in support mechanisms, strategy, finance, marketing and fundraising, helped develop two award-winning programmes and ensured Coeliac NZ was the number one source of trusted information on coeliac disease and gluten-free living in New Zealand.

I hope to bring this successful approach to MND New Zealand so we can continue to grow and provide exemplary services to New Zealanders and their families nationwide. I care very much about making sure our regions are well supported, and ensuring that people living with MND in both urban and rural environments receive the care and assistance they need, even when in-person visits are limited by distance. In this age of information overload, it's also crucial that MND New Zealand is the most trusted source of online information about living with MND, and caring for someone with MND.

Overall, I'm a big picture thinker, and hope to spend my time with MND New Zealand considering all aspects of the organisation when mapping out our sustainable future course. I'm keen to engage with our community – and I'm prepared to muck in when required, so you'll be seeing me at Auckland's Walk 2 D'Feet MND and any other MND New Zealand events and activities over the coming months.

Kia kaha,

Carl Sunderland
Acting National Manager



Easy Giving – woohoo!

MND New Zealand has joined up with Woohoo NZ Tax Refunds to make use of their new app called EasyGiving. You probably know Woohoo NZ Tax Refunds best for those ads about helping people claim refunds from the tax man. Their EasyGiving app allows people to make an online donation to selected charities, and instantly claim the 33% tax credit.

The instant tax credit either goes back to the donor, or directly to the chosen charity for an even bigger boost. Woohoo NZ Tax Refunds does all the paperwork for you.

The EasyGiving app is available to download for free across all devices.

For more information, go to www.easygiving.nz/help/faqs, or find us at www.easygiving.nz/charities/mnd-new-zealand/

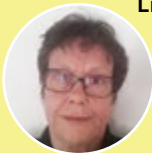
Our MND Support Team

We employ six 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.



Gilly Noon

Mangawhai based
DHBs: Northland, Waitemata
Mob: 027 202 8166
Email: northfieldwork@mnda.org.nz



Linda Oliver

Auckland based
DHBs: Waitemata (West), Auckland, Counties Manukau
Mob: 021 036 0218
Email: aklfieldwork@mnda.org.nz



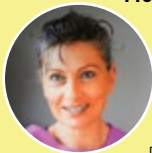
Carol Matthews

Hamilton based
DHBs: Waikato, Taranaki, Whanganui
Ph: 029 773 6662
Email: wktofieldwork@mnda.org.nz



Jacqui Drinkwater

Tauranga based
DHBs: Bay of Plenty, Lakes, Hawkes Bay, Tairāwhiti
Ph: 029 777 5588
Email: bopfieldwork@mnda.org.nz



Moira Young

Wellington based
DHBs: Capital & Coast, Wairarapa, Hutt, Nelson & Marlborough, Whanganui, Mid Central
Mob: 021 0278 4494
Email: wgtfieldwork@mnda.org.nz



Kate Moulson

Geraldine based
DHBs: Canterbury, South Canterbury, West Coast, Southern
Mob: 029 777 9944
Email: southisfieldwork@mnda.org.nz

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

MND ASSOCIATION OF NEW ZEALAND INC.

Yarnton House, 14 Erson Ave
PO Box 24036, Royal Oak
Auckland 1345
Tel: 09 624 2148
Email: admin@mnda.org.nz

STAFF

Carl Sunderland

Acting National Manager
National Office Auckland
Ph: 09 624 2148
Mob: 027 2412766
mgr@mnda.org.nz

Annabel McAleer

Communications & Engagement Advisor
Mob: 021 840 108
comms@mnda.org.nz

Claire Reilly

Fundraising Development Manager
fundraise@mnda.org.nz

NATIONAL COUNCIL

President: Beth Watson
Treasurer: Lucy Haberfield
Councillors: Andrew Pardoe-Burnett, Fiona Hewerdine, Helen Brown, Helen Palmer, Tony Treloar, Anna Chalmers

PLEASE CONTACT US

- If you have any suggestions for inclusion in the next newsletter
- If your address has changed
- If you know someone who would like to receive our newsletter
- 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
- Onehunga One Tree Hill Rotary Club

Help us make Walk 2 D'Feet MND a success!

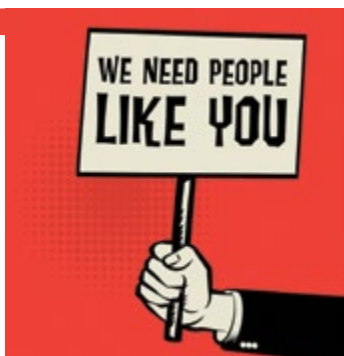
We're excited to see our MND community out in force on November 12, at the Walk 2 D'Feet MND.

Your registration fee will cover the cost of running the event, so we ask our walkers to do their best to fundraise. It's the funds you raise through Everyday Hero that will help MND New Zealand foster local research into MND and continue providing our crucial free support service.

Please go to www.mnda.org.nz/walk, and click on the walk location nearest to you. The Everyday Hero page for that walk will open. Click the yellow Start Fundraising button, and you'll be taken to the sign-up page.

Don't forget to share your fundraising page over email and on Facebook. Our top fundraisers share their page over 11 times, so don't be shy!

Thank you so very much for your hard work. Your fundraising will make a real contribution to our support service, and to MND research in New Zealand.



© 123RF STOCK PHOTO

Have you enrolled in the MND Registry?

If you have been diagnosed with MND, or have a genetic form of MND in your family, you are eligible to register with the NZ Motor Neurone Disease Registry.

The aim of the registry is to help people in New Zealand with MND to participate in national and international clinical trials and research about MND, if you would like to. It also aims to help researchers by assisting them to plan their research and helping to find people who may be interested in participating.

If you decide to participate, the registry will collect information about your clinical condition and any genetic testing results, if you have them. You will also be asked for your contact information and some demographic information. The registry curator will contact you every so often to ensure that this information is up to date.

For more information about the Registry, please see www.mnda.org.nz/registry. We hope you will choose to enrol!

If you have any enquiries, please direct them to the Registry Curator:

Email: mndregistry@adhb.govt.nz
Phone: 0800 MND REG (0800 663 734)
Post: MND Registry, Neurology, Auckland DHB, Private Bag 92024, Auckland 1142



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