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mndnews

NEWSLETTER OF THE MOTOR NEURONE DISEASE ASSOCIATION OF NEW ZEALAND INC

www.mnd.org.nz

Announcing a very special partnership

PHOTO: ETNZ

If you caught Seven Sharp on 17th June, during MND Awareness Week, you would have seen a big announcement! MND New Zealand became the official charity partner of Emirates Team New Zealand. We're delighted and deeply honoured to have begun this significant relationship.

Emirates Team New Zealand have witnessed the devastation of MND first-hand: teammate and former Emirates Team New Zealand Director and current Director of America's Cup Event Ltd (ACE) Greg Horton is living with the condition. Greg is also a member of the MND New Zealand National Council.

Grant Dalton says: "Through Greg you can see the amazing work MND New Zealand does for the 300 plus New Zealanders who are living with MND, so we are really proud to be supporting them and everything they do."

MND New Zealand representatives were able to attend the official launch of the first Emirates Team New Zealand boat on September 6th at Auckland's Viaduct Harbour.

Marcus Gerbich, pictured, who is living with MND, helped with a special and vitally important tradition: christening the new yacht "Te Aihe" (the Māori word for dolphin). It is the first AC75 to touch the water.

Marcus had this to say about his key role on the day: "Our family have been fans of Emirates Team New Zealand for many years, and it was a great honour to be able to represent MND New Zealand in the launch of our latest America's Cup yacht. And doesn't she look fast!"

We look forward to cheering on Emirates Team New Zealand when they defend the America's Cup in 2021 and thank them for supporting MND New Zealand.

From the Chair and General Manager

2019 has certainly shaped up to be a big year for MND New Zealand and our community!

After our whole team met in March for strategy day, we took the ideas generated along with feedback received through our MND Community Survey to develop our Strategic Plan 2019–2022 (p. 14) which launched in July.

It was important to collaborate with our community to shape the organisation's future direction and growth. The focus of the next three years is on improvement, development, and sustainability. We're confident that through this plan we can keep working hard to maximise the positive difference we make in the lives of those living with MND.

Recently we released the MND Community Survey results and our response (pp. 8–9). We apologise for the delay in releasing these results, but it was important to have a clear idea about the actions we would take before doing so. Through the strategy we have committed to addressing the needs and issues identified in the survey. Thank you to everyone who took part in the survey and shared their experiences with us.

Unmet practical support needs for many people living with MND, their families, and carers was a key feedback theme. In May, we were proud to announce Fulton Hogan as our Foundation Corporate Sponsor (p. 4) and their commitment to a three-year partnership, providing additional assistance to people living with MND.

The "Fulton Hogan MND New Zealand Support Fund" is available to all clients and their families via our support team. We hope the fund will help provide much-needed practical assistance, and we thank Fulton Hogan for their dedication and generosity.

MND Awareness Week 2019 in June (p. 13) was packed full of a variety of activities and announcements. We were honoured to be named as the Official Charity of Emirates Team New Zealand for the 36th America's Cup – quite a feat for our small organisation. We are looking forward to working with the team on some exciting projects to help raise awareness of this devastating disease, and hopefully much-needed funds.

MND New Zealand is committed to encouraging and supporting MND research, and during Awareness Week we launched our Research Strategy 2019-22.

At the launch event in Auckland we proudly hosted guest speakers Professor Chris Shaw, Dr Emma Scotter, and Kerry Walker, who presented "An Update on MND Research – Homegrown & Abroad" (p. 6). The well-attended event was a great start to our busy research calendar, which featured the MND New Zealand Hui at Parliament in September (p. 10–11) and includes the upcoming inaugural MND New Zealand Research Conference in December (p. 6). We are confident that these significant events will increase interest in, and awareness of, MND research in New Zealand.

We were very fortunate to be selected as this year's charity recipient at September's Grocery Charity Ball (p. 5). The event raised a whopping $245,000, and a huge thank you goes to everyone who helped make the event such a huge success by donating auction items or helping out on the night.

While lots has been happening in the community, there have also been a couple of changes at National Office. We welcomed Patricia Bell as Grants Administrator in July, and Sarah Tora as Communications Manager in August. They both bring vast amounts of experience to their respective roles.

Although the end of the year is fast approaching, we're still looking forward to some significant upcoming events. Our major annual community event and fundraiser, Walk 2 D'Feet MND, is just a few days away as this issue goes to print. We're looking forward to sharing more about this in the next issue, and hope you and your family were able to attend.

The MND New Zealand Research Conference on 9th December is shaping up to be an exciting day with a star-studded line up of local and international speakers. This is the first event of its type in New Zealand, and we're expecting a full house, so please get in quick to secure your seat.

We couldn't have had such a big year without the continued support from you, the MND community. A huge thank you to all our volunteers, supporters, fundraisers, and team for your valuable contributions in making 2019 such a successful year so far.

We rely almost completely on the generosity of the New Zealand community through donations and fundraising to continue doing the vital work we do, providing a free personalised service to people living with MND and their families.

It is essential that we keep working together to continue providing high quality support, making a positive difference in the lives of those living with MND.

Thank you!

& Carl

Lucy & Carl

In this issue

mnd New Zealand

Kitty and Georgie gather their friends and glam up for a good cause

After learning about motor neurone disease, Kitty and Georgie were keen to get involved with supporting MND New Zealand.

Kitty said, "We were shocked to hear that MND New Zealand only receives 8 per cent of its funds through government funding!"

The two friends put their heads together to brainstorm ideas on how they could help people with MND. Soon, the fantastic idea of holding a Reunion Ball for their university friends was born, with proceeds going to MND New Zealand.

On Saturday 31st August, 220 people dressed in their finest outfits gathered at Christchurch's Show Gate Room at Riccarton Park to catch up for a night of fun and entertainment in support of MND New Zealand.

The event was a resounding success, raising a whopping $6,100! Kitty had this to say about the Reunion Ball: "We had such a fantastic Reunion Ball gathering all our nearest and dearest to celebrate good health and friendship – but the cherry on the top was doing it for a worthy cause. We hope after our event there are 220 young people now aware and willing to support MND initiatives, starting with the Walk to D'Feet MND on the 10th of November!"

Reunion Ball organisers Kitty & Georgie

A huge heartfelt thanks to Kitty and Georgie, all their helpers and everyone who attended the Reunion Ball for choosing to support MND New Zealand – we appreciate it! Fundraising is vital to helping us continue to provide free personalised support to people with MND.

Action shots of the evening

Meet our new team members

Patricia Bell joined MND New Zealand as Grants Administrator in July this year, working two days per week.

After working in the non-profit sector for fifteen years, Patricia has built up a wealth of experience, holding roles in fundraising and communications as well as grant writing, which she has been doing for the past nine years.

Coming to us most recently from RNZSPCA, Patricia has also worked with The New Zealand Breast Cancer Foundation, Asthma NZ, Ako Mātātupu: Teach First NZ, YWCA, and the Auckland City Mission.

Patricia has her own writing, editing, and proofreading business and in her spare time enjoys performing in theatrical productions, keeping fit, and spending time with her daughter.

Sarah Tora started with us as Communications Manager in August, working 32 hours a week.

Sarah holds a Bachelor of Communication Studies and has worked in the corporate world for 22 years, most recently in communications roles at KiwiRail, Progressive Enterprises (Countdown) and Westpac.

"I am really enjoying the change of pace and learning more about the non-profit sector. It's great being able to use my skills in a meaningful way to help people living with MND and their families," says Sarah.

An avid reader, Sarah also enjoys cooking, yoga, writing poetry, travelling, and making memories with her family.

The Fulton Hogan MND New Zealand support fund is here!

We're always looking for ways to increase the practical support available to people living with MND.

With this in mind, we're delighted to let you know that in conjunction with corporate sponsor Fulton Hogan we've recently launched the Fulton Hogan MND New Zealand Support Fund.

The fund has been set up to provide financial assistance to help with practical home-based help, like modifications to a house, in-home support, or specialised equipment.

MND New Zealand General Manager Carl Sunderland said the challenges of living with MND made the practical nature of the fund "incredibly valuable".

"We wanted Fulton Hogan's commitment to be focused on an area with a particular and measurable need, and we're delighted with this result," Carl said.

Fulton Hogan Managing Director Cos Bruyn said MND New Zealand's focus on improving people's quality of life means the organisation has lots in common with Fulton Hogan.

"This sort of practical teamwork in the community is something we do every day, and we're pleased to help a charity that's doing something similar in a critically important area of health."

From left to right: Fulton Hogan Managing Director Cos Bruyn, MND New Zealand General Manager Carl Sunderland, Fulton Hogan Chairman David Faulkner, Fulton Hogan Executive General Manager – Culture, Jules Fulton

To find out more about the Fulton Hogan MND New Zealand Support Fund, visit our website: https://mnd.org.nz/support-fund-and-grants/.

If you're interested in applying for a grant, get in touch with your support team member, who can discuss your needs and help with the application process.

Help is at hand with Mycare

Family members are usually the main caregivers for people with MND, but from time to time everyone needs a break. It's at times like these that relief care is a great option to consider.

Mycare,funded by the Ministry of Health, is an online space where you can easily connect with local care providers to help when you need a break.

If you're supporting a disabled family member under the age of 65, and you've already been allocated carer support hours by your Needs Assessment Service, you can access the service to recruit relief carers.

Relief carers do the things that family members usually do, like providing companionship, organising outings, overnight support, and personal care. Having a relief carer means family members can relax, safe in the knowledge their loved one is well cared for.

With Mycare, you can view the profiles of people who provide relief care and exchange instant messages with them, ensuring you find the right fit for your family. You can also post your own care requests, to which carers are able to respond.

There are two ways to start accessing Mycare. You can either get in touch with your Needs Assessment Service Coordination (NASC) organisation, who can send a referral, or you can visit the Mycare website: http://www.mycare.co.nz and fill out a short form.

If your family or whanau member doesn't currently receive carer support and you are their unpaid full-time carer, the carer support subsidy could be an option to help you fund regular breaks. Get in touch with your local NASC organisation who can talk more about this with you.

mycare

Grocery Charity Ball 2019 supporting MND New Zealand

The Grocery Charity Ball Trust was established in 2004, running the premier event on the grocery industry social calendar each year, with profits going to charities all over New Zealand.

Over the past fifteen years, the trust has directed more than $3 million to charities, with support from sponsor organisations including Foodstuffs, Countdown, and the New Zealand Food and Grocery Council.

We're delighted that MND New Zealand was selected as the beneficiary of the Grocery Charity Ball 2019!

The ball was held at the Sky City Convention Centre on Saturday 14th September, and as you can see from these fabulous images captured on the night by Quikpix, it was an amazing event! The undeniable star of the evening was 14-year-old Jackson Horton, who spoke movingly about his experience supporting his dad Greg, who was diagnosed with MND in 2015.

We're thrilled to announce that through the generosity of sponsors, attendees at the ball, and everyone who placed a bid on silent auction items, $245,000 was raised in aid of MND New Zealand – one of the largest amounts raised by the event in recent years.

MND New Zealand relies almost entirely on the generosity of the New Zealand community to meet our financial needs. We're humbled and grateful to receive this contribution, which will help us continue to provide our free, personalised service for New Zealanders living with MND.

A massive thanks to the Grocery Charity Ball Trustees, S2N Events, everyone who donated auction items or their time to help out behind the scene, and those who attended on the night in support of MND New Zealand.

Brad Blaze wows the crowd with his speed painting skills

Above: MND New Zealand Fundraising Manager Kate Dalders (right) and volunteers packed goodie bags and helped out behind the scenes. Below: crowd favourite on the night, Jackson Horton

MND New Zealand representatives enjoying the evening

A day of hope and remembrance with MND NSW

Earlier this year, MND New Zealand Council member Jodie O'Doherty travelled to Sydney to spend Mother's Day with her mum Rose, who is living with MND.

While there, Jodie attended "A Day of Hope And Remembrance", an event hosted by MND NSW at the Soka Gakkai International Centre in Sydney Olympic Park, along with her mum and other family members.

Guest speakers included Dr Ian Blair from Macquarie University, who over 20 years ago travelled to the USA to help lead the way in research that uncovered the second gene related to MND.

Jodie had this to say of the day's events: "This event is held annually as a way to remember those who have died of MND, but also to show hope and support to those living with it. It is a great way to acknowledge current research projects and celebrate recent breakthroughs. I learned a lot about MND NSW and about motor neurone disease from this event."

A day of hope, Back: Jacob Degeling. Middle: Dr Ian Blair (Macquarie University), Teressa Quinn, Geraldine Pagano, Sharon Degeling, Karen Ridikas, Jodie O'Doherty, Front: Rose Attard and Emmanuel Degeling

NEW ZEALAND MND REGISTRY

Join the MND Registry!

The New Zealand MND Registry connects people living with MND to researchers. If you have MND, we encourage you to enrol. It doesn't matter if you are old or young, newly diagnosed or not, born in New Zealand or not.

We want to enrol people of all ethnicities, from Cape Reinga to Stewart Island, aiming to capture information about every single person with MND in New Zealand.

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

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

Treat yourself and support us with Rewardhub

Rewardhub

We are excited to share a new way for people to support MND New Zealand that costs nothing and can even save you money!

Rewardhub is a new platform that turns online shoppers into everyday heroes. Simply visit our page and sign up (it's free and takes about 30 seconds), then shop online from over 100 brands and retailers. Each time you make a purchase we receive a donation!

More and more retailers are getting onboard with Rewardhub, which features exclusive offers that will save you money on everything from broadband, power, mobile, banking, KiwiSaver, fashion, travel, entertainment, beauty, food, drink, and much more. With more than 60 brands on board and the list growing each week, it's an easy place to shop.

So what are you waiting for? Head on over to Rewardhub, sign up, and share our page www.Rewardhub.co.nz/mnd-new-zealand with your friends and family.

Charlotte's story

At the age of 14, my heart broke as I sat on the couch being told that my father and hero, Stephen Douglas Butcher, had MND at age 54, with a life expectancy of 2 to 5 years.

We had noticed my dad's speech starting to deteriorate, but initially doctors thought it was because of a minor stroke. A friend of the family who is an ENT doctor suspected it was MND and a neurologist soon confirmed it.

Being so young, I was clueless as to what was going to happen and the reality that my father was going to leave soon. I was in denial. Why *my* dad?

As time went on my mum, sister, and I spent numerous days and nights in the hospital – a place I now fear – with our hero as he dealt with breathing difficulties and stomach peg insertion.

Through family and friends, we heard about stem cell treatment at the Dr Hino clinic in Mexico. Although there were no guarantees it would work, we gave it a go.

As a family we wanted to make memories, and we sure did! A highlight was a trip to America, where we visited Disneyland. I will always cherish the time we had, going on rides with Dad and exploring.

By now, my life was very different from the average fifteen-year-old girl's. I spent as much time as I could helping with things like feeding my father through his stomach peg, brushing his hair and tying his shoes; things that were impossible for Dad to do for himself due to his rapidly progressing MND.

Charlotte and her dad when she was a baby.

Having to help Dad, especially talking through a whiteboard and iPad, really woke me up to the realisation that he was deteriorating before me. Instead of the usual "Love you to the moon and back" at night, there was just silence, and it really hit me.

Charlotte with her dad and sister at California Adventure Park, Disneyland.

Since my father's diagnosis we have participated in the Walk 2 D'Feet MND to raise awareness for this cruel disease and give money towards the research to one day find a cure.

As a family we had t-shirts made in honour of my dad. Our first walk was completed whilst Mum and Dad were in Mexico for his first treatment. It was special for him to know that from the other side of the world, we were walking for him.

One year and 24 days after he was diagnosed, my father passed on the 25th of September 2017. I was 15 when my capable father was taken away from me, after being trapped inside a body that no longer worked.

My father was a strong, hard-working man who loved all those around him dearly. I'll always remember him as an active man with a love for quad bikes, and most importantly as the world's best dad who put his two girls first, giving us everything we could want including our own playground at home and my first quad bike at the age of two.

MND changed our lives, making us aware of something we never knew existed: a disease I would never wish upon anyone. I now go forth in life knowing I will never have my father to be there for important moments: teaching me to drive, being at my 21st, and eventually walking me down the aisle. MND took my dad, hero, and the man I looked up to.

Charlotte's dad quad biking.

Findings of the MND Community Survey are in!

Recently, we released he findings of the MND New Zealand Community Survey. Also included in the report are our commitments to addressing the feedback received, which has been instrumental in the development of our organisational strategy 2019-2022, which you can learn more about on page 14.

Point Research developed and conducted the survey on our behalf. The survey was distributed nationwide to 4963 people, including people with MND, their carers, and previous carers of people with MND, health professionals, and other supporters/stakeholders.

It was pleasing to note that response rates were very high amongst those who were invited to participate: people with MND (70%), their families and carers (70%) and health professionals (41%). We appreciate the time and effort given by everyone who shared their views with us.

The survey focused on six key areas:

- Supporting people with MND
- Needs of people with MND
- Connecting with MND New Zealand – people with MND & Health professionals
- MND New Zealand – supported research
- MND New Zealand's purpose
- Fundraising & campaigns

Supporting people with MND

67% **of people with MND found the support team very helpful.** People with MND who live close to their support workers base were significantly **more likely** to say the organisation was very helpful.

Needs of people with MND – information

60% of people with MND, family and current carers have **unmet information needs.**

People with MND, family and carers get about **as much information from MND New Zealand's website, support workers and publications** as they do from neurologists and other medical specialists.

All respondent groups wanted **information in a timely manner.**

People with MND needed **more information about the disease and treatments.**

Family and carers needed to know **how to help** the person with MND, practically and emotionally. They also wanted to know how to cope, and how to help other family members cope.

90% In addition, 90% of **previous carers** stated they had unmet information needs.

Needs of people with MND – Practical

40% of people with MND, family and current carers have **unmet practical support needs**

Many people said practical support is provided through their DHB and its allocated service provider.

Help with practical needs included assistance with **work around the home** and **equipment** for home-based care and movement.

Younger respondents reported needing more help with **transport, personal care, financial hardship and employment issues.**

Older people and people with MND living alone reported **daily struggles** and **safety concerns** caused by these unmet practical support needs

Needs of people with MND – social and emotional

People with MND, family members and carers, and previous carers reported **needing less social, relationship, emotional and psychological support** than physical and information support.

Young people with MND, family members and carers (i.e. people under 55 of age), however, reported a **need for more social and emotional support** than older people with MND or family and carers.

40% of people with MND, family and carers said they know of, or **use a local support group**. Those who do use the groups find them helpful.

Previous carers reported having **more unmet social and emotional needs during the later stages** of the disease.

Some people with MND said they had become **isolated** and **lonely** because they were no longer able to work, and connect with people who understood.

Connecting with MND New Zealand – people with MND & Health professionals

Most people with MND (63%) said they heard about MND New Zealand at diagnosis with over half (54%) being told by their neurologist.

Fewer families and carers said they heard about MND New Zealand at diagnosis (41%) and many discovered MND New Zealand via the organisation's website (30%).

Most **health professionals** (84%) reported that **MND New Zealand works well or very well** with them to care for and support people with MND. The majority said MND New Zealand adds **valuable care and support** in addition to what clinical services provide.

MND New Zealand – supported research

91% support **fundraising** to enable **research**, especially around **developing clinical pathways**

MND New Zealand's purpose

All MND New Zealand's key purposes were considered important, but **support services**, **advocacy and research** were considered the most important of all.

Fundraising & campaigns

90% of supporters have **participated** in MND New Zealand events. More than half of these took part in **Walk 2 D'Feet MND.**

Overall, the results show that "MND New Zealand plays an important role in providing care and support to people with MND and their families and carers" (Point Research, 2018). However, the survey also identified a clear need for development in some areas, such as information provision, increased practical support, and our use of current technology.

We're committed to continuing to improve the support we offer, meeting unmet needs of people with MND and their families, continuing to encourage and support research, working with healthcare providers to advocate for the needs of people with MND, and increasing our brand awareness to maximise fundraising opportunities.

Participants pose for a group photo

Hui called to bring light to issues faced by people with MND

New Zealand has the highest known rate of MND in the world, and what's vital as people deal with this rapidly progressing disease, is access to the right care and information.

Supporting people with MND to get access to the care they need is very important to us, and we're aware that the levels and types of care available to people living with MND differ from region to region.

Because MND New Zealand is the only national organisation supporting people with MND and their families, we're in a unique position to understand the variances in care and support.

As a starting point, we thought it was best to bring everyone with an interest together in one place to discuss issues and potential solutions, and the idea of the motor neurone disease hui was born.

The hui is the brainchild of MND New Zealand Community and Research Advisor Dr Claire Reilly, who has been living with MND for the past thirteen years. Claire says:

"Having worked in the New Zealand health system, I have an advantage knowing which services I need and how to access them. This is not the case for most of our community.

MND New Zealand ambassador Tamati Coffey and Dr Claire Reilly smile for the camera


Group discussions were productive and thought provoking


MND New Zealand patron Ruth Dyson officially opening the Hui

Navigating the health system can be daunting for people with MND & whanau. Our community have told us that they want national standards of care for people with MND, that are equitable for everyone. Today's hui is a first step towards achieving that goal."

Getting dozens of people, including health professionals, the MND New Zealand team, and Members of Parliament, in the same place at the same time was a logistical challenge, so what better place to meet than in the capital city – at Parliament, to be exact!

On Wednesday 18th September, 55 people met at The Great Hall for the first ever motor neurone disease hui, focused on discussing ways to standardise care for people living with MND. Attendees included representatives from MND New Zealand, health professionals, MND New Zealand Patron the Hon. Ruth Dyson MP, Minister for Health the Hon. Dr David Clark MP, as well as representatives from district health boards across New Zealand.

The turnout was excellent, as was the opportunity to share our challenges and insights with the Minister for Health. The day was broken into two parts, with speakers in the morning and small group workshops in the afternoon.

A key outcome of the day was the establishment of a working group, made up of health care professionals from a variety of disciplines, who will start developing standardised guidelines for care of people with MND.

MND ambassador Tamati Coffey, MP for Waiariki, and his partner Tim, whose Aunt had MND, also managed to pop in for a little while with their baby Tutanekai.

Overall the hui was a huge success! It was great to have so much support and commitment for improving the lives of people with MND, and we're excited to hear more from the working group as they develop guidelines.

Support Team Leader Toni Foster and Community and Research Advisor Dr Claire Reilly address the audience

When life hands you lemons, fundraise for MND!

How cute are these two? Meet Tom and Madeline. Last year their grandad was diagnosed with MND, and they wanted to do something to help. Armed with an abundance of lemons and limes from trees in their backyard, Tom and Madeline followed in the footsteps of dozens of enterprising kids before them and set up shop outside their front gate.

A true team effort was involved, with their mum Anna helping out, along with a couple of their friends.

Was it the lovely fresh citrus fruit? The cute kids with their adorable sign? Generous passers-by? Most likely a combination of all three meant that Tom and Madeline were able to raise $166.80 for MND New Zealand! What an awesome effort. We think you are superstars!

Changes to prescribing restrictions for Riluzole

RILUTEK®

We've been closely following the Medsafe consultation on the changes to the prescribing restrictions on Riluzole (trade name "Rilutek").

Earlier this year, we raised concerns about the need for Riluzole to be prescribed only by a specialist. After hearing our concerns, Medsafe proposed an amendment to make it possible to prescribe Rilutek where the prescribing decision is made after collaboration or following consultation with physicians who care for patients with Motor Neurone Disease, neurologists and palliative care physicians.

The consultation process attracted 28 submissions, all of which supported the proposed changes. We're pleased to let you know that on Monday 7th October, the prescribing restrictions on Riluzole changed to:

"Riluzole can only be prescribed by authorised prescribers where the prescribing decision is taken in collaboration with, or following consultation with, physicians who care for patients with Motor Neurone Disease, neurologists and palliative care physicians."

We're very satisfied with this outcome, because it improves access to Rilutek for people living with MND.

Support Team News

By Support Team Leader Toni Foster

We've been busy this year providing support for those with MND and their families, whanau and health professionals, attending events, running awareness talks in the community, and collating client feedback for the recent hui.

During Awareness Week, Carol and Jane were pleased to attend "Cuppa Tea" events in their areas. Elise was invited to speak on the Breakfast Radio show on Fresh FM. The interview is available online by visiting https://www.freshfm.net/Programmes, searching for "Fresh start Tuesday with Wendy Andrews" and selecting the episode for June 18th. Elise's interview is about an hour into the programme.

Team members have also been running education sessions for staff at rest homes and private hospitals. The feedback we've received is that by raising awareness of the needs of those with MND, staff in these facilities feel more confident caring for people with MND. Our clients also say they receive improved care and understanding.

In August the team gathered in Auckland for two days, focused on professional development. We spent time discussing our service, what's working, what we can improve, and the differences between health services around New Zealand.

We also heard from a variety of speakers who provided us with information and gave us a point of contact for concerns that may arise. Getting the team together provides the opportunity not only for professional development, but also for peer support for team members, who are all based remotely.

On September 18th, Moira and I represented the support team at the MND New Zealand hui at Parliament. I presented on behalf of MND New Zealand and Moira and I both participated in the afternoon group sessions.

It was fantastic to see the enthusiasm of everyone who attended, and we are excited to see the process of developing national guidelines for the management of MND in New Zealand unfold.

LIKE US ON facebook

Want to keep abreast of all the latest news, research and events hosted by MND New Zealand?

Like us on Facebook and visit our page where we regularly post updates and share information about living with MND.

Find us on Facebook at:
https://www.facebook.com/mndanz/

MND Awareness Week 2019

Although New Zealand has a very high rate of MND, public awareness about this debilitating disease is low, with many Kiwis completely unaware that it exists.

We're aiming to change that through our annual MND Awareness Week, a chance to come together as a community and educate and inform the general public about MND, helping them to understand and support our mission to improve the lives of people living with MND and their families.

Held from the 17th to the 23rd of June, this year's MND Awareness Week was packed with lots of different events held in communities all over New Zealand.

The week started with the exciting announcement of MND New Zealand's selection as Emirates Team New Zealand's charity partner. The announcement was screened on Seven Sharp on Monday 17th June, and featured MND New Zealand Council member Greg Horton. We're delighted to embark on this new partnership, which you can read more about on the cover of this issue.

A great way for people to get involved during MND Awareness Week is by holding a "Cuppa Tea for MND" event, which gets local people together to talk about MND and how it affects the lives of so many New Zealanders.

This year, over 30 "Cuppa Tea for MND" events were held in communities across New Zealand, from the top of the North Island down to the tip of the South Island, and even one in Parliament! What an amazing show of support from all over the country.

Arwen held a Mad Hatters Tea party to raise awareness about MND

It was wonderful to hear about so many people coming together over a cup of tea, raising awareness about MND – and raising funds to go towards our work. During Awareness Week the "Cuppa Tea" events alone raised over $24,000!

We really appreciate the effort of everyone involved with organising and supporting these events all around New Zealand. Your support is vital to helping us continue to provide free, personalised support to people living with MND and their families.

In Auckland, we hosted "An Update on MND Research – Homegrown and Abroad", featuring Dr Claire Reilly presenting our 2019–2022 Research Strategy, as well as guest speakers Professor Chris Shaw, Dr Emma Scotter, and Kerry Walker. If you're interested in learning more about this, turn to page six.

If you visited our Facebook page during MND Awareness Week, you would also have seen an inspiring video featuring David Seymour courageously discussing his journey with MND and his advice to people who have recently received a diagnosis.

Once again, a massive thank you to everyone who got out and about in their local communities hosting events and raising awareness of MND. We really appreciate the support and can't wait for Awareness Week 2020!

Helen Palmer's 'Cuppa Tea for MND' event was a hit. Below: Lovely cupcakes at Angelique Lotter's 'Cuppa Tea for MND'

It's never too early to start planning. Get in touch if you are interested in showing your support during MND Awareness Week 2020 (15–21 June 2020). Email: kate.dalders@mnd.org.nz.

Our Strategic Plan for 2019–2022

This year we developed a new strategic plan designed to set the direction for our organisation for the next three years.

The Strategic Plan 2019–2022 details our commitment to successfully delivering six strategic priorities, continuing to work towards achieving our vision, and maintaining our values. People living with MND will always remain at the centre of everything we do.

In order to develop the strategic plan, it was important to consider feedback from our community, so we analysed the findings of the MND New Zealand community survey and used this to help shape the strategy (more on this on page 8).

The very high response rate to the survey "means that the survey results can be taken as a reliable indication of the support needs of MND New Zealand's clients." (Point Research, 2018).

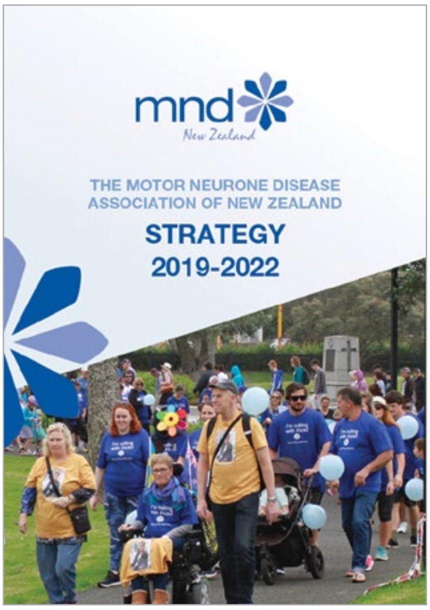
As well as considering feedback received though the community survey, the whole team got together at our national office in Auckland in March to collaborate and formulate ideas, which also contributed to the strategy.

The plan is designed to support not only those living with MND today, but also those who have yet to be diagnosed, as well as their carers and families. It shows how we will maintain our commitment to ensuring that people living with MND, as well as their carers and families, receive the best quality support, as well as championing their right to access the best healthcare and social assistance throughout New Zealand.

Outlined are our strategic goals and priorities for 2019–2022. If you'd like to know more, a copy of the full Strategic Plan 2019–2022 is available on our website: https://mnd.org.nz/our-organisation/

STRATEGIC PRIORITIES

1. To strive to provide the best quality support to people living with MND
2. To help guide health professionals so they can provide the best support and care for people living with MND
3. To raise awareness of MND and strengthen our presence and capacity as the leading authority on MND in New Zealand
4. To develop effective strategic partnerships and collaborations, working together to achieve more for people living with MND
5. To develop a globally connected, comprehensive, national MND research programme
6. To continue to improve the way we run MND New Zealand with a focus on effectiveness and sustainability, and ensuring our staff have the right tools to do the job.



mnd New Zealand

THE MOTOR NEURONE DISEASE ASSOCIATION OF NEW ZEALAND

STRATEGY 2019-2022

STRATEGIC GOALS

1. Enhancing our support services
2. Improving our information and engagement
3. Strengthening our Organisational CAPACITY and SUSTAINABILITY

Share your story

If you want to share your story and personal experiences living with MND we'd love to hear from you. We also encourage family members and carers of a loved one with MND, to share their stories. Email us: sarah.tora@mnd.org.nz or via our share your story form on our website. Raising awareness of MND is vital and sharing personal experiences is a powerful way to do this.

Hawkes Bay helping ourselves – two years on

By Dave Waugh

Dave Waugh has been living with MND for nine years and runs the Hawkes Bay MND Coffee Support Group.

Diagnosing MND is a challenge, even for the experts! I found the process exhausting, and passed through various support groups for MS, Parkinson's, CIDP, and Guillain-Barre, until eventually I was given a definite diagnosis and, of course, connected with MND New Zealand by attending a Walk 2 D'Feet MND event.

It was hard to meet others going through the same things as me, and finding useful information was also difficult.

The MND Support Team, or as I like to say, our personal angels, are busy providing support to people with MND and their families, so their time is limited, and they can't be everywhere at once.

This is where MND support groups are a great option, bringing into contact those who would like to meet other people with MND, present and past carers, and any other interested parties.

It's been almost two years since we started our MND Coffee Support Group in Hawke's Bay as a way of getting together to look at:

- encouraging Hawke's Bay medical practitioners to have a better understanding of MND and its various forms and to offer integrated services that MND sufferers need (speech therapy, physiotherapy, occupational therapy, personal care, respite care etc.)
- providing a way for people living with MND to access relevant, useful information
- generating ideas to increase awareness and understanding of MND
- sharing tips and ideas on how to increase comfort
- sharing local knowledge (e.g. DHB parking, transport and hospital appointments) to empower people with MND to help themselves.

Being diagnosed with MND can be daunting but keeping as active as possible and remaining positive improves the quality of life for people with MND and everyone around them.

I have found being involved with the Hawke's Bay Coffee Support Group a great way to meet others going through the same experience as me.

Getting together over a cup of coffee regularly to engage and support each other, sharing local knowledge, complements the wonderful work of the MND New Zealand Support Team.

It's also a great bonus to have ex-carers regularly attending the coffee group, as their knowledge and experience is invaluable.

If you're located in Hawke's Bay, why not come along to our coffee group? We meet every second month and would love to have you join us. To find out more, email me on dgwaugh22@gmail.com .

STOP PRESS!

National Council update

Our 2019 Annual General Meeting was held on Saturday 2nd November in Auckland, where we announced some changes to our National Council.

We welcomed Nick Molcsan, Caron Palmer, Chris Drennan, Michael Fuyala and Wayne Philip as Council members, and said farewell and thank you to Beth Watson and Tony Treloar who retired from Council at the meeting.

Greg Horton and Anna Chalmers were appointed as Co-chairpersons and Lucy Haberfield as Secretary/Treasurer.

Check out the next issue of MND news, where you can find out more about this year's AGM, Beth and Tony's farewell and meet our new Council members.

Introducing Lydia and the MND Research Network

The key to one day discovering a cure for MND is research. The NZ MND Research Network was created in 2017 by Jayne McLean and Dr Emma Scotter of the Centre for Brain Research at Auckland University. It's designed to facilitate the interaction between MND biomedical and clinical researchers, allied health professionals, and other researchers who have an impact on MND in New Zealand.

Still in its growth phase, the network, which is funded with help from MND New Zealand, aims to stay connected with current members by providing more opportunities for face-to-face interactions, such as participation in the recent MND hui and the upcoming inaugural MND NZ Research Conference. Another key objective is establishing a social media presence. Check out NZ MND Research Network on Facebook and Twitter!

On the network's website, https://www.mndresearch.auckland.ac.nz, you can find a wealth of information, including profiles of many of New Zealand's MND researchers, current research resources, and opportunities of interest for students and researchers (grants, scholarships, jobs, conferences/research events).

But who is the face behind the MND Research Network? Meet Lydia Everhart. Originally from the United States, Lydia moved to New Zealand late last year and has been managing the MND Research Network since May this year. Lydia has a bachelor's degree in chemical engineering and a master's in biomedical engineering.


Lydia Everhart

Lydia's research experience spans several fields, including testing clinical MRI technology for cancer and cardiac diagnostics, and developing therapies to treat blood loss after traumatic injury.

In addition to being involved in research, Lydia has previously worked in Operations Management for three years, and it is this unique combination of skills and experience that has her ideally placed to lead the NZ MND Research Network on its exciting growth journey.

There's more to Lydia than just work, though! She enjoys a wide range of hobbies, including travelling, powerlifting, dancing, and cross-stitching.

Welcome to Aotearoa and the New Zealand MND community, Lydia. It's great to have you here!

Spotlight on Research for Global MND Awareness Day 2019

Every year on June 21st is global MND Awareness Day, when MND associations the world over focus on raising awareness of the disease amongst the general public.

This year, June 21st fell on a Friday, at the end of MND Awareness Week in New Zealand, so we decided to end the week with a bang, hosting an event entitled "An Update on MND Research – Homegrown and Abroad".


Professor Chris Shaw addresses the audience

Held in Auckland, the event featured MND New Zealand Community and Research Advisor Dr Claire Reilly presenting MND New Zealand's Research Strategy 2019–2022.

The objective of the Research Strategy is to promote and foster research so that everyone with MND living in New Zealand receives the best available evidence-based care and support, and also remaining part of the international effort to identify the causes, and ultimately a cure, for MND.

As well as Dr Reilly's engaging presentation, attendees heard from guest speakers Professor Chris Shaw from Kings College in London, Dr Emma Scotter from the Centre for Brain Research in Auckland, and Kerry Walker from the MND Registry.

We're delighted to have another opportunity to host Professor Shaw and Dr Scotter again soon, as speakers at the MND New Zealand Research Conference on 9th December.

Professor Shaw will present his talk entitled "Are we there yet? Progress on the path to gene therapy for MND", while Dr Scotter will be speaking about pathways related to protein TDP-4 and genetic screening of people with MND.

MND New Zealand General Manager Carl Sunderland had this to say about the event: "The research afternoon was a great opportunity for us to facilitate face-to-face interaction between internationally recognised researchers and the New Zealand MND community, who could 'ask the experts' questions in a supportive environment."

If you couldn't attend "An update on MND Research – Homegrown and Abroad", a video of the afternoon is available under the "Research News" section of our website.

Local research examines environmental risk factors for MND

Grace Chen is a researcher based at the Centre for Public Health Research at Massey University, where she has worked since completing her Postgraduate Diploma in Public Health (with Distinction) in 2013.

At the moment, Grace is looking at occupational and environmental risk factors for MND in New Zealand. Her current PhD thesis will identify occupations, and specific occupational and environmental exposures, that are associated with increased risk of MND.

Earlier this year, the first paper and findings, “Occupation and Motor Neurone Disease: a New Zealand case-control study”, was published in *Occupational and Environmental Medicine.*

As the title eludes to, the paper examines the relationship between the occurrence of MND and the occupation of the person with MND. Grace said this about her research: “We have previously reported the results on a New Zealand population-based case-control study evaluating occupations as risk factors for MND. The aim of this study was to investigate the associations between 11 different occupational exposure groups and the risk of MND by using self-reported job-related exposures.”

321 participants were selected for the study, with the assistance of MND New Zealand and hospital discharge records, and 605 population controls from the electoral roll between 2013 and 2016. A standardised questionnaire was used to gather information on personal and demographic details, lifestyle factors and a full occupational history with detailed workplaces exposures. Analyses were adjusted for age, gender, ethnicity, socioeconomic status, education, and smoking.

The results of the study indicate that significantly elevated risks for MND were observed for self- reported job-related exposures to fibres, fumigants, animals and animal products, as well as some chemicals such as fungicides, insecticides, herbicides, and timber preservatives

While caution needs to be taken when interpreting the study results, given the lack of direct exposure measures, findings are consistent with previous results on agriculture occupations and MND risk. In the future, Grace plans to focus her research on exposures specific for certain job tasks and dose-response relationships.

If you’d like to find out more about this research, a copy of the full report can be found on our website under “Research News”, and Grace will also be speaking at the upcoming MND New Zealand Research Conference on December 9th at the Cordis Hotel in Auckland.

The MND New Zealand Research Conference is nearly here!

We’re gathering a number of the world’s leading MND experts to share their knowledge and expertise on MND right here in New Zealand!

In conjunction with the NZ MND Research Network, we’re hosting the inaugural MND New Zealand Research Conference on December 9th at the Cordis Hotel in Auckland.

Fresh from presenting at the International symposium on ALS/MND in Perth, 16 speakers, many of whom are internationally acclaimed will share their latest insights and views.

Speakers include Professor Ammar Al- Chalabi, along with Kiwi expat, Professor Chris Shaw, both from Kings College in London, Professor Martin Turner from Oxford University, Professor Orla Hardiman from Trinity College Dublin, and some of New Zealand’s leading voices on MND research such as Distinguished Professor Sir Richard Faull and Dr Emma Scotter.

The conference is an opportunity to learn more about what these leading MND experts know, what they are working to understand and where they need more support. Discounted pricing is available for students as well as people with MND and their carers. We’d love to see you there, so head to https://events.mnd.org.nz/research-conference/ to register or find out more.

Take on a challenge for MND New Zealand

This year, several supporters have taken on incredible challenges to raise both funds for and awareness of MND.

In May 2019, MND New Zealand was a charity partner for the Rotorua Marathon. Over a dozen supporters took on the marathon challenge and raised over $1,500, while raising awareness by displaying the MND New Zealand logo around the course.

Taylah West caught the bug from the Rotorua Marathon and recruited a group of friends to raise even more awareness by taking on the Taupo Half-Marathon in August.

Ben, Matt & Logan midway through their journey across the French Alps

A group of amazing young people from Knox College participated in the Dunedin Marathon on Sunday 1st September, raising $2,327 for MND New Zealand!

Ben, Matt, and Logan cycled the French Alps during September and raised $4,662.25. Ben had this to say: "The challenge went very well – great times, great weather and amazing mountains."

Noel Child, Joe Whitelaw, and a group of friends also recently participated in the 5km challenge at Auckland Marathon in October, raising over $3000!

Thank you to everyone who has taken on challenges in aid of MND New Zealand this year. As well as raising funds, increasing public awareness of MND is incredibly important. A lot of people are still unaware of MND, and increased awareness means an opportunity for increased support of the work we do.

The Knox College team ready to run for MND

Get in touch if you, a friend, or family member would like to take on a challenge next year in aid of MND New Zealand. Sign up to a run, walk, cycle or even skydive as a New Year's resolution. We can provide support and resources to help you make the most of your experience. Email: kate.dalders@mnd.org.nz.

Corporates get icy for MND!

In 2015 the ALS Ice Bucket Challenge swept the globe, significantly raising awareness of motor neurone disease (also known in America as ALS) among the general public and resulting in $115 million being donated to the ALS Association in the America. Pete Frates, a former Boston College captain who is living with MND, initiated the challenge, which involves dumping a bucket of ice-cold water over your head.

MND New Zealand, in conjunction with Angel Street, have now launched The Corporate Ice Bucket Challenge. Director of Angel Street Marcus Gerbich came up with the idea, encouraging Kiwi businesses to raise awareness and funds to support people living with motor neurone disease.

In the lead up to their drenching, nominees and their companies have been fundraising in aid of MND New Zealand and have so far raised the equivalent cost of supporting 15 families with MND for a year. Angel Street generously kicked off fundraising by donating $5,000 to MND New Zealand and nominating the first three participants.

Nominees Calum Haslop (Go Bus Director), Murray Schnuriger (PwC Managing Partner) and Andrew Carpenter (TR Group Managing Director) will attend Walk 2 D'Feet MND in Auckland at Mt Roskill Memorial Park on 10th November to be publicly drenched by a bucket of iced water!

Our MND Support Team

We employ part-time support team members 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.

Toni Foster
Support Team Leader
Mob: 021 230 3038
Email: teamldr@mnda.org.nz

Sally King
DHBs: Northland & Waitemata
Mob: 027 202 8166
Email: sally.king@mnd.org.nz

Linda Oliver
DHBs: Auckland & Counties Manukau
Mob: 021 036 0218
Email: aklfieldwork@mnda.org.nz

Carol Matthews
DHBs: Waikato, Taranaki, Whanganui (North)
Ph: 029 773 6662
Email: wktofieldwork@mnda.org.nz

Jane Kay
DHBs: Bay of Plenty, Lakes, Hawkes Bay, Tairawhiti
Ph: 029 777 5588
Email: jane.kay@mnd.org.nz

Moira Young
DHBs: Capital & Coast, Hutt, Wairarapa, Mid Central, Whanganui (South)
Mob: 021 0278 4494
Email: wgtnfieldwork@mnda.org.nz

Elise Doyer
DHBs: Nelson, Marlborough, Canterbury, Upper West Coast
Add: Mob: 027 292 8581
Email: elise.doyer@mnd.org.nz

Kate Moulson
DHBs: South Canterbury, Southern, Lower West Coast
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 James Cleland

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
General Manager
Mob: 027 2412766
carl.sunderland@mnd.org.nz

Kate Dalders
Fundraising Manager
Mob: 027 206 9606
kate.dalders@mnd.org.nz

Hayley Watkinson
Administration and Accounts
admin@mnda.org.nz

Patricia Bell
Grants Administrator
patricia.bell@mnd.org.nz

Sarah Tora
Communications Manager
sarah.tora@mnd.org.nz

Dr Claire Reilly
MND Community & Research Advisor
claire.reilly@mnd.org.nz

NATIONAL COUNCIL

Co-chair: Anna Chalmers & Greg Horton
Treasurer & Secretary: Lucy Haberfield
Members: Fiona Hewerdine, Steve Green, Jodie O'Doherty, Nick Molcsan, Caron Palmer, Chris Drennan, Michael Fuyala, Wayne Philip

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 would like to thank the following organisations for their ongoing support of our work:

Emirates Team New Zealand • Fulton Hogan • Ministry of Health

We would also like to acknowledge the following for their generous support of MND New Zealand in 2019:

COGS
Louis and Patricia Emmett Murphy Foundation
Four Winds Foundation
Hugo Charitable Trust
The Lion Foundation
Lottery Minister's Discretionary Fund
Mount Wellington Foundation
F H Muter E M Pharazyn Trusts
One Foundation
Oxford Charitable Trust
Pub Charity
The Southern Trust
The Trusts Community Foundation

If you or an organisation you represent is interested in offering financial support to MND New Zealand, please get in touch with Carl Sunderland on carl.sunderland@mnd.org.nz

MND New Zealand Research Conference
9th December 2019 | AUCKLAND

Register Now at
https://events.mnd.org.nz/research-conference/