InTouch

KIA NOHO TATA Inclusive | Inspiring | Informative Autumn 21 Issue 109

Celebrating our triumphs

To Cyprus with love

Libby's marathon run for MG

I see you…

A mother's beautiful, poetic reflection

Boxing away perceptions

Olivia is throwing jabs and hooks from her wheelchair

Muscular Dystrophy
New Zealand

InTouch

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Kōrero with Tristram

The importance of the Covid-19 immunisation campaign cannot be underestimated.

Well I'm sure, if you're feeling like me, that the relaxation of the summer break feels well behind us all now as we power into another year of hard work, big challenges, and exciting opportunities.

An important piece of news from members' perspective is the ongoing campaign to immunise the country against Covid-19.

There will be a sequenced roll-out based on those that are higher risk going first. The importance of this campaign, for our individual and collective safety, cannot be underestimated.

Some critical elements that our team are mindful of, and will advocate for, are the fact that you, our members, and everyone in your bubble, should be immunised as soon as possible when it becomes available in your area.

The Covid-19 variants are significantly more transmissable and therefore the possibility of the virus escaping our MIQ facilities and re-entering the community remains a serious concern.

Although the immunisations each provide a good level of personal protection, the pieces of evidence that are still lacking are whether the immunisation prevents someone transmitting the virus to others around them.

Currently it looks like they may not fully prevent transmission hence the usual protections of physical distancing, wearing masks if you can, handwashing and contact tracer app use are even more important now.

Additionally, as more variants are identified we need to be mindful how effective these immunisations will be in the longer term.

Bottom line, although we may already be sick of it, we haven't heard the end of Covid yet – it will be with us for some time into the future.

Meanwhile, the time-critical challenge is getting these immunisations to our most at-risk and less-connected communities of members.

As a team we are strategising about what local initiatives we can do to work with DHBs and other providers as they begin the roll-out to ensure our members are front-and-centre in the implementation.

We also want to encourage you to get your usual flu shot done and out of the way as soon as possible as the two immunisations cannot be given within several weeks of each other, and the Covid-19 campaign will be ramping up at about the same time.

Finally, I want to reassure you, from my role on the Government Covid-19 Immunisation Implementation Advisory Group, that from the data I've been seeing inside the Ministry of Health the immunisations are very safe, have been well tested (not just in trials but as deployed in several countries now) and seem to provide very good levels of protection from serious illness.

Dr Tristram Ingham
National Executive Chairperson

America's Cup more accessible thanks to minibus grant

New vans are helping to reduce transport barriers such as accessibility and affordability for MDANZ members. *By Melanie Louden.*

A generous grant and the hard work of van interior experts meant MDANZ members had improved access to America's Cup events held in Auckland this month.

Funding from the Lottery Grants Board, to the tune of $233,174, meant the association could purchase two Mercedes Benz minibuses, and have them fitted out for wheelchair transportation by the team at Jackson Van Interiors.

National Executive Chairperson Tristram Ingham says the organisation wanted to provide a free door-to-door wheelchair accessible shuttle service to members to "support active engagement in America's Cup events".

The vans transported members to observation areas in the Viaduct and at Bastion Point.

Once the racing is over, one van will be used by MDANZ's Northern region, and the other by the Central region to provide ongoing transport options for members to events.

"A number of members have been unable to attend our peer support groups, annual meetings and community events because of the lack of accessible, affordable transport," Tristram says.

Jackson Van Interiors General Manager Neil Collis says it takes up to 160 hours to kit out an empty van with reinforced floors and walls, wheelchair restraints, swing-out seats and a hoist.

Top left: A very happy bunch. On their way to the Northern Region family camp held on Waitangi weekend, are (clockwise from front left) Ethan King, Oliver King, Neil Singh, Lachlan Islip and Neil Westwood.

Top right: The vans are fitted with hoists that can lift 350kgs.

Left: Jackson Van Interiors General Manager Neil Collis, left, and Northern Region Chairperson and National Vice-Chairperson Trevor Jenkin with one of the Mercedes Benz minibuses.

He says factory minibuses don't meet the needs of everyone, so the company does everything from manufacturing and fitting seat frames and hand controls, to carrying out crash tests to prove that their seats meet NZTA safety standards.

Northern Region Chairperson and National Vice-Chairperson Trevor Jenkin says the team at Jackson Van Interiors were extremely accommodating as they worked towards getting the vans fit for purpose.

"Nothing was too much trouble for these guys." Trevor says the vans will be a vital tool in helping members attend events and access services – including attending Northern Region camps.

"In the past people haven't attended camp because they can't get there, or they've had to hire a van to get there – which is an extra cost on top of attending camp."

He says MDANZ is incredibly grateful to Lotteries for the generous grant and to Jackson Van Interiors for the great customer service. "Without the help of Lotteries, Ingham Prestige Mercedes and Jacksons our members would have struggled to attend the America's Cup events and continued to miss out on events and support services. Thank you for your support of MDANZ – it really does make a difference," Trevor says.

Dragon slaying, car racing and building entire cities with your mates

As more people pick up gaming Scott Boyle checks out the controllers of two new consoles.

2021 has finally rolled in, kicking its predecessor to the curb and daring to be even worse.

Last year was a roller coaster of epic proportions and definitely one that none of us wish to repeat. But as Covid is going to be a big part of our lives going forward perhaps we should look at new ways to have fun and socialise. And what better option than gaming.

2020 was a fairly important year for gaming, and it had a massive effect on how people view games due to millions of people wisely going into lockdown.

Our own lockdown was rather brief compared to the rest of the world, but we were still left with weeks of nothing to do.

Reports say that thousands more people purchased a new console before and after lockdown as a result of the boredom, giving them the chance to experience entirely new stories, challenges, and adventures.

Date for your diary

April 30, 7pm: MDANZ AGM via Zoom. Members will be emailed a link closer to the date.

Scott Boyle is enjoying a game about Vikings during the Scandinavian invasion of England.

From slaying dragons and surviving in apocalyptic wastelands, to racing cars and building entire cities with your mates. Games let you do it all!

Even better is that gamers are pretty inclusive and welcoming to newcomers. Take 'Skyrim Grandma' for example, a wholesome 84-year-old who streams herself playing games for the whole world to see.

But where do you start? Well thankfully October and November last year saw the launch of the Playstation 5 and Xbox Series X. Two powerful new consoles that are much faster than the previous generation and allow for the making of bigger and better games.

At the moment I'm playing a game about Vikings during the Scandinavian invasion of England, something that is thrilling from a gameplay perspective, but also very historically accurate.

Of course, none of this matters unless you can play. Having played on both consoles since release I can say that the controllers are very easy to handle.

Having weaker hands myself I am always cautious of new controllers, but both are a good size, easy to hold and with sensitive buttons.

Even better is the customisation of settings, making life much easier for those of us with physical struggles.

Throughout 2021 we aim to share articles and blogs with our amazing members about the world of gaming. Topics such as what games are right for you, the health benefits of playing, the culture of the industry and even building a career by being a gamer. So, stay tuned.

Scott Boyle is a member of the MDANZ National Council.

A cup of tea and a catch up with Jane Hazlett

Each issue we introduce a MDANZ team member.

How long have you worked for the Muscular Dystrophy Association and what do you do?

I joined the Canterbury Branch team in November 2020 as the Fieldworker for the Upper South Island.

What qualifies as a great day at work for you?

A great day at work for me is meeting our members and getting to know their personal strengths, needs and goals and being able to facilitate access to further supports, services or resources and feeling like I have made a difference to someone's life.

If resources and funds weren't an issue, what would you like to see our members enjoying?

I think the "Covid year" has taught us to make the most of everyday and the opportunities that are presented to us. I would love to see our members taking every step possible to achieve their goals and to be interacting socially in the community and supporting each other, as well as accessing and enjoying the beautiful country that we live in.

What are you passionate about?

I am passionate about the health and well-being of not only myself and family but also those around me. I believe it is important to always look at the positives in your life as otherwise it is too easy to get bogged down with the negatives, which never makes you feel very good. Ⓝ

Winner of the Henry Kelsey Scholarship

The winner of the Henry Kelsey Scholarship, 26-year-old Alex Chan of Auckland University, says he was quite shocked but pleased when he got the news that the $10,000 scholarship was his.

The scholarship provides funds for individuals to undertake research towards a PhD studying muscular function, including the causes and treatment of muscular dysfunction. MDANZ collaborates with Universities New Zealand, which administers the scholarship, and our National Executive Chairperson, Tristram Ingham, chairs the committee.

Alex, who is in the third year of his PhD, explains his research is in a new area looking into how mitochondria regulates metabolism and stress. He is investigating the effect of a small peptide naturally produced by the mitochondria called MOTS-c on muscle function. One of his referees says this is a new and exciting field of research in that MOTS-c appears to be largely produced by the muscle, and early evidence suggests it can improve the metabolic function of muscle, and perturbed mitochondria and metabolic processes are common in many muscle pathologies. The outcomes from Alex's research project has potential to be translated into clinical models of muscular dysfunction. Alex says that by understanding the mechanisms of MOTS-c, it can provide a better understanding on how MOTS-c can improve skeletal muscle function when exposed to metabolic stress.

Alex was born in Hong Kong and his family came to New Zealand when he was just two and he grew up in Auckland's Botany Downs.

Unsure what to do when he first went to university he initially went into Biomedical Sciences, but later developed an interest in nutrition. His Master's degree was investigating different dairy protein formulations on skeletal muscle protein synthesis and his PhD is in muscle and mitochondrial physiology.

As to the future, he is unsure as yet, but is open to the possibility of a career in academia, teaching or industry work. But his current goal is to finish his research and PhD. Ⓝ

Ensuring our voices are heard

Alison Riseborough, one of two MDANZ representatives on the Disabled People's Organisation Coalition, provides an update on recent and current issues.

In mid-2020 I replaced Tristram Ingham as one of MDANZ's two representatives on the Disabled People's Organisation Coalition committee (DPO Coalition). Tristram is still the DPO Coalition representative on the Integrated Monitoring Mechanism (IMM) and is on some other government working groups because of his valuable skills and expertise.

The DPO Coalition represents the voices of disabled people to the highest levels of government. Other groups in the Coalition are the Disabled Persons Assembly NZ (DPA), Blind and Low Vision NZ, People First NZ, Deaf Aotearoa, Kāpō Māori Aotearoa, and Balance Aotearoa.

Since joining the DPO Coalition committee, I have learned that its activities include monitoring and providing advice on the Disability Action Plan, meeting with the Minister for Disability Issues, meeting senior government officials and commissioning research on pressing disability issues.

The DPO Coalition has to stretch itself wide to cover the many important issues that affect disabled people in New Zealand. Some of the recent and current issues of interest to MDANZ members are:

- **Disability Action Plan progress reports:** Each government agency must report six-monthly on the work it is doing under the Disability Action Plan. The committee reviews and comments on the reports before they are published. The first progress reports on the current DAP are due to be published in early 2021.
- **Accessibility legislation**: The new Government has renewed its commitment to establishing an Accessibility for New Zealanders Act. The DPO Coalition wants to ensure that disabled people's views are gathered effectively and are reflected in the advice on options that goes to ministers in May 2021. The Access Alliance is working in partnership on the operational aspects. The engagement process was expected to get under way in the new year. There will be opportunities for discussion and input through each DPO.
- **Making disability rights real in a pandemic:** DPO members were involved in production of a report describing disabled people's experiences during the Covid-19 response last year. The report can be found at: https://www.ombudsman.parliament.nz/resources/making-disability-rights-real-pandemic

Last year, Covid-19 severely disrupted many of the proposed actions under the Disability Action Plan. It looks like the pace of work is picking up again in the first half of 2021.

Some policy areas where there could be developments are:

- System transformation (disability support services).
- Access to health services.
- Education.
- Employment.
- Welfare reform.
- Building the leadership capabilities of disabled people.

Lack of accessible and affordable housing is another critical area where urgent reform is needed.

Please look out for opportunities to have your say on these issues and others that affect you. Ⓝ

You can contact Alison at alison.riseborough@mda.nz

Pride for Dukies' achievements

MDANZ members taking part in the Duke of Edinburgh's Hillary Award are rising to the challenge, writes Award Leader Marty Price.

When I think about the Dukies as they are tracking through their goals for the Bronze or Silver Medal, it fills me with a lot of pride that I am on this journey with them.

I just want to thank our Dukies for persevering through the lockdown and after it with each of their goals. As always stated, there is no rush to complete either medal; apart from ensuring it is all completed before that Dukie turns 25 years old, as this is the oldest they can be.

For our Dukies it all depends on their abilities and their condition as to how they will work through their goals and how far they want to push themselves.

The variety of goals that have already been completed is a testament to them; I am so very proud of what they have achieved so far.

I know some of our Dukies were very nervous at putting themselves forward for this knowing that their families cannot help them do it; they can drive them to places but can't actually help. So, this was a step outside the box for all.

Currently we have Ryan from Gore who has completed all his sections and is just waiting for his assessors to sign these off.

Joy in Nelson has completed her physical and voluntary sections and is one hour away from finishing her skills section and being signed off too.

Camille is in Auckland and has also completed her three sections.

These three are our Bronze Medal Dukies and all of them have done exceptionally well so far.

Our Silver Dukies are Jack in Invercargill who has completed his physical section of walking which he has done very well at, and Dylan of Auckland who has also completed his skills section of model rocketry.

Once all the sections are completed you can prepare to do the Adventurous Journey, and this can be done in a group setting with other Dukies or individually. At MDANZ we believe it's great to do it together as the Dukies can meet each other and chat about their goals.

We are tracking very well, and we would love to see more members, who are keen to step outside their comfort zone, join us.

Please get in contact; you won't be let down. Plus, these goals can lead you to many other opportunities in the community. Ⓝ

The Duke of Edinburgh's Hillary Award is for 14 to 24-year-olds. For more information go to: https://www.mda.org.nz/What-We-Offer/Duke-of-Edinburghs-Hillary-Award

MDANZ staff on the move

The Central Region farewelled fieldworker **Raygaana Naidoo**, who was a real professional, hugely capable and much liked by members. Ray joined us in August and left at the end of 2020. We wish her the very best.

In January, the Central Region lost the skills, enthusiasm and knowledge of **Michelle Smith** – the Community Coordinator (East Coast) since June 2019. Michelle, also a member, made a tangible difference to the member engagement in the East Coast districts having coordinated, run or supported many member events, peer-support workshops or fundraising initiatives.

Our Wellington members and the team will miss both Ray and Michelle, but Philippa, Talitha and Louise will be very capable as they pick up responsibility for covering the whole central region.

The National Support Office has welcomed **Kristin Cross** who took on the new role of Fundraising and Partnerships Advisor in January. Kristin comes from a corporate marketing background, has her own sales business, and helped St John create a new revenue stream that engaged businesses. Ⓝ

Kristin Cross

Camille gave her trusty mobility dog Lewis extra training as part of her Duke of Edinburgh's Hillary Award.

A new circle of friends and a boost in confidence

From taking on a leadership role, to spending more time with her mobility dog, Camille Peterson is taking full advantage of the Duke of Edinburgh's Hillary Award. *By Melanie Louden.*

The opportunity to combine her hobbies with stepping out of her comfort zone has given teenager Camille Peterson a new circle of friends and a boost of confidence.

Camille is among the MDANZ members taking part in the Duke of Edinburgh's Hillary Award – a programme that gives 14 to 24-year-olds the chance to challenge themselves, learn new skills and meet new people.

Participants carry out tasks in three categories – service; physical recreation; and skills, and go on an Adventurous Journey to complete bronze, silver and gold levels.

Members taking part design their own programme, set goals and record progress towards their achievement – all with the help of MDANZ Award Leader Marty Price.

At the bronze level, participants average at least one hour per week on each section, plus a further three months in one of the service, skills or physical recreation sections.

Camille, who has limb-girdle muscular dystrophy, began the programme mid-2019 and has completed the first three parts of the bronze award.

The 17-year-old Aucklander picked up volunteering in the Sexuality And Gender Acceptance group at her school for the service category.

This saw her volunteer as the Year 12 leader last year, and this year she is the Year 13 leader. Among other things, she helps organise events, fundraising and meetings.

Camille says putting herself forward for the leadership role last year was a "big push" out of her comfort zone, but "it was definitely worth it".

"It helped that they were all insanely friendly people. But I had to get used to talking to a group of people. Once I got over that initial feeling of 'these people are going to think I'm weird' it was okay.

"I've made lots of friends through that group, and I'm helping the community."

Camille's physical recreation activity was swimming, which she was only doing occasionally before starting the Hillary Award.

But having a home pool with a hoist and needing to keep up her hours in the pool meant she had to commit to regular swimming.

"It was a good chance to track my progress. I got to know my limits and got into a routine."

Camille's skill category was training her mobility dog Lewis, a four-year-old golden retriever.

Lewis has been part of the Peterson family for two years and goes to school with Camille.

"If I drop anything he picks it up. He can open doors. We're pretty close to school – it's a 20-minute walk to get there – he can press the button for the pedestrian crossing with his nose or paw."

Camille says when Lewis wears his mobility dog jacket he knows he is in work mode.

The Hillary Award has been a confidence booster for Camille, and she recommends it to other MDANZ members.

"It's an amazing opportunity to take elements of your hobbies and elevate them and to see what it's like to be doing things consistently."

MDANZ is a licensed Hillary Award provider, and through Award Leader Marty Price, MDANZ can provide funding and direct support for members aged between 14 and 24 years who want to take on the challenge to achieve either bronze, silver or gold level awards.
For more information go to:
https://www.mda.org.nz/What-We-Offer/Duke-of-Edinburghs-Hillary-Award

Around 60 members attended the MD Northern family camp.

I see you…

A beautiful and poetic family camp reflection from a grateful mother.

Corinne King, mum to Ethan, 9, and Ollie, 7, who both have Duchenne muscular dystrophy, reflects on a very special weekend away at the MD Northern Branch family camp and the generosity and love she saw being shared.

I see you...

I see you rushing to help your dad out of the pool with a hoist, scooter or cane and always with a smile on your face.

I see two grown men pulling another grown man to his feet with grace and good humour, so that he could have a swim like everyone else. I see that you could do that a few years ago by yourself but now you can't, but you don't complain.

I see the fear in your eyes when you talk about how your son is declining yet you smile and ask about my child.

I see you struggle to get in and out of the pool because of your disability, but you do it anyway.

I see you sitting beside your wheelchair waiting for it to charge, not upset that you can't move because your wheelchair has no juice, just waiting.

I see you pick your brother up from his wheelchair and place him on an electric scooter so that he can have that experience.

I see you rush to get your brother changed for a swim and remember his meds at dinner time, without being asked, and you are barely a teenager yourself!

I see you run around with a little boy's kite because his little legs won't let him and seeing his smile was everything.

I see you tired yourself, but taking a group of little boys in the big van just because they wanted to go for a ride.

I see you making customised certificates and trophies till late at night, just to make those little boys eyes light up. You are a true angel and you have no idea.

I see you making an obstacle course for the boys in wheelchairs, thinking about how everyone can be included and have fun.

I see you helping other people's kids into paddle boats so they can have the experience when your arms aren't the strongest either and your neck and shoulders are already killing you.

> *"Your grace and humility are something people strive for their whole lives and never achieve, and you just do it every day without even realising it".*

I see you walking with your child holding his hand for every step and NEVER taking your eyes off him because he can't fall and he's unstable. But you never complain.

And I see you chasing an able-bodied kid down on an electric scooter because that scooter is your friend's – "And he needs that scooter for his legs!".

I see you drive in all different directions to collect wheelchairs from one location and kids from other directions. All out of the goodness of your heart and all so as many kids as possible can have fun.

You don't know you are superheroes special needs families; but you are truly beautiful people and I feel incredibly blessed to be part of this world.

This world I would never have seen had I not had my boys.

This world of truly selfless people.

This world of immense understanding for others and putting others needs before your own.

Your grace and humility are something people strive for their whole lives and never achieve, and you just do it every day without even realising it.

These are the beautiful people of my muscular dystrophy family.

And all that… I saw in just three days at family camp.

Search 'Ethan & Ollie's Journey' on Facebook to follow what they are doing. Also see their story in the Spring 2019 issue of In Touch.

David Westwood and his mum Lucy Bennett on the obstacle course.

A great time had by all

The MD Northern family camp was held on Waitangi weekend at Ngāruawāhia Christian Camp and was attended by around 60 members.

The camp was filled with lots of fun and laughter, the kids (and adults) enjoyed the pool, the waterslide, paddle boats and a very special visit from members of the Ngāruawāhia Police who handed out wheelchair licenses and trophies to the kids after they finished their obstacle course.

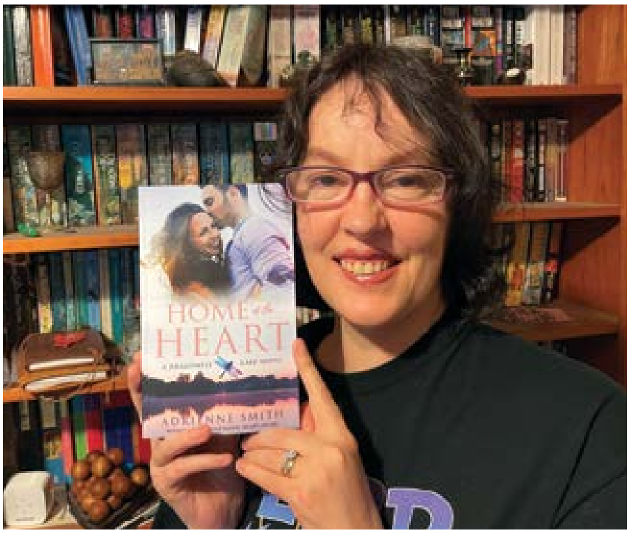
Thank you to Pub Charities and the Auckland Chapter of Harley Owners' Group (HOG) for helping fund this camp.

Neil Singh is all smiles on the water slide.

Home is where the heart is for award-winning author

Her contemporary small-town stories are winning fans

Adrienne Smith's first published romance novel has scooped three national awards. She shares her success story with Melanie Louden.



Adrienne has collected three awards for her first published novel.

Adrienne Smith's love of writing started at a young age and has followed her through to adulthood, resulting in her first published novel being an award winner.

The 48-year-old Auckland resident has been writing since she can remember.

"I recall being given a very old typewriter – back before we had computers – that didn't have a working 'L' key and I had to write them all in by hand. My parents were teachers and supported reading and writing from a very early age."

Move forward to 2021 and the romance novelist is married to fellow award-winning author and MDANZ Northern Region Fieldworker Darian Smith, and she has recently won three awards for her first published novel.

Adrienne self-published *Home of the Heart – a Dragonfly Lake Novel*, in 2019 because it allows her to keep the rights and control over her own work.

"But it does mean you won't find me in mainstream bookstores."

Home of the Heart – a Dragonfly Lake Novel won the Romance Writers of New Zealand Pacific Hearts award for Completed Unpublished Novels in 2018 and in 2020, after it was published, went on to win their Koru Award for Best First Book.

"It was so exciting to win that, since you're going up against other published authors," Adrienne says.

Her book was also a finalist in the Best Long Book category for that year.

An unpublished novel that Adrienne plans to rework and add to her current series has also won Reader's Choice for the Romance Writers of New Zealand Clendon Award.

Inspiration for her "sweet contemporary small-town stories" doesn't come from anywhere specific, she says.

"Stories just pop into my head and grow from there. Usually it will start with a character popping up and a scene about them, and before you know it, they're demanding to have their whole story told!

"I really enjoy getting the voices in my head onto paper," says Adrienne, who also likes craft, knitting her own socks and cross-stitching in front of the TV in the evening.

> *"I really enjoy getting the voices in my head onto paper."*

Home of the Heart – a Dragonfly Lake Novel took Adrienne "years" to write. She works in the claims department of an insurance company and hopes to start working part-time this year, giving her more time to write.

Adrienne was diagnosed with myotonic dystrophy 11 years ago and says she is "lucky in that I can still walk and work and type".

"But things are getting harder. I just try to focus on what I can still do."

Darian helps her with a lot of things, and she works from home to make things a bit easier.

"Going out anywhere I have to walk that's not flat and on even ground is difficult, and stairs are an absolute no-go.

"But more than that, having to give up things like playing guitar has been a big loss," she says.

Darian has published six books – three in the *Agents of Kalanon* series (murder mysteries mixed with epic fantasy), a paranormal romance set in New Zealand, a short story collection, and a non-fiction book for writers on how to use psychology to create characters.

The competition is on between award winning authors Adrienne and her husband Darian.

His works have gone on win a Sir Julius Vogel Award and he has been a finalist several times. He has won two Koru Awards and was a finalist for the Self-Published Fantasy Blog-Off. He has also received the Awesome Indies Seal of Excellence.

Neither Adrienne nor Darian have any plans to stop writing – she is working on a sequel to *Home of the Heart – a Dragonfly Lake Novel*, while he is starting a shorter young adults' novel before working on book four in his *Agents of Kalanon* series.

You can find paperback and ebook versions of Adrienne and Darian's published works at www.amazon.com

MDANZ fieldworker and Myasthenia Gravis NZ founder, Talitha Vial, left was part of Libby Carmichael Venning's support team in Queenstown.

To Cyprus (and MG) with love

First-time marathon runner raises awareness and funds for myasthenia gravis.

When MDANZ came to the aid of mum Libby Carmichael Venning, she was so grateful she decided to run a marathon – giving her one of the best days of her life.

When her daughter had a "full body failure" as a result of myasthenia gravis, Libby Carmichael Venning felt helpless.

It was November 2019 and Libby's daughter Sacha Main was living in Northern Cyprus. Libby was in Christchurch.

"I had been living permanently in New Zealand for one and a half years by then. I felt helpless, guilty, mortified. Here was my daughter on the other side of the world…"

It was then that Libby reached out to MDANZ.

"I signed up and a fieldworker came to my house. Paul Graham… what an amazing guy," Libby says.

Paul, who has since retired from MDANZ, referred Libby to fellow fieldworker Talitha Vial, who also has myasthenia gravis and is the founder of support group Myasthenia Gravis NZ.

Libby, who turns 50 this month, was impressed by the information and support she received from MDANZ, Paul and Talitha as she sought to understand and learn more about her daughter's condition.

"I just said, these guys are amazing, I'm going to run a marathon for them."

So, she did.

In November last year Libby ran the Sotheby's International Realty Queenstown Marathon to raise awareness about the condition that is thought to affect one in 100,000 New Zealanders, and raise awareness for Myasthenia Gravis NZ.

"My friends in Cyprus, my son Tomas, and Sacha, [all] said 'don't be stupid'. I definitely took myself totally out of my comfort zone."

In the previous two years Libby lost 20 kilograms and a year before the marathon she started training, with her programme intensifying in the last 16 weeks.

"It was time consuming, life consuming. And at times it was quite terrifying – you set yourself targets and sometimes your body just doesn't want to do it. Just like MG."

Libby says taking part in the 42 kilometre event was "one of the best days of my life" – after the birth of her children and getting married to her husband Geoff.

She says the race-day atmosphere was great and the reason for taking part was never far from her mind.

"I had a flannel with a photo of Sacha printed on it. I was running with Sacha all the time, so that was lovely. And I died my hair bright blue – the colour for MG."

Libby completed the marathon in six hours 38 minutes and 40 seconds and says the event was tough – mentally and physically.

"I got to water station number four and I felt really rubbish. But when I saw Geoff, Talitha and my best friend Gill, at the 20 kilometre mark I knew I was going to do it.

"I burst into tears when I crossed the finish line. Talitha was so proud and pleased that I did it for MG.

"The next day I couldn't walk. I couldn't sit down, I couldn't do anything… just like MG," Libby says. "My body wasn't working that day.

"I still think about it now and think 'wow, I did that'. My toes were a bit damaged – but it reminds me of what I did."

As part of her efforts to raise money for Myasthenia Gravis NZ, Libby set up a Givealittle page which raised $3345.

"I was totally blown away. I know 2020 wasn't a great year to be fundraising, but if I could raise awareness, then I did my job. I never wanted it to be about me.

"I felt pride to be able to spread the word."

Libby's daughter Sacha, now 21, was diagnosed with myasthenia gravis after an incident during a high school exam.

"When she was 17, she was writing her answers on what she thought was a piece of paper. But she was writing on the desk. She had double vision."

Libby was still living in Cyprus with Sacha at the time, and after a handful of tests ocular myasthenia gravis was confirmed.

There had been no obvious signs of the condition, no symptoms, until the exam.

"She had years of complaining about being tired and having sore eyes. But we thought she was just going through those teenage years."

Sacha had no more episodes until the "full body failure" in November 2019. These days she isn't on any medication and "just lives day to day aware that her body could react at any time".

Sacha is really proud of Libby, but says at first she didn't believe her mum was serious about completing a marathon.

"In Cyprus she wasn't fit. Mum was a little overweight and loved drinking beer.

"I only realised she was taking this seriously when I would call her and she would say, 'are you okay? Because right now I am training, can I call you back?'.

"I was totally amazed at mum's commitment and passion and I am eternally grateful for the love and support we have both found from MGNZ. Talitha is an amazing new friend to my mum."

Libby says anyone contemplating what looks like an "unachievable goal" should just get out there and do it.

"I'd recommend running a marathon to anyone. If anyone is thinking 'should I or shouldn't I' … just do it – to raise awareness, to know you've done something special for someone."

"I'm still running, just not stupid amounts. I like running now – but just five kilometres at a time."

Talitha used the Givealittle funds Libby raised for Myasthenia Gravis NZ to buy information booklets, keyrings, bracelets and kids' books.

Sacha's face was printed on a flannel, meaning she was with mum Libby the whole way around the marathon. Photo credit: FinisherPix®

Olivia now attends boxing classes three or four times a week. Photo: Ben Hotchin.

Boxing away perceptions and challenges

Olivia is throwing jabs, hooks and uppercuts from her wheelchair

Olivia Shivas says trying something new can be scary and exciting at the same time, and there are often additional levels of nerves when you have a disability. But, she says, you should give it a go anyway. *By Melanie Louden*.

Olivia Shivas speaks from personal experience when she encourages MDANZ members to "challenge what other people perceive about you".

"Don't let other people's negative stereotypes and perceptions of disability hold you back."

Olivia has been a wheelchair-user her whole life and says trying something new is scary and exciting at the same time.

"There's an additional level of nerves when you have a disability – especially when you're doing something you don't see normalised in the media, or in the community, as people with disabilities being capable of doing."

Olivia, who has central core disease, drove past a boxing gym one day and thought 'I wonder if I could do that?'.

"There was a sign that you get free gloves when you sign up. I'm always up for free stuff!"

She bravely called and texted the gym in advance so there were no surprises for her, or the personal trainer, when she arrived. The 27-year-old Aucklander wanted to start boxing by doing one-on-one personal training sessions to figure out if she could actually do it and to gain confidence before joining classes with non-disabled people.

However, personal training sessions are expensive, so Olivia applied to the Bradley Jenkin Memorial Fund to seek financial support.

"I knew the money would be used in a good way for me to get fit and, hopefully one day, to inspire other disabled people to do the same." The funding she received contributed to 12 weekly training sessions.

After a few months of one-on-one boxing sessions with a personal trainer, Olivia gained the confidence to join a class with non-disabled people.

"I found, if you want to try something new, your confidence might not come straightaway. Take small steps, metaphorically if you're a wheelchair-user like myself, and do what you're comfortable with first to reach that goal.

"The main thing is don't stop or give up. Progress at a pace you are comfortable with," says the former MDANZ National Council Rangatahi Youth Representative.

Olivia says going to her first class with all non-disabled people was probably "one of the scariest things I've done in my life".

"But there have been so many benefits - keeping fit and active, as well as maintaining good mental health."

She has lost weight, things are easier for her to do now – such as climbing in and out of her wheelchair from the floor, and she's able to stay independent.

"Everyone at the gym is so warm and inclusive and makes sure that I can be involved as much as possible. Yes, I might have to do some things a bit differently, but I feel just as much a part of the gym as anyone else."

Olivia, who works as a digital news producer at *Stuff.co.nz*, says boxing in a wheelchair is similar to boxing when you're standing up.

"I still throw jabs, hooks and uppercuts, and learn the same boxing sequences. But when I'm boxing with a partner I'll have my arms up higher and they need to crouch down a little bit so we are a similar height, but that just means my arms get an extra workout."

Sometimes Olivia's knees get in the way when she uses the punching bag, so she adjusts the distance and angle of her chair.

A big part of boxing is the footwork – moving back and forth from your partner or the bag – not just boxing with gloves.

"I can't move around and box at the same time, so we have to be a bit creative."

Olivia, who enjoys going out for brunch and dinner with friends, cooking and baking, reading, and is involved with her church, now attends three or four gym classes a week.

"This would not have happened without funding from the Bradley Jenkin Memorial Fund to try something I would not have otherwise have spent money on. I probably wouldn't have taken the opportunity to give boxing a go."

One of her best friends, a fellow wheelchair-user, has also now picked up the sport. "It's exciting that my experience has positively influenced her. She's the only other wheelchair boxer I know, so it's good to have someone else to encourage and talk to about the challenges and how we resolve them."

Olivia says boxing has changed her life – and it's not just about becoming fit and active.

"Boxing has improved my self-confidence, knowing that I'm more capable of doing things than I, and others, thought were possible when you have a disability.

"I didn't join a class with non-disabled people at the start because I was self-conscious and nervous – not only about being capable of being able to box and throw a punch, but of other people's opinions of me: 'What is a girl in a wheelchair doing here?'.

"Despite being a wheelchair-user my whole life and achieving a lot of great things, I still get insecure and compare myself. Everybody does, whether they live with a disability or not.

"But once you get over those initial nerves, it's fun and empowering trying new things."

The Bradley Jenkin Memorial Fund

The Bradley Jenkin Memorial Fund is designed to help MDANZ members with a neuromuscular condition receive funding for access opportunities and specialised resources that enable them to achieve freedom. The fund has helped members purchase specialised sports equipment, participate in sporting events, it has contributed towards the cost of obtaining a mobility dog, provided mobility equipment, and assisted with career development such as university and course fees.

For more information go to: https://www.mda.org.nz/What-We-Offer/Bradley-Jenkin-Memorial-Fund

The good and the bad of disability data

Quality disability data is an important tool that the disability community needs to hold the government, society and the private sector to account, write disabled persons advocate, Roger Loveless, and senior policy analyst Sam Murray.

Data is boring, but important! Disability data is no exception. Complete, accurate, and robust disability data is what government needs to make good decisions around disability policy.

All too often, however, the stories of disabled people, and their whānau are not heard.

Quality disability data must acknowledge the human aspects of disability. This means looking beyond the figures that are easy to measure. We need to value the hidden costs of disability as an important piece of the puzzle.

Quality disability data is also an important tool that the disability community needs to hold the government, society and the private sector to account.

In recent years, there has been good and bad news with nationally collected disability data.

The bad news: Back in 2012, the 2018 Disability Survey was cancelled. Since 1996, the Disability Survey had been held every five years. The next Disability Survey is planned for 2023, which is 10 years after the 2013 Disability Survey. This is far too long. The Disability Survey is an essential source of disability data because it interviews a large number of people and includes in-depth questions on disability. It is vital that the Disability Survey switches back to at least a five-year cycle.

The good news: A growing number of regular surveys now include disability questions. These surveys provide a regular source of disability data but come with some caveats.

These surveys use fewer disability identification questions than the Disability Survey. This means the variety of impairment types covered is smaller. Fewer disabled people are also identified in this data.

As a result, the data is less reliable and tends to bounce around between years. In addition, it is difficult to break the disability data down by ethnicity, impairment type, and/or gender. This makes it hard to explore the diversity of experiences in the disability community.

The data from regular surveys is best used to look at broad trends over time. For example, we can look at the Household Labour Force Survey. The June edition of this survey has had disability data since 2017.

Since 2017 there has been no real change in employment outcomes for disabled people aged 15-to-64. The employment rate for disabled people aged 15-to-64 is still under half that of non-disabled people in that age group.

A big challenge with disability data is understanding the effects of age. The disability rate rapidly increases over the age of 65. This means many disabled people over 65 have acquired their impairment after reaching the age of 65. They will still experience many of the same barriers as other disabled people, especially around access.

They, however, are likely to have more wealth and other assets.

As a result, disabled people over 65 tend to have better outcomes than younger disabled people.

For example, in 2018, disabled people under 65 were almost 2.5 times more likely to report not having enough income than non-disabled people under 65. By comparison, disabled people over 65 were only 1.5 times more likely to report not having enough income than non-disabled people over 65.

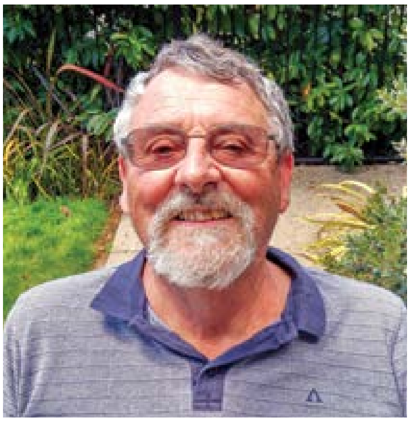
This can become a real issue because of the big differences in median age between disabled people and non-disabled people. Because so many disabled people are over 65, disabled people have a much higher median age than non-disabled people. In New Zealand, people over 65 often score better on poverty, home ownership and wellbeing measures than younger people.

With all-ages disability data, we are comparing a population with many people over 65 with a younger population. This can hide the inequality experienced by disabled people who have had their impairment from an early age. This problem may get worse with our ageing population.

For now, the best we can do is to look at younger age ranges in the data. In the future, we need data on the specific experiences of people who have had an impairment from an early age. The 2023 Disability Survey may help here, but we still need far more regular data.

Another major gap is data on the financial and time costs disabled people and their whānau experience. There has been some work done on this over the years, but again we still lack a regular and reliable source of data on this.

This is important because the government often does not understand the true depth of financial and time costs disabled people face. The often-large gap between the government's support and those costs is largely hidden.



Sam Murray (top) and Roger Loveless.

We need in-depth analysis of the hidden costs of disability. This includes looking at:

- The value of unpaid family and whānau support.
- The amount disabled people and their whānau spend privately on equipment and support.
- The opportunity costs caused when disabled people and their whānau cannot fully engage in society, for example, through lost employment or volunteering opportunities.

If we could better show the true depths of the costs, this could lead to increases in support.

Despite the challenges, slow progress is being made. The upcoming Household Economic Survey release will have disability data for the first time. You can now access disability data across a wide range of areas on a regular basis.

We still need a regular Disability Survey however to provide a much more detailed picture than provided by these regular surveys.

The Disability Survey allows us to explore the diversity of experiences within the disability community and identify the benefits of initiatives such as Enabling Good Lives.

You can find most of the recent disability data on the Statistics New Zealand pages below. Look under latest information releases and latest publications: www.stats.govt.nz/topics/disability

Surveys that now have disability data are:

- General Social Survey (2016 and 2018).
- Household Labour Force Survey (June of every year from 2017 onwards).
- Te Kupenga (2018).
- 2018 Census.
- New Zealand Crime & Victims Survey (2018/19).
- Health Survey (2019/20).

Roger Loveless is an advocate for disabled persons, an MDANZ member, and a local advisory committee member for CCS Disability Action Bay of Plenty. He has a lived experience of disability.

Sam Murray is a senior policy analyst for CCS Disability Action and is based in Dunedin. Ⓡ

Telehealth wheelchair assessments under the microscope

Research shows the Telehealth Wheelchair Assessment Service is thought to be a good idea by most wheelchair users and assessors, writes Dr Fiona Graham.

Like a lot of life's turning points, it started with a throw-away comment: 'Someone should study that and see if it really works.'

I made the comment to Sally Wallace, an occupational therapist colleague who was playing around with telehealth (video-conferencing, photo-sharing, phone calls) with clients with complex wheelchair and seating needs – most of whom had neuro-muscular changes among their physical needs.

This was a few years 'BC' (Before Covid-19) so technology software and hardware was more limited than it is today, especially within the health system.

Sally was finding that telehealth seemed to work with some people, and often it wasn't the complexity of client's needs that determined whether telehealth assessments were successful or not.

We noted too that very few wheelchair assessors used telehealth at that point. Why was this? Telehealth wheelchair assessment seemed to save time and money, but did it really when all the costs were added up?

Who did telehealth wheelchair assessment work for, how well, and in what context was all a great unknown. If telehealth was to be used more extensively in Aotearoa, the answers to these questions were important to ensure that the health dollar was well spent.

Like a lot of life's turning points, my comment was then followed by a lot of hard work.

First, without project funding, a group of my colleagues at Te Whare Whakamatutu (Rehabilitation Teaching & Research) at the University of Otago in Wellington decided to canvas the research literature on what was already known about the use of telehealth for wheelchair assessment.

We did a scoping review of research to date and found that minimal research had been done.

Lab testing reported equivalent results between in-person and telehealth wheelchair assessment. Clients were big fans when it improved their access to assessors. Assessors were more cautious, with concerns about data security and clinical accuracy.

Clearly, assuming that telehealth was a great idea and everyone in New Zealand should now do it was a risky assumption.

So, with a view to informing health policy on the New Zealand design requirements of a successful telehealth wheelchair assessment service, we applied to the Neuromuscular Research Fund in

2018 and were awarded $17,000 to determine the social and technical requirements of a Telehealth Wheelchair Assessment Service (T'WAS for short).

Our work was also generously supported by an advisory group comprising wheelchair users, tangata whenua, assessors and assessor educators and students.

We took a grass roots approach, seeking the views of wheelchair users, their families, specialist and non-specialist assessors and technicians. We also sought the views of service managers, funders and policy writers, although only recruited service managers. Understanding the perspective of Māori was also a priority.

Over 12 months, 117 people (including 47 wheelchair users, 49 wheelchair assessors, nine family members, six technicians and three service managers) shared their views about a T'WAS through a survey, and 41 also through interviews. Māori represented 12 percent of responses.

Surprisingly, most respondents thought T'WAS was a good idea, although cautioned that it shouldn't be the only option.

Unlike our scoping review findings, assessors were enthusiastic about it, although few of them were using it.

Wheelchair users, including Māori, were better equipped than assessors with the technology in place to meet via telehealth. Tablets seemed to be the optimal hardware and simple, off the shelf software (e.g., Zoom) was preferred.

The key impact voiced by all stakeholders was more timely assessment than the current in-person system allowed. Frustration with the current system was loudly expressed.


Dr Fiona Graham.

Māori were enthusiastic for T'WAS generally. While one Māori assessor questioned the quality of whanaungatanga (relationship building) for Māori through telehealth, Māori wheelchair users commented that telehealth could level the playing field, and improve the experience of being culturally safe. As one Māori wheelchair user put it:

"I think having it [wheelchair assessment] done by a video link could improve the [cultural and personal] safety of these consultations…You can just hang up if you feel unsafe. You know you have control in that moment because it's a lot more even playing field than when therapists are in your house."

We have already shared the findings from this study with assessors through several professional development workshops and shared findings in person with Ministry of Health planners. Two peer reviewed publications are in progress.

Feedback so far is that findings have prompted big insights for many assessors on how their interactions with wheelchair users might be experienced, in-person or via telehealth, and demystified what T'WAS could look like.

We are currently pursuing funding for our next step, to take a detailed look into attempts to do telehealth wheelchair assessments.

We'll map out the context around when T'WAS can work, doesn't work and the steps that make it more likely to be a positive outcome for everyone. We hope to create a freely accessible resource for assessors and wheelchair users as a key output of this next project.

To access a series of publicly available workshops on telehealth that drew from study findings, go to: https://www.youtube.com/watch?v=YebdoSmNAaU.

To access full copies of the peer reviewed articles email fi.graham@otago.ac.nz

Special thanks to our advisory group members: Pete Williams, Hemakumar Devan, Siobhan Jansen, Rita Robinson, Johnny Bourke, David Hood, Stephanie Thompson and Michael Nolan. Ⓡ

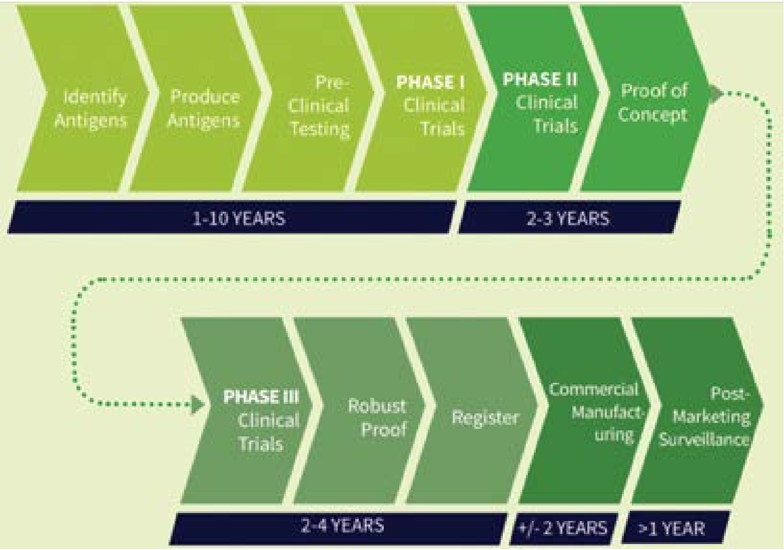
Dr Fiona (Fi) Graham is a Senior Lecturer in the Rehabilitation Teaching and Research Unit in the University of Otago's Department Of Medicine.

Why take part in clinical trials?

There are plenty of benefits to taking part in clinical trials, writes the team at New Zealanders for Health Research.

If you have an opportunity to participate in a clinical trial of a new medicine, piece of equipment or just a different way of providing care then you should seriously consider getting involved, for these reasons:

- You'll receive the best possible standards of care. If you're participating in a phase three clinical trial for a new medicine, for example, the aim of the research will be to compare the new medicine with either doing nothing or with existing medicines. This sometimes involves being given a placebo or an inert substance rather than the new medicine itself, to ensure that any observed health improvements are from the new medicine itself rather than something else. The researchers will also want to ensure that any health improvements they see are not related to different standards of care, which means that if you go on a clinical trial you'll get the best possible nursing and medical care, even if you're given a placebo, which in itself can result in better health outcomes.
- If the trial is successful you'll get early access to new medicines and therapies which won't necessarily be available to others with the same condition as you. Typically, if you're benefitting from a new intervention the organisation paying for the trial will continue to pay for it even after the trial has ended. This is a big advantage in New Zealand if there are delays (which there usually are) in getting the new medicine approved and funded by Pharmac (New Zealand's medicines and devices purchasing agency). This is sometimes extended to those who've received a placebo only under companies' compassionate access schemes.



Courtesy of Medicines NZ.

- You'll improve your knowledge of your condition, and have the satisfaction of knowing that you'll be helping others, including future generations.
- You'll have access to up-to-date best practice clinicians who, it is thought, practice medicine five years in advance of their non-research colleagues.
- Because you'll receive treatment as part of a clinical trial rather than through the normal public health system, you'll be freeing up clinical capacity giving earlier access to treatment to other members of your community.

For more information take a look at the New Zealanders for Health Research (NZHR) clinical trials discussion paper here https://www.nz4healthresearch.org.nz/wp-content/uploads/2019/02/Clinical-trials-in-New-Zealand-NZHR-op-ed-130319-V2.pdf and Dr Ed Watson's presentation to NZHR's March 2019 Clinical Trials Workshop here: https://www.nz4healthresearch.org.nz/wp-content/uploads/2019/04/7.-Ed-Watson-NZFHR-MMCT.pdf

A good place to register your interest in participating in a clinical trial for a neuromuscular condition is the New Zealand Neuromuscular Disease Registry: www.mda.org.nz/Our-Research/NZ-NMD-Registry

Myasthenia gravis

Myasthenia gravis is an auto-immune disorder meaning our immune system mistakes our own cells for foreign molecules and produces antibodies directed against the body's own proteins.

Myasthenia gravis (MG) is a chronic auto-immune neuromuscular disorder that leads to rapid weakness and fatigue of the voluntary muscles of the body.

MG occurs in all genders and ethnic groups. Onset most commonly occurs at 20-40 years of age for women and 60 years and over for men, though it can affect individuals at any age.

MG affects approximately one in 100,000 New Zealanders (or one-20 in 100,000 people worldwide – depending on the statistics in the country they are from), and life expectancy remains normal.

In some cases, the foetus of a pregnant mother with MG may acquire immune antibodies. This is called neonatal myasthenia and is generally temporary, with the child's symptoms often disappearing within a few weeks of birth. Some children may develop MG indistinguishable from adults.

Congenital myasthenia is a rare disorder where babies are born with a genetic defect in neuromuscular transmission similar to MG; however, it is not an auto-immune disorder.

Features of myasthenia gravis

Characteristically, people with MG experience muscle weakness that increases during periods of activity and may improve after periods of rest.

The muscles that control eye and eyelid movement, facial expression, chewing, talking, and swallowing are most frequently, but not always, involved in the disorder. Limb muscles and those that control breathing and the neck may also be affected.

MG can affect any voluntary muscle and the onset of symptoms may be quite sudden. Involuntary muscles such as the digestive system, heart and brain are not affected. Muscle weakness is not always symmetrical.

In most cases, the first symptoms to appear are weakness and fatigue of the eye muscles. This may cause the eye muscles to droop (ptosis). People may experience double vision or blurred eyesight (diplopia), and there may also be some difficulty in holding a steady gaze.

The degree of muscle weakness experienced varies enormously, ranging from localised symptoms, e.g. limited to eye muscles (ocular myasthenia), to more severe or generalised forms in which many muscles are involved.

The severity of muscle weakness can often fluctuate during the day, usually least severe in the morning and worsening as the day progresses, especially after prolonged use of affected muscles.

Other muscles that are commonly involved include the muscles in the throat which may cause difficulty chewing and swallowing (dysphagia). Inhaling while trying to swallow may result in a tendency to gag or choke, particularly while drinking.

Talking difficulties may be experienced (dysarthria) and a speech therapist may be beneficial to identify strategies to improve speech and assist swallowing.

Muscles of the face may also be affected and muscle weakness may progress to the hips, arms, and legs, and may result in a person experiencing an unstable or waddling gait, having difficulty climbing stairs, getting out of chairs, or lifting objects. Weakness in the neck can produce a drooping head which may benefit from support.

MG can affect the respiratory muscles which can result in breathing difficulties, snoring and sleep apnoea overnight, and/or or a weak and ineffective cough. A respiratory/sleep physician should be involved at the earliest hint of breathlessness, snoring, or difficulty with coughing.

Sometimes, a 'flare-up' of the condition (called a myasthenic crisis) can occur. These are often triggered by infections, fever, adverse reaction to medications, or emotional stress.

Causes of myasthenia gravis

MG is an auto-immune disorder. The immune system primarily protects us from infection and produces antibodies to destroy foreign molecules. In auto-immune disorders, the immune system mistakes our own cells for foreign molecules and produces antibodies directed against the body's own proteins.

Normally, in muscle contractions, impulses are sent down a nerve and the nerve ending releases a substance (a neurotransmitter) called acetylcholine. This crosses the neuromuscular junction – a place where nerves connect to the muscles they control – and activates acetylcholine receptors on the muscle membrane, generating a muscle contraction.

In MG, these receptors are mistakenly blocked, altered or destroyed by the antibodies, and fail to respond to the release of acetylcholine, preventing the muscle contraction from occurring. This results in the muscle weakness and susceptibility to fatigue experienced by people who have MG.

A secondary cause of MG is the production of antibodies against a receptor called Muscle Specific Kinase (MuSK), which is required for the formation of the neuromuscular junction. Antibodies prevent the signalling of MuSK, resulting in increased obstruction of the neuromuscular junction and the consequent symptoms of MG.

MG is not directly inherited nor is it a contagious disorder. On some occasions the disorder may occur in more than one member of the same family.

Diagnostic testing may include:

- Blood testing: Identifies the presence of acetylcholine receptor or MuSK antibodies.
- Single-Fibre Electromyography (EMG): Measures the firing pattern ("jitter") of two single muscle fibres.
- Repetitive Nerve Stimulation: Repeatedly stimulating nerves with electrical impulses to measure the fatigability of the muscle.
- Edrophonium test: Administration of edrophonium chloride (Tensilon®), which temporarily increases levels of acetylcholine at the neuromuscular junction, will briefly relieve muscle weakness in individuals with MG.
- Chest X-Rays, CT (computed tomography) or MRI (magnetic resonance imaging) Scans: Investigate the thymus gland, which is larger and easier to detect in cases of MG.

Management of MG

There is currently no known cure for MG, however symptoms can be controlled with several available therapies. Treatments primarily focus on two purposes: directly improving the muscle weakness, or reducing the auto-immune process.

Cholinesterase inhibitors, such as neostigmine and pyridostigmine, aim to directly improve muscle weakness. This is achieved by slowing the natural enzyme cholinesterase, which normally degrades acetylcholine at the neuromuscular junction. By doing so, acetylcholine is present for longer and therefore enhances neuromuscular transmissions and consequently, muscular contractions.

Immunosuppressive drugs such as prednisone, cyclosporine, and azathioprine may also be used. These improve muscle strength by suppressing the production of abnormal antibodies. Use of these must be monitored closely, as they can have important side effects. Mycophenolate mofetil, rituximab and methotrexate are also possible treatments.

In cases of myasthenia crises, plasmapheresis in which the abnormal antibodies are mechanically filtered out from the blood can be used. High dose intravenous immune globulin (IVIG) is an alternative therapy which can suppress the immune system to down-regulate antibodies that target the acetylcholine receptor and provide the body with normal antibodies from donated blood. These therapies both have short-term benefits that can typically be measured in weeks.

Thymectomy, the surgical removal of the thymus gland, has been shown to reduce symptoms in 70 percent of individuals with MG who do not possess a thymoma, and can cure some individuals – perhaps by rebalancing the immune system. Positive effects can take from weeks to years.

With treatment and appropriate support, people with MG can lead normal and fulfilling lives. As MG comes to be better understood, there is greater hope for better treatment outcomes. Ⓡ

Support for MG

The Myasthenia Gravis Support Group NZ offers information and education to people with MG, their friends, family and carers.

The group ensures people with MG can connect, however possible, to support and eliminate isolation with people who understand; focusing on positive and practical support.

The group aims to connect members either virtually or face-to-face, as well as raise awareness about MG.

For more information go to www.myastheniagravisnz.wordpress.com, call Talitha Vial on 027 220 3138, email talitha.leafy@gmail.com or join them on Facebook – search Myasthenia Gravis Support group, New Zealand. Ⓡ

Many more adventures to be had

A "zombie-ish" moment in the lead up to a major solo art exhibition led to Judy Smith's ocular myasthenia gravis diagnosis. She writes about living with the condition and her love of life.

Hello, my name is Judy Smith and I live in Gisborne. In 2016, when aged 70, I was diagnosed with ocular myasthenia gravis with complexities.

I am a trained artist and my career was lecturing in the Scottish art schools and developing my own work in ceramic sculpture. I had to retire from this in 1996, on medical grounds, due to fibromyalgia and chronic fatigue.

In 2003 my husband Jim and I emigrated to New Zealand and became permanent residents in 2005. We have family who live in Auckland and they have been a great support to us both. The two grandchildren are a delight.

I continued practising my art but changed to drawing, painting and printmaking as they were less physically demanding.

It was in 2016, while gathering work for a major solo exhibition at Tairāwhiti Museum and Art Gallery, that I became unusually fatigued and what I called 'zombie-ish'!

My eyelids wouldn't stay open and my speech was slurred.

Initially I put it down to nervous exhaustion, but after struggling for about a week I went to my GP who sent me to A&E at Gisborne Hospital.

They quite quickly diagnosed ocular myasthenia gravis. I was then sent to Waikato Hospital after a particularly bad crisis, when my breathing was hampered, and I ended up on a ventilator. I was in the Neurological Unit for a few weeks having tests and they diagnosed I had complexities. These complexities are numb toes on both feet and sometimes very sore toes, muscular problems, breathing problems etc.

I love life and my attitude is to have as many stress-free activities as my health allows. My husband Jim has been an amazing support.

Activities that I can pick up and put down, as needs must, are important. About two years ago I created a charity project for myself, where I would design 10 greetings cards and make numerous fabric dolls, depicting aspects of myasthenia gravis. They all have a slight humorous side to them!

These are ongoing but suffer from long spells of inactivity due to health hiccups.

In fact, the fabric dolls haven't started yet. But they will. I was lucky enough to gain $500 from the Bradley Jenkin Memorial Fund which helped me buy equipment for this project.

Hopefully I'll gain more momentum this year. It all depends on how many viruses and infections sneak into my system!

For the first few years I really struggled to keep my head above water, as my neurological input was very sporadic and I became allergic to all the myasthenia gravis drugs I was offered.

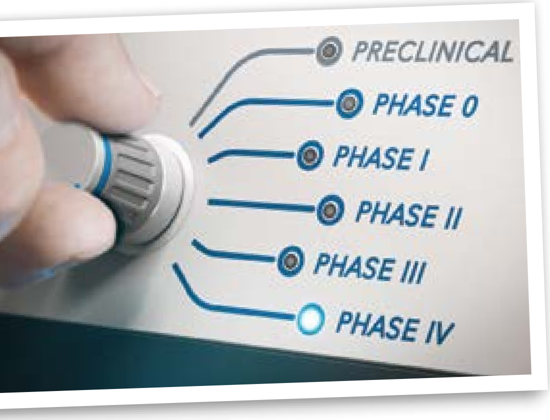
Judy is pictured in her studio working on an oil on canvas work titled *Home Sweet Home in Covid-19.*

Two years ago I linked up with a neurologist called Dr Stuart Mossman, who travels to Gisborne Hospital every few months, and he has given me more stability and found a new drug called rituximab which is given intravenously.

This drug and Dr Mossman have given me confidence and with the help of blood plasma infusions on rare occasions, I'm nearly bouncing!

Life has to go on and the more you put into it the more you'll get out of it. Dwelling on your ill health can be very negative.

I love people, and when I feel a bit isolated, I pick up the phone and arrange to meet a friend. They will not always come to you. You often have to make the first move. People can get fed up with ill health. I'm aware that I'm getting older and that gradually I'll have to slow down, but there is life in the old dog yet and many more adventures to be had!



A rough guide to vaccine testing and approval processes

BY SHANTHI AMERATUNGA

Outlining the main stages of development and delivery of a new vaccine.

A new vaccine's development and approval processes generally follows principles similar to those used to test, evaluate, approve and implement therapeutics (pharmacological drugs for clinical conditions).

These procedures are designed to follow rigorously developed scientific guidelines to ensure that the products administered to patients have a high probability of being safe and effective. The information submitted for review by regulatory authorities in a country are typically considered alongside other factors before approval for clinical use.

The CDC (US Centers for Disease Control and Prevention) outlines the main stages of development and delivery of a new vaccine as follows (https://www.cdc.gov/vaccines/basics/test-approve.html):

- Exploratory stage.
- Pre-clinical stage.
- Clinical development.
- Regulatory review and approval.
- Manufacturing.
- Quality Control.

After investigators have determined the potential effectiveness of a vaccine through pre-clinical research involving human cell cultures or animal models, they move to the clinical development stage to investigate how well the vaccine works in humans.

The clinical development stage involves a sequence of three to four phases, each responding to different, but linked, questions that build on the results of previous phases.

All trials are expected to follow strict ethical guidelines relating to research participation, including fully informed consent.

Phase I: In this phase, small groups of people (usually healthy volunteers) receive the trial vaccine. The aims of this phase are to assess the tolerability of different doses to avoid serious side effects and a greater understanding of how humans react to the vaccine/medication potentially provided in different formulations or combinations.

Phase II: This phase usually involves larger groups of participants than in Phase I, and is designed to gather more evidence regarding the safety and side effects of the vaccine in people similar to the populations of particular interest or concern in relation to the disease. The preliminary information gathered in this phase informs the methods of the next important phase.

Phase III: This phase usually involves thousands of people with characteristics similar to the population the vaccine is intended for. The intention of this phase is to demonstrate the efficacy of the vaccine, typically using a double-blind randomised controlled trial design, where the effect of the new vaccine is compared with the effect of not getting the vaccine (determined in a 'control' group receiving an alternate or inert product).

The 'control' group (determined in a randomised way) in randomised controlled trials helps reduce common biases that can lead to confounded or misleading results. The Phase III trials (which take longer than Phase I and II studies) are designed to demonstrate that the vaccine is safe and effective, at least in experimental conditions. Study participants are monitored carefully with a systematic protocol of testing and research evaluation, as these form the basis for applications for regulatory review, approval and licensing in various settings.

Phase IV: Many vaccines continue to be evaluated in studies after they are approved and licensed for public use, to ensure the evidence of safety and effectiveness in the rigorous pre-

> *All trials are expected to follow strict ethical guidelines relating to research participation, including fully informed consent.*

licensure phases remains valid when the vaccine is used in the field.

It is important to note that a vaccine licensure process will consider many issues over and above the evidence of vaccine safety and efficacy to determine the approach to funding and delivery of a vaccine, and these are active considerations in New Zealand with respect to the Covid-19 vaccines. Particular issues of note include:

- Clinical and public health significance of Covid-19 including those most at risk of severe disease (these raise important health equity and access considerations).
- Risks and benefits of the vaccine relative to the risk of transmission and occurrence of disease.
- Cost-effectiveness of the product.
- Feasibility of safe and effective delivery and administration of the vaccine to ensure equitable access to effective vaccines.

All new medicines (including Covid vaccines) are evaluated by Medsafe for approval and recommendation for use in New Zealand. Medsafe reviews the regulatory information provided by manufacturers and the international evidence to ensure the products approved "comply with international standards and local requirements for quality, safety and efficacy". (https://www.medsafe.govt.nz/COVID-19/vaccine-approval-process.asp).

Professor Shanthi Ameratunga was previously MDANZ's Clinical and Scientific Advisor.

Muscular Dystrophy
New Zealand

About us

MDANZ is a trusted source of specialist information and provides a range of free services and practical support for individuals, families and whānau with lived experience of rare neuromuscular conditions.

The Muscular Dystrophy Association of New Zealand Inc., commonly known as MDANZ, began in the late 1950s. Since then MDANZ has broadened its scope to support many other neuromuscular conditions. We are proud to have Judy Bailey and Dame Susan Devoy as our longstanding patrons.

Our unique governance structure ensures leadership of the organisation by individuals and family members with lived experience of a neuromuscular condition. We have four regional branches that are supported by the National Office based in Auckland.

We want New Zealanders with lived experience of neuromuscular conditions to experience freedom of choice in a responsive society.

To achieve this mission, we provide;

- Free information and advice, through our website, an 0800 info line and in paper booklet form
- A nationwide fieldworker service for personalised support
- Free loan of resources, such as library books, recreational beach chairs and cough assist machines
- Funded support for counselling
- Discretionary funding for life enhancing resources not covered by government
- A high quality quarterly magazine to inform and inspire our membership and broader communities of support
- Funding for neuromuscular research and a mechanism to help New Zealanders to access clinical trials and new treatments
- Education workshops for members, health professionals, schools and others
- Advocacy and lobbying at a community or national level
- A platform for support groups and peer to peer networking.

MDANZ is a registered charity and relies almost entirely on donations from the public, trusts and other businesses/organisations to continue its work in the community.

National Support Team

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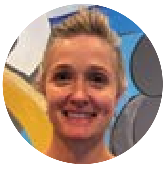
National Executive
Chairperson

Brian Hadley
Accountant and
Business Manager

Chris Stichbury
Manager for Research,
Development and
Monitoring

Melanie Louden
Communications and
Marketing Advisor



Kristin Cross
Fundraising and
Partnerships Advisor

Shelley Butler
Accounts Assistant

Calls 4 Charity Ltd

(formerly the Contact Centre)

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Supervisors: Maatuakore Wirihana-Tawake, Samuel Boyd.
Senior Customer Service Representatives: Kelly Williams, Melissa Jamieson, Simone Wareham, Vicky Ferguson.

Customer Service Representatives: Abbey Gunn, Alaric Bragg, Ashia Porteous, Annette Glasglow, Carlos Bennett, Elisha Pamata, Jackie Roberts, Kelly McIlhatton, Maureen Jenkins, Tamara Sergent.
Administrative Assistant: Janine Gardner.

See more about our team at www.mda.org.nz

Our branches

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Office Manager: *Denise Ganley*

Ph: 09 415 5682 or 0800 636 787 Email: support@mdn.org.nz

Central Region

Community Co-ordinator – Wellington Region: *Pip McLean*

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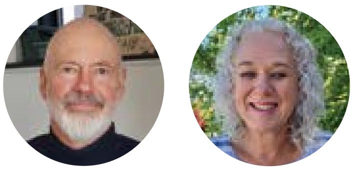
Canterbury Region



Fieldworkers: *Ross Paterson (left)* and *Jane Hazlett*

Southern Regions

Fieldworker: *Jackie Stewart*

Office Manager: *Vivienne Fitzgerald*

Canterbury: 03 377 8010 or 0800 463 222 Email: mdacanty@xtra.co.nz
Southern: 0800 800 337 Email: southern@mda.org.nz

Council Representatives

If you want issues brought to National Council meetings, talk to your branch representative. They have the responsibility to raise your issues at National Council meetings and to make sure you are heard. Your branch representatives and their contact details are as follows:

Northern Branch
Michael Schneider
support@mdn.org.nz

Central Branch
Bernadette Ingham
members.central@mda.nz

Canterbury Branch
Mike Nolan
chairperson@mda-canterbury.org.nz

Southern Branch
Tristram Ingham
chairperson@mda.org.nz

Conditions covered by MDANZ

Muscular Dystrophies:

Becker Muscular Dystrophy

Congenital Muscular Dystrophies and Congenital Myopathies

Distal Muscular Dystrophy

Duchenne Muscular Dystrophy

Emery-Dreifuss Muscular Dystrophy

Facioscapulohumeral Muscular Dystrophy

Limb-Girdle Muscular Dystrophy

Manifesting carrier of Muscular Dystrophy

Myotonic Dystrophy

Oculopharyngeal Muscular Dystrophy

Diseases of the Motor Neurons:

Spinal Bulbar Muscular Atrophy (Kennedy's Disease and X-Linked SBMA)

Spinal Muscular Atrophy - all types including Type 1 Infantile Progressive Spinal Muscular Atrophy (also known as Werdnig Hoffman Disease)

Type 2 Intermediate Spinal Muscular Atrophy

Type 3 Juvenile Spinal Muscular Atrophy (Kugelberg Welander Disease)

Type 4 Adult Spinal Muscular Atrophy

Hereditary Spastic Paraplegias (HSP)

- *all types:*

Also called Familial Spastic Paraparesis

Leucodystrophies

- all types.

Metabolic Diseases of muscle - *all types including:*

Acid Maltase Deficiency (also known as Pompe's Disease)

Debrancher Enzyme Deficiency (also known as Cori's or Forbes' Disease)

Mitochondrial Myopathy (including MELAS, MERRF, NARP and MIDD)

Phosphofructokinase Deficiency (also known as Tarui's Disease)

Phosphorylase Deficiency (also known as McArdle's Disease)

Diseases of the Peripheral Nerve:

Charcot-Marie-Tooth Disease (CMT) (Hereditary Motor and Sensory Neuropathy) - all types

Dejerine-Sottas Disease (CMT Type 3)

Hereditary Sensory Neuropathy

Inflammatory Myopathies:

Dermatomyositis

Inclusion Body Myositis

Polymyositis

Diseases of the Neuromuscular Junction:

Congenital Myasthenic Syndrome

Lambert-Eaton Syndrome

Myasthenia Gravis

Myopathies - *all types:*

Andersen-Tawil syndrome

Central Core Disease

GNE Myopathy

Hyperthyroid Myopathy

Hypothyroid Myopathy

Myofibrillar myopathy

Myotonia Congenita (Two forms: Thomsen's and Becker's Disease)

Myotubular Myopathy

Nemaline Myopathy

Paramyotonia Congenita

Periodic Paralysis

Inherited Ataxias:

CANVAS

Friedreich Ataxia (FA)

Spinocerebellar Ataxia (SCA)

Neurocutaneous Syndromes - *conditions affecting the brain and the skin:*

Central Cavernous Hemangioma

Neurofibromatosis Type 1

Neurofibromatosis Type 2

Schwannamatosis

Tuberous Sclerosis

Von Hippel Lindau Syndrome

Should you have a query regarding a condition not listed please contact us on 0800 800 337 or email info@mda.org.nz

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