InTouch

KIA NOHO TATA Inclusive | Inspiring | Informative Summer 21 Issue 112

Living life independently: A flatting journey

Humbling & magical: A community of support

Identity: One small change at a time

Muscular Dystrophy New Zealand

InTouch

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Also thanks to the ANZ Bank Staff Fund, ARA Lodge No 348 IC Charitable Trust, NZ Post Community Post, One Foundation, Richdale Charitable Trust and the Independent Living Service for their continuing support.

Kōrero with Trevor

Supporting you through transition

As I sat down to write my kōrero, Auckland reached day 100 in lockdown. That is 100 days of restrictions, upheaval, mixed emotions, and change for many of our members and the majority of our staff.

Over that time, you may have been faced with personal challenges of working from home while home schooling or caring for children or having disruptions to your care services with changes to the Covid-19 vaccination mandates.

There has been lots of change to our lives over the past six months which can be scary and upsetting. However change is a constant and we must find ways to adapt and manage as best we can.

In this issue we feature some amazing and emotional member stories of change and transition; from Mums adjusting to children leaving home and cutting their apron strings to members learning to drive, these stories will hopefully make you feel inspired to make your own changes or take comfort that others are going through similar things to you.

MDANZ had a very successful Annual Appeal in September, the Roll 1k for MDA campaign. Together with members, staff, whānau, and communities, we raised more than $25,000.

This was a HUGE effort from everyone involved and I am incredibly proud of this achievement.

I loved seeing all of the pictures and videos you shared of your rolls on bikes, scooters, and chairs. We cannot wait to do it all again in 2022 with some refinements and changes to make it more inclusive to all members.

For many of our members and staff, the past few months have been tough, and we empathise that many are feeling emotional.

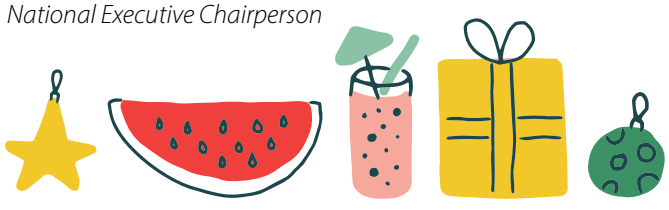
Change is inevitable but how you deal with and adjust to that change is key. Our Fieldwork staff are there to support you and your whānau through periods of transition and we also have free counselling services through Raise for members, should you need to speak with someone.

As we reach the end of 2021, I want to thank our hard-working team of staff, National Councillors, branch committees, and volunteers throughout New Zealand who have coped so well with disruptions and change this year, all while working hard to continue our services for you, our members.

I am really proud of what we have managed to achieve this year in such trying times.

On behalf of the National Council and staff, I wish you and your whānau a very Merry Christmas and a Happy New Year. Enjoy the break and hopefully you get a chance to head away and check out one of the amazing accessible beaches around the country.

Trevor Jenkin
National Executive Chairperson



Our annual fundraiser is a huge success

Despite the various lockdowns, the enthusiasm and commitment to our cause remains unchanged. *By Natalie Foote.*

The Roll 1k for MDA challenge was the Muscular Dystrophy Association of New Zealand's (MDANZ) 2021 Annual Appeal fundraising and awareness campaign that saw our supporters rolling one kilometre in distance on any kind of wheels and fundraising amongst family and friends.

Our members and their whanau are no strangers to fundraising for MDANZ, but this year's appeal was the first time MDANZ has used the peer-to-peer fundraising model. Fundraisers were encouraged to sign up, create their own fundraising page and then spread the word far and wide – asking family, friends, and colleagues for donations.

Kristin Cross, Fundraising and Partnerships Advisor, was up for the challenge to try something different.

"We knew this year's campaign had to be a virtual fundraising challenge due to the uncertainty of Covid-19 and lockdowns and we're glad we went with peer-to-peer fundraising as we ended up in lockdown a month out from launching," she says.

More than 55 fundraisers, made up of members, families, staff, and supporters signed up to roll during the official challenge week from the 20th – 26th September and together raised more than $25,000.

"This amazing result exceeded our goals of raising awareness and vital funds for our important Fieldwork service which provides essential support to members and their families," Kristin says.

Members from as far south as Gore and to Whangarei in the north rolled on skates, got pushed in wheelbarrows or biked their way to the one kilometre mark being supported by their friends, whanau, and communities.

National Executive Chairperson, Trevor Jenkin, says: "We were deeply touched by everyone's efforts, and it was tremendous to see that it inspired and gave confidence for members to share their journey with others."

And the winner is….


Frank Talataina and his sons.

Rolling his way to the top of the fundraising leaderboard was Central Region member, Frank Talataina, raising just shy of $4,500, and taking out an amazing first place prize of an Apple iWatch.

Frank biked from Whitereia Park in Porirua to Tawa and back supported by his wife Bridget, five-year-old son Boston, and other whanau members.

"I feel very lucky and blessed to have a strong support crew in my friends, family as well as MDANZ. This was a great opportunity for me to do my bit in spreading awareness of muscular dystrophy," he told *In Touch*.

Frank joined MDANZ in July 2021 and since joining "has had nothing but the best support, guidance, and advice from our Fieldworker Philipa McLean. She also linked us up with other members with muscular dystrophy which was great".

Not far behind Frank with some incredible fundraising efforts were Jess Barnes, Andy Blay and Marie Biland followed by a hotly contested battle of the Fieldworkers Ross Paterson and Jane Hazlett, both from the Canterbury branch.

All of these amazing supporters raised funds that will go to the region they were collected in to contribute towards the Fieldwork service.

With a successful first campaign behind us raising an extraordinary amount of money for the Fieldworkers, this means members like Frank can continue to receive the same personalised support service he has found so useful.

Roll on 2022 for a bigger, better (and hopefully lockdown free) campaign!

A special thanks to our key partners One Technology and Rothbury's Insurance for supporting our 2021 campaign.

Living with the changes Covid brings

Covid may have bought change to the wider New Zealand society, writes Scott Boyle, but for those living with a condition, it's really just another day at the office.

How often does your life change? For most people that's an easy answer. Maybe once a year, or every two. For those folk that change is typically defined by their employment, relationships, or where they live.

But what about you? It's certainly an understatement to say that those of us with conditions have a lot of struggles in life. We can feel more pain, anxiety, or depression in a year than most people will in their entire lives, and that takes an unimaginable toll.

It's somewhat of a poorly kept secret that we struggle with change. The old phrase 'change can be good' is one people love to use, but never when it applies to themselves.

For us, change is defined differently. We barely notice the positive changes or are too immersed to recognise them until later, but the other changes are much different. We see them for what they are, and regardless of the scale they can hurt us all the same.

It could be losing strength in your hand, feeling more fatigued than usual, or even toilet issues. Big or small they affect all of us the same way: they p**s us off. Some will express that for people to witness, whereas others will keep it buried and internalise it all.

While there's no right or wrong way to react, most outsiders will interpret either wrongly.

We all have that one moment, or even several if you're really lucky, where someone able bodied will say we're 'brave'. In a way it's meant as a compliment but really it's just condescending. Yet whenever we face a challenge or hurdle in our lives there isn't really anything brave about how we endure it, because for us it's simply a way of life.

This year has brought about a lot of change. Not just for us, but for the country as a whole.

Prior to August we were going about our lives as though Covid wasn't a problem, with the only permanent restrictions really being at our borders.

Compared to the rest of the world we were lucky. We had a Government that acted swiftly and gave us a year of normality when the rest of the world was burning. But that all changed.

Last year the country banded together and made the sacrifice to lockdown, eliminating the virus by doing so. This year things are different. For me, lockdown was rather enjoyable. I talked with friends more, finished a few games, and wrote a couple chapters of my book.

While everybody else was going stir-crazy I simply enjoyed the peace and simplicity of things. So why is that? Why would I happily go into lockdown and be able to cope?

Well, there's the obvious health reasons. Like most of you I'm immunocompromised and would probably make it three days with the virus before giving up the ghost.

But I suppose the real reason is I'm used to it. We all know what it's like to spend too much time at home, either for those pesky health reasons or because it feels easier to just stay in.

During lockdown I actually felt most at peace because I wasn't worried about being judged for staying home. It was liberating. And I know a lot of members I've spoken to feel the same.

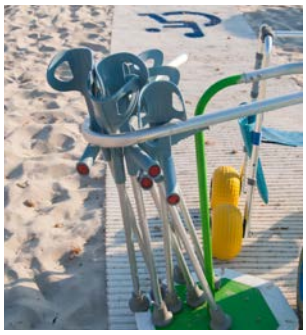
So, what makes things so different this year? There's a rise in resistance to lockdowns and mandates, as well as the vaccine. And unlike before there's greater resentment and less compliance. But why? Why are so many resisting? Because of change. For our community these hardships are just one more in the list of things to endure.

We're uniquely experienced with isolation, illness, and rules. In a lot of

ways it can make life simpler for us. Alas, too many of our able-bodied counterparts aren't so adaptable. Covid has brought about the most significant changes they've likely ever experienced in their lives, and deep down they don't know how to handle it.

For them, change is terrifying. But for us? It's just another day at the office. Perhaps someday soon they'll pull it together and adapt like we have. To see the virus for what it is: a herald of change.

Scott Boyle is MDANZ's National Vice Chairperson.



Getting to the beach

As summer starts to finally roll out around the country, *In Touch* went searching for resources for our readers on accessible beaches in Aotearoa.

The national disability information advisory service, Firstport, owned by Enable New Zealand and funded by the Ministry of Health, has a good guide to accessible beaches in New Zealand, listing where beach wheelchairs designed to be used on sand can be hired, and the beaches which have mats so people with mobility aids can get to the beach more easily.

While it is citing the 2020 summer, it says beach wheelchair hire is available in six locations around the country, thanks to the Halberg Disability Sport Foundation, the Flight Centre Foundation, and Wellington City Council. These are in Wellington, Mount Maunganui, Whakatane, Northland, Taranaki, Christchurch and Dunedin. And Firstport says you can hire them in Auckland too.

It says some beaches around the country have beach access mats in use during the summer including in Mount Maunganui, Ohope, and Wellington. You can find all the details at https://firstport.co.nz/news-and-articles/articles/accessibility/guide-to-accessible-beaches-in-new-zealand/

Another excellent guide is *Stuff* reporter Kimberley Graham's story on the best accessible beaches in New Zealand, which has a great deal of useful information about both wheelchair accessibility and beach mats. www.stuff.co.nz/travel/experiences/beaches/300407683/the-best-accessible-beaches-in-new-zealand

Do you use a cough assistance device?

MDANZ is funding research by the University of Otago to understand the need for mechanical cough assistance devices for people with neuromuscular disorders in New Zealand. The researchers want to know how you were feeling when you made the decision to use the cough assistance machine, who helped you make this decision, and what help you were given to use the machine either in the hospital, or at home.

They say this will help them to understand if everyone in NZ is getting the same help, if funding for more machines is needed, and if health professionals might need to gain some more skills to help support you.

The research team are looking for adults and children 10 years and older who have been administered a cough assistance machine in the last 12 months. They would like to ask you some questions, which will take about an hour. If you are interested, please contact Dr Meredith Perry: 021 2795357 or meredith.perry@otago.ac.nz

DPO Coalition Update

A brief overview of the DPO Coalition's activities over the last month. *By Alison Riseborough.*

Health reforms: The DPO Coalition held a workshop with the Transition Unit about different aspects of the health reforms.

- **Legislation.** Progress is being made on writing a Bill to give effect to the health reforms. Cabinet needs to make some decisions, then the Bill will be introduced to the House. As well as working on getting Cabinet approval, there is also work being done on helping people to access the Bill and to give their feedback through the Select Committee process.
- **Health system performance assurance.** It's important that there are ways to ensure that the health reforms result in positive changes for disabled people. The coalition discussed a range of mechanisms. The need to meaningfully engage disabled people at all levels of the system was emphasised.
- **Interim New Zealand Health Plan working groups.** There is a proposal to develop working groups related to the Interim New Zealand Health Plan. All of the working groups will be asked to make sure that they fully consider the needs of disabled people.
- **Commissioning Framework.** There will need to be changes to how commissioning is done. There needs to be a move from contracts that are low trust and high bureaucracy, to high trust and low bureaucracy. Commissioners in the current system will transfer to Health NZ and the Maori Health Authority.

Media Content Review, Department of Internal Affairs: The Department of Internal Affairs is reviewing how content is regulated in New Zealand. The coalition met with the team leading the media content review.

The aim of the review is to ensure that all people can safely engage with content. Part of the review involves thinking about what harm means to different people. The coalition discussed how content can harm disabled people.

Disabled people are often invisible in television programmes and media. Young disabled people are growing up not seeing themselves anywhere.

When disabled people are included, they are often presented with negative stereotypes/attitudes. Negative representations of disabled people impact on social expectations and opinion.

Electoral Participation Fund: The coalition met with a delegation from the Electoral Commission. The purpose of the fund is to support the participation of disabled people as candidates by covering disability-related costs.

The coalition provided advice on how to ensure that consultation about the fund is fully accessible and discussed the governance of the fund.

He Waka eke Noa: The DPO Coalition met with Grace Stratton from All is for All, who is working on the He Waka eke Noa project. This focuses on leadership development in the health and disability system. The Ministry of Health has recognised that there is a fragmented approach to leadership development, and low representation of disabled people in the workforce.

The coalition discussed the barriers in the current system to disabled people becoming leaders. There is institutionalised discrimination, ableism, and a lack of understanding of disability rights. The coalition emphasised that as well as investing in disabled leaders, there needs to be investment in educating others on a human rights approach to disability.

End of Life Choice Act - The End of Life Choice Act came into force on November 7. An assisted dying service is being implemented. The Ministry of Health would like to ensure that specific pathways for New Zealanders with disabilities are built into the service. There are safeguards built into the Act to protect people, including disabled people, from being pressured into accessing the service.

The Coalition discussed the safeguards in the system with Ministry of Health officials. It is important that there are clear ways to measure how disabled people are using the service, to ensure they are not over- or under-represented.

The DPO Coalition is:
DPA, Blind Citizens NZ, People First NZ, Deaf Aotearoa, Kāpo Māori O Aotearoa, Balance Aotearoa and the Muscular Dystrophy Association of New Zealand.

Christmas hours

MDANZ National Office will close on December 24th and re-open on January 5th.

A cup of tea and a catch up with ... Kristin Cross

Each issue we introduce a MDANZ team member.

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

I started as the Fundraising & Partnerships Advisor in the National Office in January.

As MDANZ relies almost entirely on voluntary donations, I have been brought on to understand and better engage with all our key supporters. I, am lucky that so many of our donors have such a great connection and long history with the association.

I will also be looking at expanding our circle of influence, to introduce new supporters to the organisation. This includes a new business partnership. So, if you know of anyone that has a connection to our cause, and in return will enjoy prime position across all our communication channels, then please let me know.

What qualifies as a great day at work for you?

A phone call with a donor normally makes my day. When you talk to someone who's retired but still is supporting the organisation because of what it did for their son's nephew 15 years ago, it really warms my heart and completes the circle.

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

The value our Fieldwork service provides cannot be underestimated. I would love to see more of them as face-to-face support is what matters in terms of making our members' lives easier.

I would love to see MDANZ get funds to double the number of Bradley Jenkin Memorial Fund grants available. It's amazing to be able to give members access to specialised resources that are not covered by the government.

What are you passionate about?

I'm an outdoors girl at heart which sees me out in nature whenever I can. Normally this is with the three males in my life as we hike or ride up mountains and then ski down them.

I'm also passionate about food and cooking and have been making really good use of my pressure cooker after so many weeks in Auckland's lockdown.

Yummy (and healthy) chocolate and raspberry slice

Julia Scott shares a delicious recipe for those with a sweet tooth.

Julia Scott is a dietitian with a passion for holistic health and encouraging people to live their best life.

She believes the best diet is one you can stick to so her goal is to help people create healthy habits that lead to sustainable lifestyle changes.

Julia is a New Zealand Registered Dietitian with a Master of Science Majoring in Nutrition and Dietetics, and a Bachelor of Science Majoring in Human Nutrition. She is happy to share her recipes with MDANZ members.

Ingredients

- 3 eggs
- 2 Tbsp olive oil
- ⅓ cup brown sugar
- 120g dark chocolate
- 1 medium beetroot, grated
- 1 medium pear, grated
- 1 ¼ cups almond meal
- ½ cup cocoa

- 1 tsp cinnamon
- ⅔ cup frozen raspberries

Instructions

- Preheat the oven to 160°C. Line a cake tin with baking paper and grease the sides.
- Whisk the eggs, oil and sugar in a large mixing bowl until the sugar dissolves.
- Place chocolate in a microwave safe container and microwave until smooth, stirring every 20 seconds.
- Absorb some of the water from the grated beetroot and pear using paper towels.
- Whisk melted chocolate into egg mixture. Stir in beetroot, pear, almond meal, cocoa and cinnamon. Gently fold raspberries into batter.
- Transfer into cake tin and bake for 75 minutes or until a skewer inserted into the centre comes out clean. Set aside to cool before slicing. Ⓝ

You can follow Julia on
Facebook: @JuliaScottDietitian
Instagram: @juliascott_dietitian
Or on her website: www.juliascott.co.nz

Government hails 'transformative changes' for disabled people

The new Ministry for Disabled People will join up all of the supports and services available to disabled people.

In what has generally been welcomed as good news for people with disabilities, the Government has announced the establishment of a Ministry for Disabled People and that it will be implementing the Enabling Good Lives approach to Disability Support Services on a national scale.

The Disability Rights Commissioner, Paula Tesoriero, said in a statement she was strongly supportive of the announcement of the new ministry and of the establishment of a framework for improving accessibility for disabled people.

The official announcement from Minister for Disability Issues, Carmel Sepuloni, and Health Minister Andrew Little, also highlighted the introduction of The Accessibility for New Zealanders Bill – new stand-alone legislation that will make Aotearoa more accessible and the establishment of a new Accessibility Governance Board.

In a media release Carmel Sepuloni said the Government was delivering on its promise to reform the disability system.

"The current disability system is broken and puts too many barriers in place for disabled people and whānau.

"This is why we are establishing a new Ministry for Disabled People as the heart of this change. It will join up all of the supports and services available to disabled people and

Minister for Disability Issues, Carmel Sepuloni.

replace a fragmented system where there is no single agency responsible for driving improved overall outcomes for disabled people."

She said the Government is also accelerating efforts to make Aotearoa New Zealand more accessible by introducing the new accessibility framework, "backed by legislation and a new Accessibility Governance Board. The Governance Board will be led by and represent disabled people and whānau.

"The disabled community's voices will be embedded at all levels of decision-making, from the formation and running of the Ministry, to the development of accessibility legislation."

Health Minister Andrew Little said: "The disabled community told us that disability issues are not just health issues. We've heard and responded to their desire to lift disability support out of the health system, which is why we're establishing a new Ministry for Disabled People to deliver support for all disabled people."

The Ministry of Social Development will host the new Ministry for Disabled People.

Carmel Sepuloni said the establishment of a new Ministry recognises that a broader and 'whole-of-life' approach to disability is needed, as opposed to viewing disability as a 'health issue'.

"We have listened to the disabled community and ensured that the mantra of 'Nothing About Us Without Us' sits at the heart of the most transformative changes to the disability system in more than a decade."

Support us!

Any donation, big or small makes a difference. Donations of $5 or more are tax deductible.

Call: 0900 426 93 to make an automatic $15 donation.

Online: Donate any amount securely online **www.mda.org.nz**

Post: Make a donation by post. PO Box 12063, Penrose, Auckland, 1642.

Thank you. We greatly appreciate your support.

Living life independently

Flatting independently has had its ups and downs

Leaving home and moving into your own flat is a rite of passage for young adults and one that Jack Lovett-Hurst, his mother Debbie Houkamau and step father Greg have embraced – even if it has been a hard wrench for Debbie.

Like many, many mothers who have a young adult about to leave the family home and set up independently for the first time, Debbie Houkamau admits she found it difficult when Jack, who is 24, moved out in March this year.

His flat is still in Invercargill, where the family is based, about three kilometres from the family home.

Jack, who has spinal muscular atrophy, is living with three flat mates, ranging in age from 35 to 19 – all of whom have a disability.

Jack tells *In Touch* he found the flat through Habitat for Humanity which leases the house, once known as the Manse, from a local church. Habitat redecorated the whole house, including installing a wet area for Jack and MDANZ's Bradley Jenkin Memorial Fund helped pay for a bidet for Jack in his new flat.

It is an older style house with five bedrooms and two bathrooms and both Debbie and Jack say it's a nice space with a big outside area.

A carer only comes in in the morning and in the evening to make dinner for Jack.

Jack says he is enjoying flatting although sometimes he thinks about moving back home as he misses the family's dogs. And he admits that, as in any shared living environment, there have been teething problems as the flat mates all get used to living with people other than their families.

Debbie adds that initially it was 'party central' every night as the flat mates were doing what all young adults like to do. But, she says, they have all settled into things more now.

When the whole country went into lockdown earlier this year Jack moved back home for a few weeks as he was finding it difficult with nothing to do. Debbie says he was a bit stressed and they felt it was time to bring him back for a couple of weeks.

Jack Lovett-Hurst, his mother Debbie Houkamau outside Jack's new flat.

Debbie, who runs a successful beauty therapy business from home, admits that for her Jack's move into the flat has been a big transition and that she found it rough.

Like most mothers of young adults, she wasn't ready and

As to what they would say to other parents and young adults about flatting, Debbie says she wants to give other parents hope, knowing their kids can lead independent lives. And to tell them to just keep striving for that opportunity for their young adults.

was full of worries and really felt "the empty nest" after 24 years of having Jack at home.

She says Jack is enjoying the flatting and when the opportunity to live independently came up he had leapt at it.

Debbie goes over to Jack's new residence every few days to catch up and they have lunch together, go shopping or just hang out.

Jack works at the Nga Kete Matauranga Pounamu Trust, where the CEO created a job for Jack as part of its Disability Services: S.O.A.R. or Securing Our Aspirational Realities.

Debbie explains this is a programme aimed to better understand and grow awareness and knowledge around working alongside whanau with disabilities. And to appreciate more fully the service options and needs they have to live full, enriched lives.

Jack and another employee host a weekly radio show, run a Facebook page and are on Radio Southland.

Jack is also heavily involved with MDANZ's Duke of Edinburgh Awards and has nearly finished his Silver Award, having undertaken the Round the Bays half marathon last year. Debbie has also been running lately for her own fitness.

Jack undertook the New York City Marathon in 2017 with his stepdad Greg and local news stories about Jack's undertaking attest to how the wider Southland community had got behind them and helped fundraise for the trip.

Debbie joined them in running at the end of the marathon and the family met a Dutch film maker who was live streaming part of the event and is now making a film around five athletes who took part, including Jack.

Jack, his mum and stepdad Greg are a close-knit team and Debbie admits she has had to step back.

As to what they would say to other parents and young adults about flatting, Debbie says she wants to give other parents hope, knowing their kids can lead independent lives. And to tell them to just keep striving for that opportunity for their young adults.

She adds that it is stretching Jack, who already leads a busy social life and, as a massive sports fan, watches every sports game whether it is Southland rugby, basketball or the Warriors.

As to what Jack would say to other young adults about flatting, he says if they are nervous, he would tell them it's actually not bad. "Give it a go if you want to – do it."

Jack Lovett-Hurst shares his flat with three flat mates.

A community of support

A 'humbling' and 'magical' weekend

Ryan O'Rourke's local Gore community got right behind the 18-year-old and his family when they needed to raise money to convert their vehicle so Ryan could learn to drive. And the Bradley Jenkin Memorial Fund helped with his driving lessons.

It can be somewhat humbling, to say the least, when your local community supports a two-day basketball tournament to help raise money for your family.

And 'humbling' and 'magical' are the words that 18-year-old Ryan O'Rourke and his mother Colleen McKinnel use when describing the weekend-long basketball tournament last year that Eastern Southland Basketball Association in Gore, suggested to raise money towards the cost of modifying their existing wheelchair van so Ryan could drive it.

Colleen explains that they had bought the wheelchair van four or five years ago, thinking they would convert it one day for Ryan to drive and when that time came the family discovered modifying the vehicle with hand controls would cost around $14,500.

She says the family, including stepfather Peter and Ryan's brother Liam, sat down to think how they could raise the money.

Initially they decided on a raffle and asked local businesses to help supply some really good prizes. At this stage Eastern Southland Basketball Association where Colleen works, and where Ryan, who has SMA Type 3, is the official photographer, offered the idea of a basketball tournament for Ryan.

And in November last year, groups from throughout the Gore community put teams together to compete in Ryan's tournament.

Ryan and Colleen explain the teams were made up of basketball enthusiasts from local schools, old boys' teams and groups of friends and families.

The weekend of basketball raised about $6,000 from the entry fees and from money the players and supporters spent at the canteen and the bar.

Ryan O'Rourke with three of the referees who volunteered at his basketball tournament.

Colleen says it was a humbling weekend and while organising the tournament was a massive amount of work, they reached the $14,500 needed for the vehicle conversion.

It was just magic, says Colleen and she and Ryan agree they are both very grateful and were overwhelmed by the support shown.

The family raised another $4,000 from the raffle tickets they sold after local businesses had donated prizes including gondola rides, jet boating, loads of firewood etc.

"Even if you think you haven't got the strength, you can work out a way to build up the strength needed."

A cousin in Pukekohe undertook a bike-athon and raised a substantial amount while other local businesses also donated sums of money.

Colleen says it was a humbling weekend and while organising the tournament was a massive amount of work, they reached the $14,500 needed for the vehicle conversion.

So is it just a community like Gore, that can do this? Ryan and Colleen are not sure but they also point towards a concert held in Gore some years ago for another MDANZ member to help raise money for a vehicle to transport her electric wheelchair. Newspaper reports from the time say that the concert looked to be a sell-out.

Once the family's Mercedes Sprinter had been converted in Christchurch, Ryan had to go to an occupational therapist to ensure he was strong and adept enough to use the car's hand controls.

Ryan says he picked up the use of the hand controls in the van pretty easily.

He quite quickly moved onto a restricted licence and has now been driving the car to school at Gore High for about six months. He intends to go for his full licence next year once he has done a defensive driving course.

Colleen says the independence having a licence has given Ryan has been huge.

The Bradley Jenkin Memorial Fund also played a role, providing $700 in funding for 10 driving lessons for Ryan and Colleen offered a massive thank you to the BJMF saying the family was very grateful for the assistance.

Next year Ryan will be heading to Lincoln University in Christchurch, which is about six hours drive away. He will be staying in the Halls of Residence and undertaking a Bachelor of Commerce degree.

Ryan getting measured for hand controls to be installed in the family van.

Colleen says it is reassuring he will be in the halls with plenty of support on site.

Asked what driving has done for him, Ryan says it has given him so much more freedom and made him more independent in getting around the Gore district.

Colleen adds that as a parent, it has also meant more freedom for her too as she no longer has to ferry Ryan to and from things like exams and it has freed up her time considerably.

But driving has also meant that Ryan must keep up his upper body strength and he works with a physio on a variety of exercises and weights to ensure he does so.

Colleen says while everyone looks to keep their legs working, they tend to forget about their upper body strength and that for Ryan spending a few hours with the physio helps enormously.

They advise other MDANZ members to never give up on wanting to drive and, even if you think you haven't got the strength, you can work out a way to build up the strength needed.

My identity journey

A slow journey of small changes

Small and slow changes has helped Noah find their place in the world.

My name is Noah and I am 22 years old. I was diagnosed with Charcot Marie Tooth (CMT) from a young age so dealing with that is a big part of my life.

I like to draw and play video games in my spare time and have recently started to post my artwork on Instagram (@valentinegirlz).

I have a younger sister who I am very close to. I also have two lovely parents and my dad has CMT too.

When my dad was younger, his condition was referred to as 'the feet' so we are both lucky to have clarity on what our condition is now.

I am currently finishing my Bachelor of Arts majoring in Anthropology and Gender Studies. I am not sure what I'll do after that though!

My study on Gender Studies has been helpful with my own journey.

Although a little challenging at times, it's been great to think critically about my own gender and place in the world.

It's also helped me to understand identity as historically fluid and constructed. It can be freeing to know that because the rules for identities are socially constructed, they can be broken or shifted.

In making this image, Noah was thinking about how negative experiences can 'haunt' spaces and memories.

I started using Noah as well as my legal name two years ago and just Noah for around a year and a half. Although I am still having to tell people I'm Noah.

You do have to come out to people over and over which is tiring. It has

This artwork is about how surgery is meaningful to Noah as someone who is transgender and disabled.

I think everyone should question their gender at some point. It can be very useful to think critically about what assumptions about gender you may have picked up along the way.

taken me awhile to feel confident in my identity.

I started thinking that I might be non-binary around six years ago and it's been a slow journey of small changes.

I think a lot of people expect transgender people to have always known they were transgender, and I definitely didn't.

This idea fits into a convenient narrative for cisgender people [a person whose gender identity is the same as their sex assigned at birth] as if transgender people have always been transgender, it means they can stay confident in their identity as 'normal' people.

However, gender can change. My feelings about gender aren't any less real because I've only started feeling confident in my identity for around two to three years.

Even if they weren't 'real' (by this I mean having some sort of scientific or biological basis) I don't think that would matter!

A lot of gender is socially constructed. Gender is culturally and historically specific. And there is no 'essential' core to being non-binary! No one has a claim on what it means to be non-binary, and it certainly does not have to have a biological basis to make sense.

I identify as non-binary and use they/them pronouns. I like to play around with the way I present, but I am still a long way away from where I'd like to be with that.

Most people who don't know me perceive me as female, and I'd like my presentation to be more confusing than that!

If I could give advice to someone struggling to identify themselves, I would say to focus on what makes you feel good and happy.

A lot of people say to look at what doesn't feel right. Knowing that can be very useful but it is also very difficult to determine.

Feelings of gender euphoria can be simpler to understand, although they might be accompanied by feelings of guilt or disgust.

I would also say that it is okay to get it wrong! It's more than okay to question your gender and realise that you're cisgender.

I think everyone should question their gender at some point. It can be very useful to think critically about what assumptions about gender you may have picked up along the way.

A fun image about what chess might be like on an alien planet.

If I could give advice to someone struggling to identify themselves, I would say to focus on what makes you feel good and happy.

For example, are you doing something because you feel like you should, or because you like it? It will probably be a bit of both, which is fine as long as you're aware of that.

I think no matter where you end up on your gender journey, the small realisations you'll have on the way are super important.

I also think small changes can be great! You don't have to do everything at once and it might be terrifying to.

But something small like a haircut could be helpful. You might also find that you don't want to change anything at all, which is also great.

Driving to a new freedom

Taking the controls

Learning to drive has taken Logan McColl and his family on quite a journey.

As soon as he turned 16 Logan McColl wanted to get his learner driving licence, just as his two older sisters had done before him. And his mother, Sharron, and dad Sean, readily agreed, not thinking he would want to drive.

But Logan, who is now 17, definitely did want to do so and his learning to drive has taken the family on quite a journey too.

Sharron and Logan tell *In Touch* that once Logan made it clear he wanted to start driving, it was quite a process to go through "and was actually very difficult as no one knew what we had to do."

They finally found a driving school which could put them in touch with an occupational therapist whose specialty was helping disabled drivers. The therapist looked at how Logan would get in to a car and how he would steer and what type of hand controls were needed.

Sharron says Logan, who has Duchenne muscular dystrophy, also had to be assessed to make sure he was cognitively able to understand the principles of driving and all that it would entail.

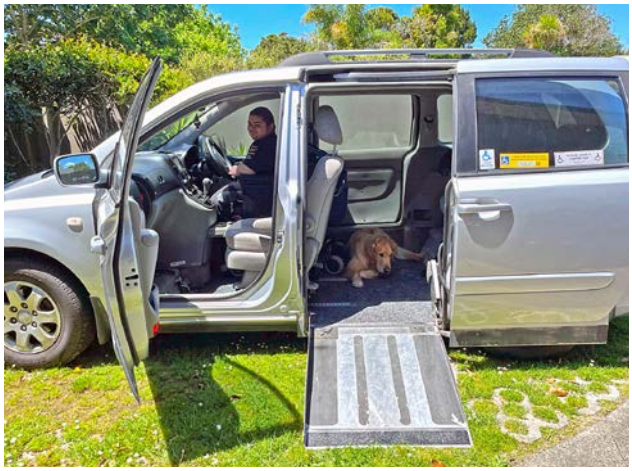
The family began keeping an eye out for a suitable car and finally found a car for sale which had been used by an ACC client.

Logan can drive his wheelchair into the driver's seat and it has full hand controls so Logan uses his left hand for the steering wheel and his right hand for the accelerator and brake.

The car is also modified so there is a seat on the driver's side if Sharron or Sean want to drive the car.

Through a car dealership, which specialises in disability vehicles, they bought a 2008 Kia Carnival, although Sharron says they had to get further modifications done as the hand controls were not quite right for Logan.

She says driving is tiring for him and he hasn't



Logan McColl can drive his wheelchair into the driver's seat (above) and uses his left hand for the steering wheel and his right hand for the accelerator and brake.

Asked about the challenges in learning to drive, Logan says that turning the steering wheel to go around a sharp corner can sometimes be difficult when he has to brake and then accelerate around the turn.

undertaken any long trips so far. He drives with Sharron from home on the Whangaparaoa Peninsula in North Auckland to school at Gulf Harbour, about five kilometres away, for practice.

He hasn't as yet gone for his restricted licence. "They need to be pretty au fait when they go for their restricted licence," Sharron says, pointing to driving skills such as being able to pull out into a certain gap in the passing traffic and reverse parallel parking.

Logan had been practicing for a couple of months when he spoke to *In Touch* and says he really enjoys the driving and aims to drive most days, so he can get that restricted licence, which means he will be able to drive alone.

And like most mothers of teen drivers, Sharron is somewhat nervous about the day Logan can drive on his own. But she adds that Logan enjoys the fact that he is learning to drive at the same time all his mates are.

Asked about the challenges in learning to drive, Logan says that turning the steering wheel to go around a sharp corner can sometimes be difficult when he has to brake and then accelerate around the turn.

Sharron adds that because he can drive a power wheel chair this has helped his reaction time with the car's hand controls.

Logan McColl masters the hand controls.

Logan is also an accomplished Power Chair Football player so it's probably safe to assume he has also learned excellent motor control in the fast-paced game.

So, what advice would the family would give to other MDANZ members whose have teenagers or young adults who want to start driving?

Sharron says from a parent's perspective, she advises letting your teenager do it and not to hold them back. Logan loves it, but it definitely isn't easy for her, she adds.

She also suggests talking to people to find out what is needed to get started and to find someone who has been through it already. She is happy for any parents or teens to contact her directly so she can pass on what the family has learned. Her email is ssmccoll@xtra.co.nz

And the big question: Is Logan a good driver?

He is very good, says Sharron, he has mastered the hand controls and is driving really well.

Finding the right funding

A guide to the funding options available

Here we highlight a number of the funding opportunities available to people with disabilities.

Funding available to people with a disability can cover everything from equipment, modifications and mobility aids, through to personal care and respite. Funding can also help children at school and people in the workforce.

Lottery Individuals with Disabilities

Lottery Individuals with Disabilities can help fund equipment to support individuals to contribute, participate in and connect with their communities.

This can include assistance dogs, communication equipment, vehicles, vehicle modifications, scooters and other mobility equipment.

For Lottery Individuals with Disabilities, a disability refers to a long-term (six months or longer) limiting condition that affects a person's ability to participate in the community.

Funding requests can only be accepted from New Zealand Citizens or permanent residents currently living in New Zealand.

www.communitymatters.govt.nz/lottery-individuals-with-disabilities/

Individualised Funding –Ministry of Health

Individualised Funding (IF) gives disabled people a way of directly managing their disability supports.

IF gives disabled people more choice in how they are supported. It is available throughout New Zealand for eligible people who have either:

- Home and Community Support Services, which include help with household management and personal care.
- Respite services, which include Facility Based Respite, Carer Support and In-home Support.

IF increases your choice and control about who provides this support, and how and when you use it. Your options range from engaging support workers and planning how to use your supports, to employing your own care providers and managing all aspects of service delivery.

Individualised Funding gives disabled people a way of directly managing their disability supports and more choice in how they are supported.

You can use IF to:

- Purchase household management and personal care provided by support workers (where your employees can include family members, contracted personnel or organisations) and pay costs relating to the employment of support workers.

- Purchase respite through support workers or other suitable alternatives so that the full-time carer can have a break (including school holiday programmes or facilities). You cannot use IF to pay parents and spouses for respite care.

You can continue to spend your IF on any disability support or service that:

- Helps you to live your life or makes your life better and
- gives you a break from caring for your family member with a disability, or to provide a break for the disabled person and
- the use of funding if it is reasonable and cost-effective and
- it's not funded through other funding options such as a Disability Allowance.

www.health.govt.nz/your-health/services-and-support/disability-services/types-disability-support/individualised-funding-funded-ministry-health

Disability Allowance – Work and Income

The Disability Allowance is a weekly payment for people who have regular, ongoing costs because of a disability, such as visits to the doctor or hospital, medicines, extra clothing or travel.

You don't have to be on a benefit to qualify for a Disability Allowance.

You may get a Disability Allowance if you:

- Have a disability that is likely to last at least six months.
- Have regular, ongoing costs because of your disability that are not fully covered by another agency.
- Are a New Zealand citizen or permanent resident.
- Normally live in New Zealand and intend to stay here.

It also depends on how much you and your partner earn.

www.workandincome.govt.nz/products/a-z-benefits/disability-allowance.html

Students with learning support needs - Ministry of Education

Schools are required to be inclusive under the Education and Training Act 2020 and this is reinforced by the New Zealand Disability Strategy.

Learning support is available for children and young people:

- With Autism spectrum disorder.
- Who are blind or have low vision.
- Identified as deaf and hard of hearing.
- With speech, language and communication needs.
- That need extra help when they are being assessed for their NCEA (National Certificate Educational Achievement – Special Assessment Conditions (SAC).
- Who can't attend school because they are unwell – health schools.
- With additional learning needs as they transition from school to adult life – National Transition Guidelines for students with additional learning needs.
- With the highest ongoing levels of need for specialist support – Ongoing Resourcing Scheme (ORS – see below).
- With additional learning needs that require specialised equipment and technology to use in class to increase or improve their ability to learn and participate – assistive technology.

www.education.govt.nz/school/student-support/special-education/

Ongoing Resourcing Scheme (ORS)

The Ongoing Resourcing Scheme (ORS) is for students who have the highest ongoing levels of need for specialist support at school. Approximately one percent of the school population require the support of ORS funding.

ORS support helps students to join in, and learn, alongside other students at school. Any student who meets the ORS criteria is included in the scheme.

Once a student is in ORS, their funding and support stays with them throughout their time at school.

ORS provides services and support, including:

- Specialists such as speech-language therapists, psychologists, occupational therapists, physiotherapists, advisers on deaf children, special education advisors, orientation and mobility instructors and others.
- Additional or specialist teachers who coordinate the student's learning programme with the class teacher.
- Teacher aides to support the student's learning programme in the classroom and to include students in class programmes and activities.
- Consumables – small items such as computer software,

extra-size pens and pen grips, disposable gloves, Braille machine paper, laminating pouches or CDs and DVDs.

www.education.govt.nz/school/student-support/special-education/ors/overview-of-ors/

Workbridge - Support Funds

Workbridge administers Support Funds on behalf of the Ministry of Social Development. Workbridge has established a dedicated team called Support Funds Services. You don't need to register with Workbridge to apply for funding.

The Support Funds Services team can discuss eligibility criteria or other questions with potential applicants. They receive and assess all applications against the Operational Guidelines for Job Support Funds and Training Support Funds to decide whether to approve your funding application.

Support Funds is a fund of last resort and can only be accessed after other government funding programmes have been considered. It is not available where the funding costs of an applicant's disability or health condition are the responsibility of the Ministry of Health, Ministry of Education or ACC.

Assistance categories include: Equipment, Interpreter Services, Support Person, Transport, Assessments, Training, Job Coach, Productivity Allowance and Workplace Modifications.

www.supportfunds.co.nz/

Enable - Government funded equipment

Enable New Zealand specialises in supplying equipment to help disabled people and older people in their everyday lives.

It provides government-funded equipment to people with a long-term (lasting at least six months) disability. Their equipment service is for eligible disabled people in these areas:

- North Island: All areas south of Meremere (Bombay Hills).
- South Island, Stewart Island, Chatham Islands.

The equipment belongs to the Ministry of Health and Enable lends it out, free of charge, for as long as the person needs it.

Enable New Zealand is bound by the Ministry of Health funding criteria. To apply people need to be assessed by an Equipment and Modification Services (EMS) assessor to ensure they meet the ministry's funding criteria for equipment.

www.enable.co.nz/services/equipment-for-disabled-people/government-funded/

Bradley Jenkin Memorial Fund

The Muscular Dystrophy Association of New Zealand administers the Bradley Jenkin Memorial Fund.

Examples of grant applications that might be considered are:

- Specialised sports equipment.
- Contribution towards the costs of a Mobility Dog being placed with you.
- Travel to attend an international forum for a rare condition.
- Participation in a sporting event.
- Career development (eg university or course fees).
- House/vehicle modifications.
- Mobility equipment.
- Technology.

This discretionary fund is for members who have applied elsewhere, and been declined, or no other alternatives are available.

www.mda.org.nz/What-We-Offer/Bradley-Jenkin-Memorial-Fund

What's wrong with you?

What's Wrong With You? is a Stuff podcast about disability made with the support of NZ On Air. In the series, hosts Olivia Shivas, Rebecca Dubber and guests tackle the big questions about life with a disability. They discuss sex, religion, mobility carparks and how to fend off outrageous questions. *By Olivia Shivas.*

If I was to ask 'what's wrong with you', how would you answer? Personally, I would assume people were asking me in relation to using a wheelchair (more on that later!), but I would probably answer that I can be too loud sometimes, I watch too many trashy reality TV shows and I leave my tea bag in a cup of tea for too long.

You might be wondering, do people actually ask that question? And yes, I'd estimate I get asked 'what's wrong with you?', or a variation of that question, on a weekly basis.

Growing up with muscular dystrophy central core disease, it's all I've ever known and using a wheelchair is just part of my everyday life. I've got to plan accessible routes if I'm going somewhere new and check in advance if restaurants have a mobility bathroom.

If there's something I want to buy in the supermarket that's on a high shelf and no one is around to help me, I've just got to settle with not buying it.

When it comes to answering 'what's wrong with you?' from random strangers in the street, I'll try to be kind and educational, but no matter how often I'm asked that question, I'm still surprised people will ask it out of the blue.

It's one of the reasons I produced a podcast titled by that very question. A couple of best friends and I (who are also wheelchair-users) kept sharing these funny stories about comments and questions strangers would ask us on the street or in the supermarket. On top of going the extra mile to plan our lives to adapt to a world that is not designed for people who use wheelchairs, it's also tiring having to respond to these same questions again and again.

Across the seven episodes of the podcast series, we interviewed 16 guests within the disability community and with different backgrounds.

The podcast helps answer some of these intrusive and annoying questions, in a confronting but humorous way.

We also share some of the funnier moments that happen when you're disabled – like what happens when you travel on a plane with other wheelchair-users and how to confront people over mobility car parks.

Olivia works on the podcast.

We also hope the podcast is a place where people can hear stories and not feel so alone. When I was growing up, I never saw stories about young women with disabilities that I could relate to. So, I hope young people and families impacted with disability listen and see what a thriving life with a disability can look like.

One of the benefits of having my interviews edited by a professional sound mixer was that he could tone down my loud voice and laugh – and there was a lot of laughter but, of course, we kept in the best bits for authenticity!

So, the next time someone asks me, 'what's wrong with you?' – I'll reply that I still sometimes forget to take the tea bag out of my tea, but if you're wondering what's up with the wheelchair, go listen to my podcast. *Listen to What Is Wrong With You on Spotify, Apple Podcasts or at Stuff.co.nz/whatswrongwithyou*

Congenital muscular dystrophy

Congenital muscular dystrophy (CMD) refers to a group of muscular dystrophies that become apparent at, or near, birth. Muscular dystrophies in general are genetic, degenerative diseases primarily affecting voluntary muscles.

CMD is rare (affecting about one in 50,000 babies) and both males and females are equally likely to have this condition. CMD causes muscle weakness early in life – within the first six months of birth.

The first symptoms are poor head control and weak muscles, which make the baby seem floppy. There may be stiff joints (contractures) due to the baby not being able to move the joints enough.

There are different types of CMD, which vary from person to person in how severe they are, and in whether or not they get worse (progress).

In many cases, CMD is not progressive, so that although the child continues to have difficulties, their muscle strength improves with time, and the child should have a normal lifespan.

Some types of CMD are more severe or progressive. In these cases, the muscle weakness is more pronounced, and the child may have other problems such as seizures, learning difficulties, and/or breathing problems.

The more severe types of CMD have a poorer outlook. Extensive and ongoing research in the area of muscular dystrophies is promising, however there is currently no known cure for CMD. Intervention is directed towards helping CMD patients to enjoy the quality of life that others may take for granted.

With the discovery of defects in several genes in the last two decades, the concept of CMD has evolved from a narrowly defined clinical diagnosis (onset in the first months of life) and histologic diagnosis (dystrophic muscle on biopsy) to a more inclusive group of subtypes defined by the specific genes in which these defects occur.

In many cases, CMD is not progressive, so that although the child continues to have difficulties, their muscle strength improves with time.

However, no complete or satisfactory classification system exists. To make things a little bit more confusing the presentations of the several types of CMD overlap. The overlap is not only within CMD subtypes but also among other congenital muscular dystrophies, congenital myopathies, and limb-girdle muscular dystrophies.

There is still benefit to using the umbrella term CMD because it provides a framework for the diagnostic approach to the infant or young child who presents with muscle weakness.

What are the features of CMD?

Signs of CMD include general muscle weakness and joint deformities. More severe forms of CMD may include severe mental and speech problems, and seizures. At least 30 different types of CMD are now recognised.

At first glance, the various types of CMD seem to have little in common other than their early onset. But on the molecular level, the types can be grouped by how their faulty protein affects the muscle cells.

The vast majority of CMD types are related to proteins that make up or interact with the extracellular matrix that surrounds muscle fibres.

Several types of CMD that arise from gene mutations that initially seemed unrelated now appear to be related to defects in proteins that "sugar-coat" (glycosylate) a matrix protein, allowing it to connect with other proteins. Several less known CMD subtypes have been reported in a limited number of individuals.

Several researchers have proposed classifications for CMD. Here are the currently accepted four categories of

CMD with the known affected gene in brackets:

1. Defects in structural proteins
    a. Laminin-alpha2-deficient CMD (MDC1A).
    b. Ullrich CMD (UCMD 1, 2, 3).
    c. Integrin-alpha7 deficiency (Integrinalpha7) .
    d. CMD with epidermolysis bullosa (Plectin).
2. Defects of Glycosolation
    a. Walker-Warburg syndrome (multiple genes) .
    b. Muscle Eye Brain disease (multiple genes).
    c. Fukuyama CMD (Fukutin).
    d. CMD + secondary laminin deficiency 1 (MDC1B).
    e. CMD + secondary laminin deficiency 2 (fukitin related protein deficiency, MDC1C).
    f. CMD with mental retardation and pachygyria (mutation in LARGE, MDC1D).
3. Proteins of the endoplasmic reticulum and nucleus
    a. Rigid spine syndrome (Selenoprotein N, 1).
    b. Rigid spine syndrome (Selenocysteine insertion sequence-binding protein 2).
    c. LMNA-deficient CMD (Laminin A/C) .
4. Mitochondrial membrane protein
    a. CMD with mitochondrial structural abnormalities (Choline kinase beta).

Greater detail of each of these types can be found on the MDANZ website at www.mda.org.nz/Neuromuscular-Conditions/Conditions-Overview/Muscular-Dystrophies/Congenital-Muscular-Dystrophies

The causes

CMD is a genetic disease, caused by a fault in any number of different genes. Genes contain the recipes for proteins and, when faulty, may result in the reduction or complete absence of the protein. In the case of CMD, the proteins affected are muscle proteins. The reduction or loss of these muscle proteins create the characteristic symptoms of muscle wasting and weakness. Only about 25-50 percent of patients with CMD have an identifiable genetic mutation.

CMD may be inherited, or it may arise spontaneously. Spontaneous or sporadic mutations occur randomly during a child's conception. When the mutation is inherited, it is usually in an autosomal recessive pattern. This means that the condition will only become apparent in a child if both parents carry the faulty gene, yet do not display symptoms. Other forms may be autosomal dominant, and one severe form is X-linked, affecting boy babies.

Diagnosis

There are often difficulties in diagnosing CMD, as signs and symptoms of the disease vary. Where there is no family history, CMD is unlikely to be suspected straight away. The earliest sign of CMD is likely to be a 'floppy baby' – severe proximal weakness at birth or within 12 months of birth. Once CMD is suspected, diagnostic tests will be offered to establish a definite diagnosis. These may include:

- **CK Testing:** As in many of the muscular dystrophies, blood levels of the muscle enzyme creatine phosphokinase (CK, or CPK), may be increased. This enzyme is normally found in muscle cells. When the muscle cell is damaged, CK leaks out into the blood stream. A blood test will show elevated levels of CK, up to 10 times that of normal.
- **Magnetic resonance imaging (MRI)** is a technique that is able to generate an image of the soft tissue in the brain. This allows visualisation of the characteristic brain changes that occur with some CMD disorders.
- **EMG:** An electromyography investigates the electrical activity of a muscle. In CMD, the EMG will typically show activity that is smaller and shorter than usual. Nerve conduction velocity (NCV) tests measure the speed with which a nerve is able to transmit information. This test is more accurate in the older child than in infancy.
- **Muscle Biopsy:** A muscle biopsy is required for diagnosis. Normal muscle fibres are regular in size; in CMD they may appear irregular, or poorly formed. There may be evidence of muscle degeneration and repair.
- **Genetic counselling** provides information about possible diagnostic tests, including prenatal testing.

Management of CMD

As yet, there is no cure for CMD. It is possible, however, to minimise the complications by adhering to a management programme specially designed by a team of medical

Continued on page 25...

A member's STORY

Yes, you can: Conquering CMD

Rachel Hore is not one to give up. After being made redundant from her long-time job, she persevered until another opportunity finally arose. As she writes, she just didn't like the alternative.

Rachel Hore says she finds she needs to be working to have a sense of purpose.

I was born two months premature and it was touch and go for a long time as I was incubated with breathing and numerous other difficulties.

As a toddler I wasn't able to walk unaided until I was four years old, involving many falls. (Nothing too serious though and I guess it wasn't as far to fall then as it is now.)

I was first diagnosed at the age of four with Congenital Fibretype Muscular Dysproportion. This is still (again) being further investigated.

I was lucky enough to grow up in the Maniototo and attend the same school all the way through my school years, so I didn't need to deal with too much change.

After I finished school I went on to study Business Studies at Otago Polytechnic. This brought a new set of challenges but I was ready for them and had great supportive friends around me always willing to lend a hand when needed.

Walking too far is difficult and I was lucky I had friends with transport who were only too happy to play taxi.

My first two jobs were part time. Fatigue has always been a huge factor to overcome and I always thought working full time would be too big a challenge.

However, in my mid 20s a job opportunity came up for full time work on a six- month temp contract in transport/logistics.

I gave it a go, thinking it would be only short term. But 20 years later… (although it had been on and off as I left a couple of times to try other things in life, but the company kept taking me back when I needed work again)... I finally finished with the company last year as unfortunately, due to Covid, I was made redundant.

It was a difficult time, being made redundant and not knowing if employers would take a chance on a disabled woman in her late 40s, not to mention the loss of the income I'd been used to.

I came close to giving up and moving back to the Maniototo, but I wasn't ready for that reality yet.

I got stuck into to applying for every office job I could and luckily admin jobs were plentiful in Dunedin, even in Covid times.

One thing I did learn, which was very helpful, was that unlike previously I was narrowing my options to places that had parking and easy access. By that I mean parking outside the office, as any further is too far for me.

However, I was able to get funding for transport to and from work so I can get door-to-door service – an absolute godsend, that opened my options up to being able to work in the CBD, which I had never thought would be possible.

So, after 15 or so interviews I finally nailed a job in logistics again, this time with Silver Fern Farms, initially on an eight-month contract, but I was hoping that once I got my foot in the door, it would lead to a permanent position.

Then we went into lockdown again. This time, however, I was working for an essential service and fully able to work from home, and I am very grateful for that!

Then in the middle of lockdown I secured a permanent job in logistics in another part of the business. It is very different from last year, and I'm very excited to be secure and happy in my employment again!

It's fantastic to be working for a company that's not afraid to have a diverse workforce from all walks of life and actually practice that.

Don't get me wrong, this full time thing has its moments and I get totally exhausted.

A lot of people commended me for not giving up but, honestly, I

didn't like the alternative. I need to be working to have a sense of purpose.

I now work one day a week from home and the rest of the week in the office. Everyone is able to do that as the company has an amazing flexi-work policy.

If there is anyone out there in the same kind of position, please don't give up. Reach out to resources for help, sometimes the simplest of things we are unaware of can be an absolute game changer.

A big thanks to the wonderful Leisa at Workbridge here in Dunedin, for her amazing support and the knowledge she shared while I was on my job quest, and to Jackie at MDANZ who is always lending support.

Always believe in your abilities and don't let anyone tell you that you 'can't' do something. You CAN!

Congenital muscular dystrophy

... continued from page 23.

professionals. The team will usually be headed by a paediatric specialist, and includes a physiotherapist, together with specialists in other areas as required.

Exercise: Passive exercise, or assisted stretching, should be established as early as possible. It is valuable to have regular contact with a physiotherapist who can assist in the development of an exercise programme to delay the onset of contractures.

Supportive equipment: Braces and walking sticks may prolong mobility, but it is likely that a motorised or light-weight manual wheelchair will be required. An occupational therapist and/or seating therapist can advise on the most appropriate type of chair and supportive seating.

Nutrition: Excessive weight gain can occur due to reduced physical activity produced by the muscle weakness. Being overweight can place extra stress on already weak heart and bowel function, on joints, and also with breathing.

Surgery: If contractures develop at the ankle joints, these can be surgically treated by release of the Achilles tendon. This helps improve foot position. Having a comfortable foot position may help prolong mobility for some CMD children. Spinal fusion surgery is performed to correct scoliosis.

Respiration: As muscles become gradually weaker, respiratory function starts to decline enough to produce changes in the way the lungs pull air in and push it out. Family and caregivers must watch carefully for signs of disrupted sleep due to respiratory problems. Signs include morning drowsiness, lack of concentration, headaches, confusion, sleepiness during the day and wakefulness at night with an increased need to be turned. When respiratory problems become apparent, ventilation machines are available to assist with ventilation during the night.

Research

Research in the congenital muscular dystrophies centres around understanding the molecular processes that lead to muscle loss in these disorders and experimenting with methods to counteract these processes.

Among the approaches being tried in laboratory rodents is gene addition (insertion of new genes, sometimes called gene therapy or gene transfer), either to directly supply the missing protein or to supply proteins that can help compensate for a missing or abnormal protein.

A variant on this theme is blocking the activity of harmful genes, which is also being tried in lab models of CMD.

Another theme in CMD research is the need to fully understand the process of glycosylation of proteins, such as alpha-dystroglycan, in the muscle-fibre membrane. Glycoslyation of a protein means the addition of sugar molecules to the protein, which changes the way the protein interacts with other substances.

Alpha-dystroglycan is not sufficiently glycosylated in several forms of CMD, so understanding and correcting this process is a promising avenue for treatment of these disorders. Several forms of CMD share three common muscle abnormalities:

- Excessive apoptosis (also known as programmed cell death);
- Inflammation; and
- Fibrosis (scar tissue formation).

Drugs and other strategies that combat these processes are being tried in laboratory-based CMD research. ®

Observational and clinical studies underway

The Neurogenetics Research Group is coordinating a number of observational and clinical studies in an effort to improve outcomes for people with neurogenetic conditions.

The neurogenetics research group, led by Associate Professor Richard Roxburgh, is part of the Academic Health Alliance between the University of Auckland and Auckland DHB.

We've partnered with the Duncan Foundation to provide physiotherapy and occupational therapy to people with rare neuromuscular conditions as well as upskill allied health practitioners from throughout the country.

We coordinate a number of observational and clinical studies in an effort to improve outcomes for people with neurogenetic conditions.

In observational studies no drug or intervention is trialled but people with these conditions are assessed and their progression monitored.

Biomarkers and measures of clinical outcomes are sought. Importantly, in the studies we run, allied health input such as physiotherapy, occupational therapy, speech language therapy is provided.

The Friedreich Ataxia Clinical Outcome Measures (FACOMs) study is supported by FARA NZ www.fara.org.nz/ and you can learn more about the study at ClinicalTrials.gov – just enter Friedreich Ataxia and New Zealand into the search.

As part of the international **Myotonic Dystrophy Clinical Research Network** (DMCRN) we're aiming to better understand the variability of myotonic dystrophy through the END DM1 study.

If you have myotonic dystrophy and are aged 18 or over you'll receive information and an invitation to consider participating in this study from Pūnaha Io the New Zealand Registry & Biobank.

We're also enrolling people with **inherited ataxia**, including all types of **spinocerebellar ataxia** and **CANVAS**, and also **adults with SMA** into observational studies.

We run a number of clinical trials at the CBR Neurogenetic Research Clinic at the University of Auckland and we're always interested in adding more.

Pompe disease causes muscle weakness and breathing difficulties. It's caused by an inherited deficiency of the enzyme acid alpha-glucosidase (GAA), which causes glycogen to build up in the lysosomes in the cells of muscles and other tissues.

Regular treatment with enzyme replacement therapy (ERT) alleviates this. Amicus Therapeutics has a new version of ERT aimed at improving outcomes for patients with Pompe disease, which is being provided through an open-label extension study at the Neurogenetic Research Clinic.

PTC Therapeutics are trialling Vatiquinone in **young adults with Friedreich Ataxia**. Vatiquinone is a drug belonging to a group of potent antioxidants. The regulation of oxidative stress is disturbed in people with FA and Vatiquinone is thought to improve the control of oxidative stress.

We run a number of clinical trials at the CBR Neurogenetic Research Clinic at the University of Auckland and we're always interested in adding more.

Because FA causes problems with the mitochondria – the batteries of the cell – the drug is aimed to improve mitochondrial function and therefore cellular energy.

Recruitment for this phase 3 study has now closed and we'll keep you informed on how the trial progresses.

STRIDE is a double-blind, placebo-controlled study to evaluate the efficacy and safety of 24 weeks treatment with REN001 in patients with **mitochondrial myopathy**.

CLINICAL Perspectives

We're pleased to announce we've screened our first person for this study and we're looking forward to being able to include more people in this study over the next few months.

In addition, there are currently clinical trials underway for **children with congenital myotonic dystrophy** and also an exon skipping trial for **boys with Duchenne muscular dystrophy**.

2022 looks to be another busy year with a clinical trial of Arrowhead's ARO-DUX4 getting underway for people with **facioscapulohumeral muscular dystrophy**.

All recruitment for the studies at the CBR Neurogenetic Research clinic takes place through Pūnaha Io the New Zealand Registry & Biobank. More information about Pūnaha Io and how to enrol can be found on MDANZ's website.

Information supplied by
The Neurogenetic Research Group & Associates.

The Neurogenetic Research Group & Associates: Miriam Rodrigues, Dr Christina Buchanan, Dympna Mulroy, Claire Stewart, Julie Rope, Christine Tooke, Val Yeong, Jaimee Orrellana, Karen Spray, Dr Annie Bradley, Dr Andrea Thomas, Dr Melanie Doerflinger, Dr Luciana Pelosi, Dr Gina O'Grady, Dr James Cleland, Dr Rachael Taylor, Associate Professor Denise Taylor, Avroneel Ghosh, Marcelli Coronet, Ashleigh O'Mara Baker, Associate Professor Richard Roxburgh.

The Bradley Jenkin Memorial Fund

The Bradley Jenkin Memorial Fund helps 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 criteria, info and to apply, go to **www.mda.org.nz** > What We Offer

Funds must be spent within three months.

Applications close

January 31 • April 30
July 31 • October 31

Joy and Bradley Jenkin

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

Trevor Jenkin
National Chairperson

Natalie Foote
Executive Assistant

Brian Hadley
Accountant and Business Manager

TBC
Communications and Marketing Advisor

Kristin Cross
Fundraising and Partnerships Advisor

Shelley Butler
Accounts Assistant

Our branches

Northern Region

Fieldworker: *Mike Schneider* 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*

Fieldworker: *Talitha Vial*

Ph: 0800 886 626 Email: members.central@mda.nz

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: canterbury@mda.org.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
Joy Jenkin
support@mdn.org.nz

Central Branch
Tristram Ingham
members.central@mda.nz

Canterbury Branch
TBC
chairperson@mda-canterbury.org.nz

Southern Branch
Trevor Jenkin
chairperson@mdn.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

Schwannomatosis

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

THANK YOU ONE AND ALL:

OUR ROLL 1K FOR MDA CHALLENGE WAS A ROARING SUCCESS!

AND THANKS TO ALL YOUR PEER-TO-PEER EFFORTS WE RAISED MORE THAN $25,000.

Roll 1K For MDA

AND IT'S STILL NOT TOO LATE IF FRIENDS AND FAMILY WANT TO CONTINUE TO SUPPORT YOU, OUR MEMBERS.

Muscular Dystrophy New Zealand

Internet Banking
Account number: 12 3077 0474718 02
Reference: Roll1k

At your Bank
One-off donations can be made in person.

MDA Website
www.roll1kformda.co.nz

Giving over the phone
Phone us on 0800 800 337

Muscular Dystrophy Association of NZ Inc (Charities Commission Registration No: CC31123) Phone 0800 800 337. PO Box 12063, Penrose, Auckland. www.mda.org.nz info@mda.org.nz