InTouch

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The Pandemic: What we have learned

Matariki

A farewell and a welcome

Disability Rights Commissioner

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InTouch

PO Box 12063, Penrose,
Auckland 1642, New Zealand.
Freephone 0800 800 337
NZ Phone: (09) 815 0247
International prefix (00649)

Editor: MDANZ National Office
info@mda.org.nz
0800 800 337

Design: The Artset
the.artset@gmail.com

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Kōrero with Tristram

MDANZ has been working hard as an organisation to become more agile, more flexible in the ways our teams work, and especially to explore new ways of supporting you, as members.

A very warm winter greeting to everyone. I guess this year, even more than usual, we are getting used to hibernating to stay warm, healthy, and even safe. 2020 so far has been tough for many of us and while we may have won the opening gambit against COVID-19 as a nation, it is still far too early to become complacent.

To respond and recover, MDANZ has been working hard as an organisation to become more agile, more flexible in the ways our teams work, and especially to explore new ways of supporting you as members. A lot of our activities and efforts have been behind the scenes in programmes to improve our infrastructure, data privacy and security, business processes, communications and to enable remote working.

Now in the last few months since Alert Level 1 you will hopefully have noticed our community team back out in your neighbourhoods trying to catch up with each and every member – to touch base, grab a coffee, or chat about how things are going in your life right now.

We also recognise your needs and aspirations may have changed post COVID-19, so whether you want some extra support with your condition, health and disability services, or need access to digital technology, training opportunities, employment or peer support – our community team would love to help. Our Bradley Jenkin Memorial fund will no doubt also play an increasingly important role in supporting member needs in this recovery period.

It's also a time of change and renewal within the Association. We have said goodbye to some long-time personnel: Miriam Rodrigues (Programme & Services Advisor) and Dympna Mulroy (Practice Leader) who have both moved back to clinical roles, Amelia Noyes (Marketing Assistant) who is going to work at AUT, Aroha Governor (Contact Centre) who is on parental leave, and at the end of this month we farewell Paul Graham (Canterbury Fieldworker) who is retiring after a long and full career with us. We wish them all well with their future endeavours.

We are delighted to welcome some new personnel including Fiona Tolich (Member Refence Group Coordinator), Professor Shanthi Ameratunga (Clinical & Scientific Advisor), Steffan Brunner (HR Advisor) and two further Community team members in the Central Region.

September is a super-busy month for the Association nationwide as we launch into another 'Freedom' Awareness and Appeal month with a range of events, initiatives, fundraisers and condition-specific awareness days. Please look out for us in your area or let us know if there is any fundraising or awareness raising activity you are keen to help with. More than ever we would love you to be involved in your local areas in whatever capacity you can.

MDANZ is your Association; members helping members, and collectively striving to find our 'Freedom beyond Limits'. It's an honour to be part of an Association that is member-led, has such passion for making our members lives better, and an Association that has been doing just that for over 60 years.

Thank you to every one of you for your ongoing support. Stay warm, stay well, and best wishes from us at MDANZ.

Dr Tristram Ingham
National Executive Chairperson

People moves

The last few months have seen some valuable members of MDANZ leave to take on new challenges as we welcome new team members.

Trevor Jenkin has resigned his position as National Chairperson to focus his efforts on further strengthening the sustainability of the Northern Branch during these unprecedented times.

We are immensely grateful for the all the work Trevor has done over the past 18 months as he gave an incredible amount of time, passion and energy to the association in this leadership role, and all on a voluntary basis.

Trevor will, of course, continue his valuable contribution on National Council as Branch Chairperson.

Dr. Tristram Ingham has been appointed as the new national Executive Chairperson.

Tristram is currently working with the National Council to prepare a comprehensive Covid-19 recovery plan to take our organisation forward, to ensure that our branches get the full support of our national organisation, and especially to recognise and respond to the new challenges and opportunities our members are facing.

Michael Schneider has been appointed as the National Vice-Chairperson effective immediately.

The National Council also wishes to acknowledge the recent resignation of our Programmes & Services Manager **Miriam Rodrigues**. MDANZ is always sad to see a longstanding employee leave our organisation, and wish her well with her future endeavours.

And we are also sorry to see **Dympna Mulroy** leaving us for new pastures. She too has been a hugely valuable member of our National Office team.

But we are pleased to announce the appointment of a new Member Reference Group Coordinator – **Fiona Tolich**, who many of you already know.

Fiona is a member with a neuromuscular condition who currently co-chairs the very successful SMA Reference Group. She will be working alongside other members to support them to establish reference groups for several other conditions.

Shanthi Ameratunga has now been appointed as Clinical and Scientific Advisor to MDANZ. She is a Professor of Public Health at the University of Auckland and Senior Researcher at Counties Manukau Health.

She graduated from the Otago Medical School and specialised in paediatrics before undertaking postgraduate studies at Johns Hopkins University (Baltimore).

Her work has focused on injury, trauma and disability, focusing on physical, social and health care issues impacting on quality of life and social wellbeing.

She has led research collaborations in New Zealand, Australia, and the Asia-Pacific region and is an advisor to the WHO.

Shanthi tells *In Touch* she is strongly motivated by a passion to facilitate clinicians and policy makers to make equity-focused evidence-based decisions that leave no one behind.

Four new reference groups

MDANZ is now recruiting for members of four new reference groups.

After the success of the SMA (Spinal Muscular Atrophy) Reference Group, we are excited to announce that we are now beginning our recruitment process for four new Reference Groups:

- Charcot-Marie-Tooth disease.
- Duchenne muscular dystrophy.
- Myotonic muscular dystrophy.
- Limb-girdle muscular dystrophy.

This is just the beginning; we are keen to ensure that we stand by our position of being a member-led organisation and that means we need you – the members.

These voluntary roles are about informing MDANZ. We need a collective of people who are not afraid to bring their insight into what the organisation needs to do in terms of advocacy, support and new initiatives.

It is an exciting opportunity to share your perspective and lived experience to help us move forward.

You can dial in from anywhere and we would love to see a geographical spread. So, if you are a member and have one of these conditions or are a family member wanting to make a difference, then please contact us.

The only prerequisite is that you are passionate about seeing the best outcome and have at least one day a month to commit time to supporting this cause.

If you wish to get involved, then please send an email to Fiona Tolich (Member Reference Group Coordinator): membergroups@mda.org.nz explaining which group you are interested in being a part of, why you are interested and the best number to contact you on.

We seek to have all expressions of interest in by September 30.

An update on the Dukies Awards

Our Dukies haven't let the pandemic stop them working towards their goals.

The past six months have been a great success so far, despite the COVID-19 pandemic.

Our Dukies Awards leader, Marty Price says it was great to connect with each Dukie and their families and to see everyone getting back into reaching their goals since the country has started to return to some sort of normal.

"This is a testament to our Dukies. Each Dukie is not only doing the award but some are still undertaking schoolwork or other work and as their award leader, I am extremely proud of each and every one of them."

He says Ryan O'Rourke of Gore, Joy Gutschlag from Nelson and Camille Peterson in Auckland are all participating in the Bronze Level with great achievements made so far this year.

"Unfortunately Alisha Mills from Christchurch has had to pull out from the Bronze Award due to her many sporting, school and Special Olympics commitments.

Some of the Dukies at the Maritime Museum last year.

"Well done Alisha on all you achieved during your time with the Duke of Edinburgh's Hillary Awards programme."

Jack Lovett-Hurst from Invercargill and Dylan Schneider from Auckland are on their second level with the Silver Award.

Meanwhile, Marty Price has been recognised by the Duke of Edinburgh's Hillary Awards as an experienced Award Leader. Well done Marty – we are lucky to have you lead our Dukies.

Life is what you bake it

Our virtual Bake a Difference campaign was a great success.

Amidst the COVID-19 pandemic lockdown, MDANZ members and supporters came together virtually with friends, family and work colleagues for our virtual Bake a Difference campaign.

Some of our supporters challenged others to a baking competition online while others simply organised a coffee and cake morning tea via online group chats.

It was great to see so many of you getting amongst the campaign to raise vital dough and awareness for MDANZ.

Despite everyone being under lockdown and the country saving their pennies (and flour) we managed to raise more than $1,500 for MDANZ.

Many thanks to all who took part.

Left: Vivienne Fitzgerald (South Island Community Co-ordinator) and her daughter Isabelle hard at work for our Bake a Difference campaign. Right: A cake from Darian Smith, Northern Fieldworker.

The Bradley Jenkin Memorial Fund: The story behind the name

InTouch reflects on a family legacy with Trevor and Joy Jenkin.

Bradley had Duchenne muscular dystrophy (DMD). He was a boisterous yet loving young man. He was a typical teenager, full of life, and so proud of the red and black Nike shoes he bought himself shortly before this photo – they were more about image than practicality.

Bradley knew that the profound muscle weakness that DMD causes was going to limit his lifespan, so he was determined to pack in as much as he could, while he still could – games, sport, the great outdoors, his friends.

Bradley was a generous and giving young man. One who could not let an injustice go past or someone go without something they needed.

Sadly, Bradley passed away aged 17 years as a result of a cardiomyopathy (weakened heart muscle) that is a rare but important complication of this condition.

Bradley's parents have taken up his cause, recognising the support that MDANZ offered their son while he was alive. Joy and Trevor now continue to work tirelessly to support other children with DMD, and via MDANZ help ensure that all DMD children get the vital cardiac screening tests they need but are not always offered, and their families receive the support they so desperately need.

Both Trevor and Joy have been active members of the Northern branch for many years, as Chair and Secretary, fundraising coordinators, camp organisers, and social media influencers on our member Facebook groups.

In particular, and in the spirit of generosity that he shared with his late son, Trevor recently served as the National Executive Chairperson for 18 months. In that role Trevor was a passionate and dedicated leader, and upon his resignation National Council unanimously resolved to express their sincerest and heartfelt thanks for the important work he did in the role.

The Council recognises that he gave tirelessly and selflessly to the staff and membership, and without any remuneration in his full-time yet voluntary capacity. Trevor was always on the phone and email from dawn till well after dusk, keeping in touch, reaching out to members, and supporting our teams around the country.

Trevor came into the role at a critical moment in the Association's history, at a time of fiscal constraint, a health and disability system that was overstretched and under pressure, and with low staff morale. He stepped up and progressively worked to rebuild staff morale, organisational transparency, and collegial relations between the branches, fitting running his own business in between all that.

Trevor's recognition of the value of branches, and the community-based fieldwork service they collectively run, saw him support and guide several branches through critical transitions. While we still have work to do to build on the groundwork Trevor laid out, National Council is very aware that his efforts have paved the way for the branches to survive, grow, and indeed thrive.

So on our 60th Anniversary celebration, and recognising the enormous contribution that both Trevor and Joy have made, National Council chose to rename our member discretionary grant fund, in memory of Bradley Jenkin, as a way to pay tribute to the generous spirit that Bradley had, and also to recognise the work that Trevor and Joy have done, and still do – a value that cannot be quantified in money, but that epitomises the values of this member-led organisation.

Bradley and his mum, Joy.

An update from the DPO Coalition

The DPO Coalition had several key messages it wanted to share in May.

Voice of disabled people: An update for for the DPO partners from the coalition says it is working in challenging times with COVID-19. "While there is good engagement with Government overall, the speed of change is making it harder to ensure Government meets its commitments to engage with disabled people early and in partnership. Our focus is accessible formats and early consultation. We also need to ensure that disabled peoples' representatives are included in the new governance and decision-making groups that are emerging. We have strong support from Minister Sepuloni on this," the coalition says.

COVID-19 issues for disabled people: In addition, to accessible formats and early consultation, the coalition has raised issues around support at home, working at home, rent freeze, access to personal protective equipment to allow disabled people to protect themselves, public transport and many other issues. "If you have issues you believe need more attention, please let your DPO know."

Health and Disability Sector Standards: The coalition says that two DPO Coalition representatives are now representing the voice of disabled people in the review of these important standards. "This has happened because we wrote to the Ministry of Health raising concerns that disabled people have not been involved in the review of these standards. The standards last for 10 years and so full involvement is crucial. There will be more information soon on how we will achieve engagement with disabled people."

Workbridge: In turn, the coalition is engaging with Workbridge about how its services and funding approach can be improved. Again, it says, if you have comments on this, please connect with your DPO.

Disabled people-led monitoring: The coalition says its Housing Report is almost completed and will be available in the full range of alternate formats, and Te Reo. "There will be a launch (date yet to be set) and we will also hold a workshop with Government agencies that have a role in improving housing. Our next report on health and well-being is starting. This will include a wide look across all aspects of well-being plus research into the impact of the Government's response to Covid-19.

Education: The coalition notes that it continues to work closely with the Ministry of Education across all their strategy work. It has been holding regular workshops on topics important to disabled people and was planning a further half-day workshop. "We will soon have two DPO Coalition representatives on the Review Panel for the National Certificate of Educational Achievement (NCEA)."

Disability Action Plan: It says that the Government has committed to important actions in the Disability Action Plan and progress must continue. "Now that we are in the COVID-19 recovery phase, we are re-engaging with the Office for Disability Issues and Government agencies to re-activate the Disability Action Plan."

Tatou Whaikaha – All of Government Network of Networks: The coalition says this new group has been established to coordinate the ongoing response to COVID-19 across Government. The DPO Coalition Chair, Leo McIntyre is representing the DPO Coalition on this group.

Feedback: To provide feedback please email the DPO Coalition at us-dpo@groups.io

A very big thank you

MDANZ is privileged to have a number of major companies supporting us in our work and this month we'd like to acknowledge Grant Thornton for their support with providing pro bono advice.

Grant Thornton

A farewell note from Dympna

I moved to New Zealand in 2010 from Ireland and joined MDANZ in 2012 as fieldworker for Central Branch. During my time at MDANZ I was fortunate to be practice leader for the fieldworker service and part of the MD prevalence study.

I relocated to Auckland in October 2018 to take on the position of member services manager at national office and completed my Masters in 2019 on the impact of myotonic dystrophy on employment.

When I first started at MDANZ I had very little knowledge of neuromuscular

conditions. Thanks to our members and learning opportunities provided to me I have developed a passion and learnt a lot about how these conditions impact on individuals, their whanau, friends and family.

I hope to build on this experience in my career when I relocate back to Ireland. After eight years at MDA I have made the decision to start a new career pathway in research and continue in my profession as an occupational therapist.

I want to thank you, the members and supporters of MDANZ, especially those in Central Branch, who allowed me to walk alongside and support you on your journey with a neuromuscular condition.

MDANZ is my New Zealand family. I will miss everyone and will take away many good memories.

Research: Novel regenerative therapy for DMD

A US company plans to continue to progress its new novel treatment towards clinical trials and plans to bring it forward for other congenital muscular dystrophy diseases as well.

Vita Therapeutics, Inc. has announced that it received orphan drug designation (ODD) from the U.S. Food and Drug Administration (FDA) for VTA-110, a novel regenerative therapy for the treatment of Duchenne's muscular dystrophy (DMD).

The company says in a media release that VTA-110, is a "potential first-in-class allogenic iPSC-based therapy that has shown the ability to repair and regenerate healthy muscle in preclinical studies and has the potential to benefit patients with DMD".

The company says it plans to continue to progress this treatment towards clinical trials and plans to bring it forward for other congenital muscular dystrophy diseases as well.

This therapy was exclusively licensed from technology originally invented at Johns Hopkins University and the Kennedy Krieger Institute in the labs of Dr. Kathryn Wagner and Dr. Gabsang Lee.

Douglas Falk, M.S., CEO of Vita Therapeutics says they are very pleased the FDA granted orphan drug designation for VTA-110.

"This represents an important step in the right direction for developing innovative treatments for patients with an incredibly high unmet medical need.

"We believe VTA-110 has the potential to be a long-term disease-modifying treatment for patients living with DMD and other types of muscular dystrophy."

The FDA grants ODD status to medicines intended for the treatment, diagnosis or prevention of rare diseases or disorders that affect fewer than 200,000 people annually.

For a drug to qualify for orphan designation both the drug and the disease or condition must meet certain criteria specified in the ODA and FDA's implementing regulations.

More information about Vita Therapeutics at www.vitatx.com.

Lauren's words

Lauren's speech on what it's like living with a disability

One of our Auckland Rangitahi members, Lauren Turnbull, who is 13 years old, made a beautiful speech on living with myotonic dystrophy which she delivered to her class at Carmel College on Auckland's North Shore.

I've been living with myotonic dystrophy for all my life. I'm here to tell you that it doesn't stop me doing inspiring things and to persuade you that boys and girls with any type of disability should be treated equally.

What having myotonic dystrophy means is that my muscles are weaker and I can't really do stuff easily like other people can.

For example, we were having a running race and the starting pistol went off and everybody else shot off like a bullet, I tried to run but my muscles being weaker means I am as slow as a tortoise.

I also find writing for too long uncomfortable because after 10 minutes my fingers start to ache so badly.

I get hurt way more easily, I have broken both of my arms [and the breaks] were two years apart.

My muscles have to work twice as hard as regular people. I go to the children's hospital every year for tests with various doctors, however, my health is awesome and I rarely get sick.

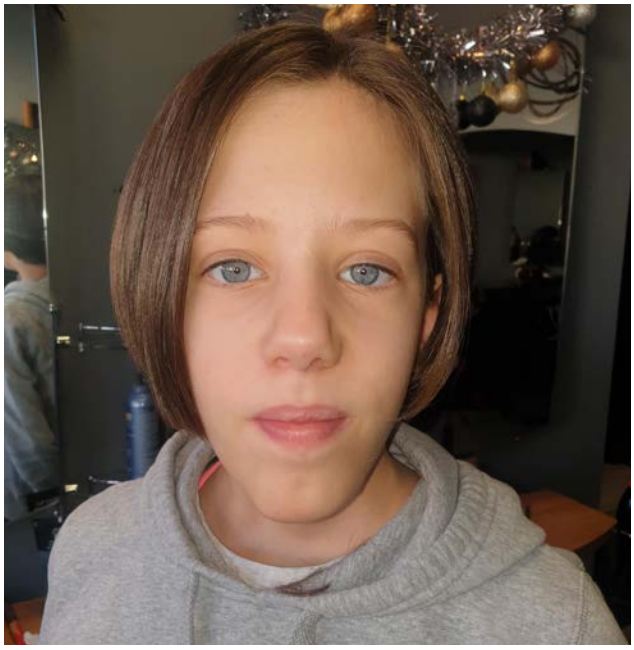
If I watch emotional movies, specifically about animals or dogs I can get upset.

I get really tired easily. For example if I do any physical activities like netball, running, basketball or dance I need to sit out for a while to recover from what just happened.

When I was born the doctors said that I might not be able to walk or talk but now I can walk, run, sing and talk.

A good thing about having a medical condition is that I can go to activities at the Wilson Home such as art, baking and music.

The Wilson Home, for those that don't know, is a special centre where kids with conditions get a bit of extra care and attention to help them with their every-day lives.



Lauren Turnbull.

Finally, there are trials going on in the USA to hopefully find a cure for my medical condition. One day I hope to be able to run and jump and have the same energy as all you guys.

Thanks for listening.

I'm here to tell you that it doesn't stop me doing inspiring things and to persuade you that boys and girls with any type of disability should be treated equally.

Lessons from the pandemic

A case of the good, the bad and the ugly

The pandemic response activated, transformed, challenged and motivated disabled people, but the impacts varied widely. Shanthi Ameratunga examines the high points and low points of disabled people's experiences since COVID-19 entered our world.

COVID-19 has propelled us into a world that has never seemed more connected and disconnected, at the same time. Media commentators use words like 'unprecedented' and 'surreal'. And the team of five million swings between relief and disbelief.

Life is complex, the future is uncertain, and people look for fixes that serve the loudest voices. Times like this can lead to profound neglect of the unique experiences, needs, aspirations and insights of disabled people.

To counter this significant risk, a group of committed people, led by Dr Tristram Ingham (MDANZ Executive Chairperson), Paula Tesoriero (Disability Commissioner) and Brian Coffey (Director, Office of Disability Issues), set up a Network of Networks to strengthen the voices of disabled people in all matters relating to the pandemic response.

The initiative, launched as the country was heading to the Level 4 lockdown, is called *Tātou Whaikaha*, which means 'Together we are strong and enabled'. Its standpoint was simple. Disabled people must have access to healthcare, lifesaving measures, and support services on an equal basis with others. And resource allocation in the pandemic response must not discriminate against disabled people. These principles are embodied in the UN Convention of the Rights of Persons with Disabilities and enshrined in New Zealand's Human Rights Act, Disability Action Plan (2019-2023) and *Te Tiriti o Waitangi*. But honouring these rights is something else.

When I took up the role of Advisor to the *Tātou Whaikaha* Network Response Team, I was acutely aware of three critical issues.

- Disabled people are at increased risk from COVID-19 and serious complications.
- Current systems challenge disabled people's opportunities for health, wellbeing and independence, at the best of times.
- The pandemic and the response to it were highly likely to expose long-standing barriers experienced by disabled people that would require urgent and specific attention.

We learned a lot from the Network Coordinators covering

a broad spectrum of the disability community working tirelessly in the field.

Most obviously, COVID-19 and the pandemic response activated, transformed, challenged and motivated disabled people, but the impacts varied widely. As Matua Peter Allan (*Enabling Good Lives* programme in MidCentral) told me, "It was a case of the good, the bad, and the ugly! We have to be there for the long haul."

So, what are the high points and low points of disabled people's experiences since COVID-19 entered our world?

Well, as the readers of *In Touch* would know better than most, the rich and unique accounts could fill a library! I will touch on a few memorable points from the feedback received – and these tell me that we have a long way to go if we want to leave no one behind. But we are on the road, and this hikoi is led by disabled people.

The Good…

More obvious use of NZ Sign Language in daily briefings on COVID brought cheer to many. And we heard a resounding vote of approval for greater flexibility of disability contracts in the face of the lockdown.

Disabled people could now resource family members as alternative support workers protecting all involved in a safe bubble. This meant more choice, more control, and more opportunities to use innovative strategies to manage their lives. Not only was this a lifeline in what could have otherwise been hazardous situations, it also meant disabled people were at long last provided the confidence and trust to manage the supports they needed.

We heard how disabled people were proactively co-designing solutions that suited their needs with families and support workers. Examples of innovative approaches that overcame obstacles encountered in the mainstream were plentiful. People living in areas where the *Enabling Good Lives* programme was in operation had a head start here.

Network coordinators talked of how the crisis was leading to a 'coming together' of different disability groups to consider common challenges and solutions. And they talked of the power of real-life stories, big wins and small, at local levels.

But several added a cautionary note to early wins. There were deep concerns that innovation can only go so far when challenges wear on, the economy takes a down-turn, and hard-won resources become scarce.

As one disabled person said, "I sincerely hope these options we now have don't get rolled back. They have made a real difference to my quality of life at no extra cost of delivery."

We are on the road, and this hikoi is led by disabled people.

The Bad, going on Ugly…

The reports we received made it clear that even if the COVID case numbers did not 'take off' as expected, the implied threats led to high levels of stress, anxiety and fear among many disabled New Zealanders. This was made worse by inadequate information and time to prepare for changes in alert levels; increased costs of food, energy, and transport; and difficulties accessing supermarket and pharmacy supplies.

Needing to rapidly organise more complicated systems of cover when regular support staff became unavailable and changes to living arrangements, sometimes to more complicated family situations, made some disabled people feel unsafe and vulnerable, and burdened by extra out-of-pocket expenses.

Network members were also concerned about the lack of visibility of efforts upholding the rights of disabled Māori.

As one coordinator noted, "*Te Tiriti o Waitangi* needs to be more than a bureaucratic tagline". More general concerns regarding equity (or lack thereof) also loomed large. Coordinators observed how the most marginalised were often reached last.

The 'digital divide' played a big role. People with unreliable cellphone connectivity due to financial or technical issues were especially at risk. Some disabled people also became too scared or uncomfortable to seek medical help when the dominant symbols at their usual points of care were the threats of COVID.

Taken together, these experiences provide a glimpse of what's required if our aim is to 'build back better'.

As one respondent observed, "The sooner we allow disabled people to have control over their choices, the sooner we will see better outcomes for disabled people across all areas, that includes health, employment, everything. This will benefit society as a whole."

Professor Shanthi Ameratunga is MDANZ's new Clinical & Scientific Advisor.

The Pleiades M45 open star cluster in the constellation of Taurus.

Matariki: A farewell and a welcome

Farewelling our loved ones

Dion Ponga, a member of Central Branch, writes about Matariki based on the knowledge of his ancestor, expert Maori astronomer, Piki Kotuku.

Matariki is a part of the Māori world, our way of living. As I was born and bred in Palmerston North, Matariki wasn't celebrated as much or hardly spoken about throughout my upbringing.

It was not till I went back home to the Whanganui River where my elders talked about it. That is how I was introduced to Matariki, or Puanga as we know, and see it, in the Whanganui river area.

Matariki means hello and goodbye. To me it is about farewelling those who have passed on and welcoming the new year.

"Mata" translated means "face" and "riki" means "small or many", so in translation it means "the many faces".

Matariki is short for Ngā Mata o te Ariki a Tāwhirimātea - the little faces or eyes (stars) of Tāwhirimātea - the Māori God of the Winds.

This phrase stems from Māori legend, when Rangi (sky father) and Papa (mother earth) were separated by some of their children.

Tāwhirimātea, one of their sons, disagreed with his siblings separating them and sought utu (revenge) and to fight and punish each sibling.

Once he reached Tūmatauenga – the Maori god of humanity, they fought but Tāwhirimātea was unsuccessful. Out of rage, he tore his eyes out, crushed them and threw them into the chest of his sky father, who then formed

the stars and the constellation of Matariki - this act of rage leaving Tawhirimatea as the blind god.

In Greek mythology, there are seven stars (Pleiades) but in Māori philosophy, there are nine stars that make up Matariki.

Matariki is the main star, symbolising well-being and viewed as an omen of good fortune and health. She had eight children with Rehua (Medicine star). There's Tupuanuku – she is connected to food grown in the ground, kumara etc; Tupuarangi – he is connected to food that comes from the sky, birds etc; Waiti – she is connected to fresh water and its animals; Waita – he is connected to the ocean and its fish; Waipunarangi – she is connected to rain; Ururangi – he is connected to the winds; Pohutukawa – she is connected to death; and Hiwa-i-Te-Rangi – she is connected to hopes and dreams, wishes.

Matariki appears in the Maori lunar system generally between May to July to the left of the Melting Pot and Orion's Belt.

When all of Matariki's stars align, they form a canoe, Te Waka o Rangi – the canoe of our Sky Father.

Pohutukawa is in the middle of the canoe. At the end of the canoe when darkness sets, it dives under the earth and throws a net to collect all the souls that have passed, an annual process.

It comes up before sunrise, dispersing the souls of the loved ones we've lost casting them into the sky and they too become one, and join the myriad of stars.

Our elders would view the stars of Matariki to tell how the new year would go.

If a star is bright, it would represent abundance during the year. If a star is dull, that would represent a lack of that particular resource.

This year, Pohutukawa was hardly seen, so this means there will be a few deaths for Māori. Whereas, Waita and Tupuanuku were bright so ground cultivation and fishing will be good this year.

Traditionally, Māori would gather on a mountain and make a hangi/uku (earth oven) or have a fire, Hau tapu – sacred offering to the gods.

They would place things that represent each star. Food would be gathered, cooked and a karakia would be shared. When Matariki appears, they would let the steam rise as an offering to the gods and let the steam carry up their good wishes for the year.

Dion Ponga and his moko - Taiao and Aumarire.

Matariki means hello and goodbye. To me it is about farewelling those who have passed on and welcoming the new year.

Some people continue to do this, others generally light fires and send up smoke with goodwill, and some people celebrate by having a celebration dinner or a quiet karakia – prayer.

All in all, Matatriki to me is:

Te Poroporoaki ki te mate –
farewelling our loved ones, and

Te Matahi o te tau hou
– welcoming the new year.

Referendum on the End of Life Choice Act

Understanding the complexities of the Act

Disability Rights Commissioner, Paula Tesoriero MNZM, explains her concerns with the safeguards in the legislation.

As Disability Rights Commissioner, my role is to protect and promote the rights of the disabled people in New Zealand (24 percent of our population).

Many of you will have heard me talk about the human rights issues with the End of Life Choice Act that is one of the referenda in this year's election.

Parliament has handed it to voters to decide 'Yes' or 'No' to enforce a specific piece of legislation, not whether we agree or not with the concept of assisted dying.

A November 2019 poll showed between 70-75 percent of New Zealanders are confused about the current law and the new Act, with some mistakenly believing it means things such as permission to turn off a ventilator.

So, we all need to get our heads around the complexities of this Act, not the philosophical issue of assisted dying.

Although improved somewhat on when it was introduced, I still do not consider the Act balances protections for those most at risk of wrongful death with the rights of those who want the choice to request assisted dying.

The New Zealand Human Rights Commission has always been clear in its view that any assisted dying regime must have sufficient safeguards in place. It's now up to voters to be satisfied that the safeguards in the Act are sufficient to protect wrongful deaths.

Many hundreds of disabled people and their whānau as well as members of the legal profession have raised concerns with me about the poor safeguards in the legislation.

My concerns with the safeguards are set out below.

There is no bright-line test between disability and terminal illness which means that claims the Act prevents

Disability Rights Commissioner, Paula Tesoriero MNZM.

people from accessing the regime because they are disabled is incorrect.

There are many types of impairments that by their nature are terminal and the point at which someone becomes certain they are in the six-month prognosis is not clear. A number of disabled people are very likely to be eligible, or become eligible very easily, under the criteria because of the absence of a bright-line test.

Supporters of the Act say that the steps a doctor has to take a person through are robust. I disagree.

The first doctor makes an initial assessment about eligibility. There is no requirement for them to even know the applicant, or to be trained in assessing for eligibility for this regime.

They are required to encourage the person to talk with others but also required to tell them they do not have to. In terms of assessing the person is free from coercion, the doctor is simply required to "do their best" to ensure that the person expresses their wish free from pressure from any

other person by talking with other medical practitioners and family approved by the person requesting.

So, it's possible the group contacted will be the protagonists in the situation if coercion is a factor.

On the point of coercion, while health professionals are banned from initiating discussing the option, there is nothing to stop family members or others from raising it. Even if coercion is detected it is not an offence.

The assessment of competency in the Act may impact on disabled people. Of course, we must respect people's right to make decisions when they are competent to exercise free will but that isn't always clear.

According to the Act a person is considered competent if they have an ability to understand the nature of assisted dying and its consequences. This is an extremely simplistic definition which falls well short of common interpretations both in a legal and clinical sense.

At no point is the person assessed for their mental health condition or physical health condition that may affect judgment, behaviour or decision-making.

An individual could experience severe depression or be affected by potentially transient factors such as fear, despair or loneliness yet still be able to pass the Act's 'competence' test.

This Act also misses a number of important safeguards present in other jurisdictions. For example, there's no judicial oversight. There's also no disabled person representation included in the SCENZ Group (Support and Consultation for End-of-life in New Zealand) – a public body that will be created to oversee assisted dying. The review mechanisms are weak with no requirement to monitor for reasons for choosing the option or inconsistencies across the country in its application.

There's no 'cooling off' period for those applying for assisted dying which is especially important for disabled people. In New Zealand, all that's needed is 48 hours for the paperwork to get to the registrar. Several laws internationally require at least 10 days to prevent emotional decision-making.

In other jurisdictions independent witnesses are required when the person expresses their wish, signs the form, or when they receive the lethal dose. But this is not required in New Zealand's Act making any pressure from a health professional hard to detect.

Supporters of the Act say Parliament has thoroughly debated it. The Select Committee spent hundreds of hours on the Bill yet could not suggest it be passed and only recommended minor changes. When Parliament considered it, there were 113 Supplementary Order Papers (SOPs), with minimal debate or changes made as a result. So many SOPs highlights the complexity of the issues. The Victorian legislation is four times longer than ours with a level of complexity and detail, and input by disability advocates, that ours is seriously lacking.

I still do not consider the Act balances protections for those most at risk of wrongful death with the rights of those who want the choice to request assisted dying.

Many people argue this is simply about choice. We aren't all on the same level playing field when it comes to someone's "right to choose". Many disabled people don't get to choose who they live with, where they live, whether they consent to medical treatment, or about service provision.

It is premature to have an assisted dying regime ahead of creating the supports for disabled people to live good lives and ahead of improving palliative care services in New Zealand.

The top motivational factors for people overseas choosing assisted dying include loss of independence, being unable to participate in community, loss of control and becoming a burden on others.

Many disabled New Zealanders deal with these issues every day as part of their daily lives, and as part of living in a disabling society and many disabled people have raised concerns with me about the message this Act sends.

The arguments about choice, premature debate and the message the Act sends are an important part of the context within which this Act will operate in if passed.

But I circle back to my critical concern with this Act – that being the significant gaps in the safeguards. It's not good enough in my view to have an Act with such serious consequences to be so weak in its safeguards.

OPINION

The cannabis referendum

MDANZ member, Dr Huhana Hickey, offers her perspective on the upcoming cannabis legalisation and control referendum.

In this referendum, you are asked: Do you support the proposed Cannabis Legalisation and Control Bill? If 50 percent of people vote 'yes', the law will go through the process of coming into effect. If 50 percent vote 'no', the law will fail.

Details of the proposed law are covered in the referendum website www.referendums.govt.nz. In brief, the Bill sets out how the government will control and regulate cannabis, and covers how people can produce, supply or consume cannabis. The bill's main purpose is to reduce cannabis-related harm to individuals, families/whānau and communities.

The proposed Bill aims to legalise restricted access. That is, it will allow people to possess and consume cannabis in limited circumstances including that a person aged 20 or over would be able to:

- Buy up to 14 grams of dried cannabis (or its equivalent) per day only from licensed outlets.
- Enter licensed premises where cannabis is sold or consumed.
- Consume cannabis on private property or at a licensed premise.
- Grow up to two plants, with a maximum of four plants per household.

The Bill proposes to reduce cannabis related harm to individuals, families/whānau and communities by:

- Providing access to legal cannabis that meets quality and potency requirements.
- Eliminating the illegal supply of cannabis.
- Raising awareness of the health risks associated with use.
- Restricting young people's access to cannabis.
- Limiting the public visibility of cannabis.
- Requiring health warnings on packaging.
- Improving access to health and social services and other support for families/whānau.
- Making sure the response to any breach of law is fair.

Issues around medicinal cannabis are not set out in this Bill as this was made legal in previous legislation, but there are some important implications.

By legalising cannabis, there is an opportunity for medicinal cannabis to not only be cheaper but to also provide the variety of different textures, balms, or wheels needed to be effective pain relief.

Some people are concerned about the issue of reducing harm. To understand the issue more generally, we need look no further than the harm that has been caused through the legal use of alcohol and the impact on people families/whānau. My family were heavily impacted by alcohol and as a result I don't drink. I do, however, use medicinal cannabis due to my medical condition. The cost of that is so high that it is prohibitive to most disabled people and to anyone in poverty. There are also challenges with the lack of variety of medicinal cannabis, such as difficulties accessing a balm product that's more effective with neuropathic pain compared with gabapentin. Cannabis has been used as a medicine for thousands of years prior to it being made illegal.

It is well documented that young Māori are far more likely to be charged for growing, cultivating and using cannabis and jailed than non-Māori. The social, economic and emotional consequences of having a jail term affects the rest of their lives and these are experiences unfairly and disproportionately imposed on Māori.

In my view, the referendum website provides an unbiased view on the referendum. I urge you to do your own research but don't buy into some of the propaganda on both sides of these arguments. Check the facts and the evidence presented. In making your decision I would suggest you consider not just you and your family but the community as a whole, and whether this would benefit or hurt them.

Dr Huhana Hickey, MNZM, MInstD, LLB/BSocSci, LLM (distinction), PhD in Law and tikanga Māori is a scholar of disabilities research and legal theory.

Limb-girdle muscular dystrophy

The onset of LGMD can occur in childhood or symptoms may not be apparent until adolescence or adulthood.

Limb-girdle muscular dystrophy (LGMD) is a highly variable group of inherited disorders that cause weakness and wasting of the proximal skeletal muscles. These are the muscles closest to the body such as the hip and shoulder areas. These conditions are progressive and worsen over time, often leading to loss of mobility.

The onset of LGMD can occur in childhood or symptoms may not be apparent until adolescence or adulthood. LGMD is often faster and more severe when the onset is earlier, in comparison to individuals who develop LGMD later in adolescence or adulthood.

The main features of LGMD are:

- Weakness in hip and thigh muscles result in an unusual walking gait, and may lead to difficulty climbing stairs and getting up from a seated position.
- Muscle weakness in the shoulder area can make reaching over the head or carrying heavy objects difficult. Some individuals find it increasingly hard to type and may have trouble feeding themselves.
- Postural changes – weak shoulder muscles tend to make the shoulder blades protrude (scapular winging) and some individuals may have spinal curvature.
- Progressively, muscles of the face and distal muscles, such as the lower legs, feet, forearms and hands, may become affected and lead to considerable weakness.
- Mobility may become increasingly restricted and 20-30 years from onset, individuals may require a wheelchair.
- Cardiac problems can arise such as weakness of the heart muscle (cardiomyopathy) or abnormal heartbeat (conduction abnormalities or arrhythmias). The heart must be monitored regularly.
- Respiratory muscles may also be affected resulting in breathing difficulties and should be monitored closely.

Classification of LGMD

The classification of LGMD has changed in the last two years. Previously LGMD1 represented the condition when the mode of inheritance was autosomal dominant (one of the parents has the gene defect and children have a 50 percent chance of inheriting the disease) and LGMD2 represented the condition which was inherited in an autosomal recessive manner (both father and mother need to have the gene defect to pass it onto their children, children have a 25 percent chance of inheriting the disease).

Specific gene defects were assigned a letter of the alphabet in the order that they were discovered. For example, LGMD2A was caused by a defect in the Calpain 3 gene, and was the recessive gene (hence the 2) defect to be discovered first (hence the A).

The new classification has the letter "D" when the disease is inherited in an autosomal dominant manner and an "R" if it is inherited in a recessive manner.

Subsequently, the disease is given a number in the order in which the disease is discovered over time and the name of the protein that is not or incorrectly produced. For example, LGMD2A is now known as LGMDR1 Calpain 3-related.

The list of classifications is available on MDANZ website.

LGDM community

There are several different Facebook groups for these conditions, either generic or sub type specific, and they are a good forum to learn from others' experiences or discuss issues. These are listed on MDANZ website. R

A member's STORY

Advocating for social change

Alice Mander says people living with a disability should be loud, proud and out there and should know their own self-worth.


Alice Mander

Advocating and leading social change for people living with a disability is something 20-year-old Alice Mander undertakes on an almost daily basis in her role as president of the Disabled Students Association, a disability advocacy group at Victoria University in Wellington.

And she would love to do more of this work. It's not a paid position but takes as much time as a part-time job.

"It's a lot of work, but I greatly enjoy it," she says.

Alice, who has limb girdle muscular dystrophy, is also in the process of setting up a National Disabled Students Association and that too takes a lot of her time. She is studying both law and an arts degree majoring in sociology and film studies.

She tells *In Touch* that film studies are very interesting as she has always loved film and story-telling, especially around improving peoples' understanding of disability. She sees film as an important mechanism for social change.

Alice's family lives in Auckland's Grey Lynn but she opted to study in Wellington as she has always loved its arty vibe. She is currently flatting in bohemian Aro Valley, near the centre of the city, with a group of friends and says while the access isn't great, it is better than many flats in Wellington where much of the accommodation perches high on the hills.

Alice found out she had LGMD when she was 11 years old although there was a long period of uncertainty as to what was going on with her physically.

She tells *In Touch* that she had always walked on her tiptoes and could not run very fast. She also found it difficult to get up off the ground. She was given exercises for stretching her tendons but finally the LGMD diagnosis was made.

At present she doesn't use any mobility devices but says she can't walk far or go up the stairs. She is on the lookout for a mobility device.

Asked about her advice to other young people, she says that living with a disability is hard, because you live in a world that doesn't accommodate itself to you. When she was around 15-years-old she really struggled with that and was not happy with herself and was angry at the situation.

But she says she has learnt to overcome that and harness her anger and to be proud of who she is. She says she is using that energy to try and effect change.

And, she says, young people with a disability should be proud of who they are and she'd encourage everyone to know their self-worth.

"It's not your problem that the world can't accommodate your disability."

Advocating for change has been a big part of her life since she was 18 years old and it's very important to her.

And things are improving, she says, challenging people to be loud, proud and out there – which she says is becoming more common.

"These issues affect a lot of people but things are definitely getting better."

Younger people especially are quite aware of different groups in the community that are marginalised.

And it's not just words for Alice, she lives by these principles, telling *In Touch* that if any readers want to learn about going to university and living away from home she is more than happy for them to get in touch with her either through MDANZ or via her email alicecmander@gmail.com

Alice explains that she had older mentors before she went to university in city away from home and talking to them helped her a great deal.

Charcot-Marie-Tooth disease

CMT is managed symptomatically via a number of therapies including podiatry, orthopaedic surgery, physiotherapy and occupational therapy.

Charcot-Marie-Tooth disease (CMT) also known as hereditary motor and sensory neuropathy (HMSN) comprises a family of genetic conditions that mainly affect the motor and sensory nerves, which run from the spinal cord down the arms and legs.

It is caused by alterations in genes that produce proteins involved in the structure and function of either the peripheral nerve cell (axon), or the myelin sheath that wraps around the axon to insulate it and in normal circumstances allows the signals to travel faster and better.

They are many types of CMT based on the specific gene abnormalities involved in the structure and function of axons or myelin sheath.

The principal types include CMT1, CMT2, CMT3, and CMT4. Age of onset varies between types of CMT, with symptoms becoming apparent between the ages of 5-15 years for those with CMT1, and between 10 -20 years for those with CMT2.

Onset of CMT3 and 4 will usually occur before three years of age. The severity of symptoms will vary greatly from person to person even within the same family.

Features of CMT include:

- Foot problems – high arches, hammer toes, foot drop.

- Muscle weakness in lower legs causing problems with running, walking and balance.
- Hand function can be affected resulting in problems holding pens, grasping, and performing fine motor tasks.
- Tingling and burning sensations in the hands and feet due to the loss of nerve function.
- The sense of touch is diminished, as is the ability to perceive changes in temperature due to sensory loss.
- Sensitive to the cold due to loss of insulating muscle mass, which can leave people with chronically cold hands and feet and lead to swelling of the feet and ankles.
- Loss of deep-tendon reflexes, such as the knee jerk reaction.
- Scoliosis or mild curvature of the spine.

Management of CMT

CMT is managed symptomatically via a number of therapies depending on the needs of the individual. These include:

- Podiatry: Care and monitoring of foot problems.
- Orthotics clinics: Manufacture and fitting of braces and customised footware.
- Orthopaedic surgery: Straighten toes, lengthen heel cords, or lower arches.
- Physiotherapy and occupational therapy: Design exercise programmes to strengthen muscles; learn about energy conservation; provide assistive devices.
- Dietitian: To maintain a healthy balanced diet and weight.

CMT: A practical guide published and updated in 2014 by CMT United Kingdom is tailored for those affected by CMT and health professionals. It covers theoretical and practical issues – understanding the genetics and mechanics of CMT, diagnosis, advice on coping and managing the condition day to day. It can be downloaded on the MDANZ website.

Medications

There is a list of medications that are potentially toxic to people with CMT. This list is available on the MDANZ website. Please share this with your GP and relevant health providers. Ⓡ

A member's STORY

Tomorrow is another day

Wayne Tanner says that if you are having a bad day, it is important to remember tomorrow might be a better day.

Wayne Tanner is a great believer in "use it or lose it" and jokes that he is very stubborn and is holding onto his mobility as long as he can, although it is becoming increasingly difficult.

The Lower Hutt based 58-year-old, has Charcot Marie Tooth, which was diagnosed when he was nine years old. His sister also has the condition.

He explains that CMT affects the nerves that transmit information and signals from the brain and spinal cord to and from the rest of the body, as well as sensory information, like hot and cold, so he has a very high pain threshold which can be dangerous in itself.

But he hasn't let CMT hold him back and throughout his working life he has worked in both furniture removals and driven trucks. He says he wore cowboy boots that came to just below the knee which gave his legs some extra support.

Wayne tells *In Touch* he is still able to get around at the moment, although he is no longer working, but may have to look at a wheelchair soon. He still drives and says when he does fall he has been very lucky in that he manages to twist himself around and land on his back.

Wayne lives on his own, and he has home help coming in to help with cleaning but says the main objective is that they are just in the house while he showers in case he falls and needs assistance.

He says physically and mentally he gets very tired and he's finding it more difficult to get up and down from chairs, so he has blocks to raise the level of the seats. He also has handrails throughout his home, funded though Enable, which he can grab if need be.

He says the hospital staff think he should apply for a wheelchair now, because he will eventually need it but he is still very reluctant.

His advice to others living with a neuromuscular condition is that you are going to have days that aren't great, but to remember that the next day could be a better day.

"You will have up and down days that are not just physically exhausting but also mentally exhausting," adding that there is help out there and that it's important to ask for help and to never feel you are being an inconvenience to anyone.

Wayne wore cowboy boots that came to just below the knee which gave his legs some extra support.

"Physically there are people you can talk to and mentally there are also people out there who can help." He says counsellors can be useful because even though loved ones may want to talk, you may not feel comfortable totally opening up to them. Somebody outside the square can help.

Over the years, he has had a lot of dealings with MDANZ, particularly with his former fieldworker Dympna Mulroy, who helped him get a grant towards buying a car. He also used to attend a woodwork group which he enjoyed.

Wayne was part of an email group for people living with a disability and asked that we include in the story that is he is keen to be in contact (via email) with anybody who would like to talk. His email is tanner.wt@xtra.co.nz.

Online resources for DMD

There is a wealth of online resources and support for those involved in the care of someone with DMD.

The following online resources and publications may be of interest to medical specialists, educators, families, and those involved in the care of a person with Duchenne muscular dystrophy (DMD). These can be accessed on our website www.mda.org.nz or contact national office for advice on how to access them.

Care considerations for health providers

Since the publication of the Duchenne muscular dystrophy care considerations in 2010, multidisciplinary care of this condition has evolved.

In conjunction with improved patient survival, a shift to more anticipatory diagnostic and therapeutic strategies has occurred, with a renewed focus on quality of life.

The new care considerations published in *Lancet Neurology 2018* acknowledge the effects of long-term glucocorticoid use on the natural history of DMD, and the need for care guidance across the lifespan as patients live longer.

The care considerations provide a guide for primary care and emergency medicine clinicians on the acute and chronic medical conditions associated to DMD.

They also consider psychosocial issues, transitions of care and interventions that are designed to improve mental health and independence, functionality, and quality of life in critical domains of living, including health care, education, employment, interpersonal relationships, and intimacy.

Family guide – diagnosis and management of DMD

A family guide has been made available for families affected by DMD based on the care considerations. It can be used in two different ways:

1. To concentrate on a specific stage of Duchenne.
2. To concentrate on a specific area of Duchenne care.

The guide is broken down into sections addressing: Care at diagnosis; neuromuscular management; steroid management; endocrine management; orthopaedic management; bone health; rehabilitation management; cardiac management; pulmonary management; psychosocial management; gastrointestinal management; considerations for surgery; emergency care consideration; transitions of care across the lifespan.

Support group

Kiwi Kids with DMD is a Facebook support group for parents of children with DMD. They describe themselves as "a group where we can all chat and share our experiences and ideas together, and support each other, friends, families and our Kiwi Kids with DMD." Anybody is welcome to join.

The psychology of DMD

Dutch Duchenne Parent Project in conjunction with Parent Project Muscular Dystrophy have produced this resource on the psychology of DMD.

This booklet contains information about intelligence, physical functioning, learning, behaviour, cognitive functioning, psychosocial adjustment, and other relevant issues associated with DMD. It is for parents, family members, teachers, paramedics, and other persons involved in the care of an individual with DMD. It can be accessed on the DMD page of our website.

Emergency Information card

This is a wallet-sized card that provides information to safeguard the person with DMD from harmful medical intervention in an emergency situation. There is a space provided on the back panel for you to write your doctor's details. If you do not have one of these please contact national office.

A member's STORY

Team Hastie – Samuel's big family team

The Hastie family in Christchurch is making sure every day counts.

The Hastie's: Lukas, dad Vincent, Samuel, Rylee and Morgan with Samuel's dog Liam.

Seven-year-old Samuel Hastie and his tight-knit family are living with his severe form of Duchenne muscular dystrophy but they are not letting his condition define who he is, his mum Angela Hastie tells *In Touch*.

When asked about her advice to other parents with children with a neuromuscular condition, she says you need to make every day count.

"We don't look at dwelling on this. DMD is part of him, it is not who he is, it is just a condition he has."

She says her son has "that Duchenne sense of humour" which people mentioned when he was first diagnosed – he likes a good laugh and has a real sense of fun.

The Christchurch based Hastie family – Angela, dad Vincent, nine-year-old Lukas, Morgan who is six years old and two-year-old Rylee, have a busy life. Samuel is the only sibling with DMD.

Angela says the couple felt early on that Samuel was not quite right developmentally.

"We knew from birth, from day one he was a dribbler," she says adding that at 14 months he could not sit up. He was also a late walker and didn't crawl.

Samuel goes to school with his brother Lukas, who has ADHD and autism, but their younger sister Morgan now attends a school closer to their new home.

Samuel has a severe form of Duchenne, and Angela says the family knows they can't change this.

She says he copes pretty well but around Christmas last year, he started deteriorating and his walking is quite minimal now. When they saw his neurologist he was still able to walk pretty well, but within six weeks he was down to 10 steps and within another two weeks he had stopped walking.

Everything has been very sudden, she says.

Samuel, had his first power wheelchair when he as two years old as he has never had any upper body strength. Now, she says, he is at the stage when he can't hold up his head and needs neck support.

He is also on bipap and has been since he was four years old and Angela says he has also been tube fed since he was two because of the DMD.

This year in the past four to five months he stopped using his power wheelchair as it makes him too fatigued. Angela says this mental fatigue is very severe and knocks him out for days.

Everything is now in a manual chair and he is always in the tilt position.

All Samuel's care is done by the family.

Vincent works full time and the couple married last year with Samuel and Lukas taking on the role of page boys while Morgan, Rylee and Vincent's older daughter Ataahua, who is 12, were flower girls.

Angela says even the nieces and nephews got to play a part.

She admits things can be tough but the family sees every day as a bonus.

Fatigue is the hard part, she says and managing the day to day life, which sometimes means the other kids need to stay home. Samuel loves getting out and about and would like to do so more often, but the fatigue is the stumbling block.

And it is two-year-old Rylee who is Samuel's little sidekick.

Angela agrees it is lovely to see them and Rylee is always beside Samuel when he is home.

Samuel also has an assistance dog, a labrador retriever called ADNZ Liam, who is specially trained and will alert the family if there is any problem with Samuel.

Samuel with two-year-old Rylee and his mum Angela Hastie.

We don't look at dwelling on this. DMD is part of him, it is not who he is, it is just a condition he has.

Liam and Samuel are great mates as well as Liam being able to undertake practical tasks, like picking up things, for Samuel.

She laughs that the dog came into the family about the same time Rylee was born.

Asked about the family's involvement with MDANZ she says the local fieldworker Paul has helped in getting housing modified and has been a good support for Vincent as someone to talk things through with.

Ask an **EXPERT**

COVID-19 and neuromuscular disorders

BY SHANTHI AMERATUNGA

The risk from COVID-19 for people with NMDs and approaches to mitigate these risks.

COVID-19 is a public health challenge confronting all populations but the potential risks of infection and severe disease can be greater for people living with neuromuscular disorders (NMDs). COVID-19 could also worsen the progression of NMDs.

Here, we outline the risks and approaches to mitigate these risks, drawing on a recent scientific review by Drs Guidon and Amato from Harvard Medical School.[1]

While specific data on the impacts of COVID-19 on patients with NMDs remain scant, these authors "do not expect the majority of patients, even in the higher risk categories, to have severe complications of COVID-19".

This is reassuring but not a reason for complacency. We hope our summary helps New Zealanders with NMDs gain insights that will minimise risks of COVID-19 during these challenging times.

Which NMDs or patient groups may be at increased risk?

While experiences within specific conditions can vary, the following situations can place patients with most NMDs at increased risk of COVID-19 or its complications:

- Underlying respiratory, heart, and swallowing muscle weakness.
- Treatment with immunotherapy or immunosuppression (although immunoglobulin therapy does not appear to be a significant risk).
- Presence of other health conditions, for example, hypertension, renal (kidney) impairment, diabetes mellitus, liver disease, ischaemic heart disease, low white cell counts (neutropenia, lymphopenia).
- Older age.
- Pregnancy (possibly).

The risk of severe COVID-19 is increased among patients with the following specific NMDs:

- More advanced stages of motor neuron disease due to the involvement of breathing and swallowing muscles, ventilator requirements and other health complications.
- Various muscular dystrophies including myotonic dystrophy and metabolic diseases who have breathing or heart muscle involvement (cardiomypathies).
- Neuropathies with autonomic, cardiac, or respiratory involvement.

How can risks be reduced?

The most important advice for patients and caregivers is to be fastidious with standard guidance (www.COVID19.govt.nz):

- Practising good hygiene, including washing hands with soap and water; coughing or sneezing into your elbow; cleaning surfaces.
- Physical distancing, wearing a mask or face covering, and following requirements consistent with Alert levels in your area.
- Staying home if not well to reduce risk of spreading infections.

It is important to seek advice from health professionals in relation to any symptoms or exposure relating to infection as well as concerns regarding underlying health conditions.

Clinicians managing patients with NMDs who are at high risk may consider changes to, or postponement of, some types of immunosuppressive treatment; stronger personal protective provisions; and more intensive surveillance or treatment for COVID-19.

There may also be variations to the modes and settings for high-flow non-invasive ventilator treatment to reduce the risk of aerosolised infectious particles escaping into the local environment.

Discussions between clinicians and patients regarding the risks and benefits of COVID-19 and underlying NMDs are important prerequisites when determining the best course of action.

Treatment guidance for COVID-19

The mainstay of management remains medical and intensive care support for the disease and any complications, with more serious infections treated in hospital settings.

[1] *AC Guidon and AA Amato (2020). COVID-19 and neuromuscular disorders. Neurology 94(22): 959-969*

A range of medical therapies are being deployed, drawing on unprecedented levels of research initiatives that are testing the most effective options in this rapidly evolving field.

In the context of additional precautions to reduce transmission of COVID-19 and protect patients, health providers, other staff and members of the community, there can be differences in the ways in which health care is being delivered.

For example, patients may encounter variations to use of personal protective equipment; greater use of telemedicine, phone or video consultation; different approaches to investigation; and deferral of elective or non-urgent procedures and operations.

These may vary depending on the severity of symptoms, COVID-19 alert levels, and other factors.

The MDANZ will continue to strongly advocate for the best available options to prevent COVID-19 among New Zealanders with NMDs, as well as support and reasonable accommodation in the event of infection or need to access care so that the impacts are minimised.

Professor Shanthi Ameratunga is MDANZ's new Clinical & Scientific Advisor.

Research Grants 2020

Neuromuscular Research New Zealand

is once again accepting funding applications for research relevant to New Zealanders living with neuromuscular conditions.

Proposals most likely to be considered will be those which address standards of care (including best and/or innovative practice in supporting people with neuromuscular conditions); effectiveness and/or cost benefit of service delivery modes and interventions; prevalence and incidence of neuromuscular conditions; and proposals which extend existing research into treatment and cures.

Research of a preliminary nature with the intention of developing further proposals for substantial financial support from elsewhere will also be favoured.

Closing date for applications is 30th September each year and we hope to advise the outcome by 1st December.

Register your application in advance by emailing nrft@mda.org.nz or go to the MDA's website www.mda.org.nz/Our-Research/Apply-for-Funding

Neuromuscular Research New Zealand

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 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

Dr. Tristram Ingham
National Executive Chairperson

Shanthi Ameratunga
Clinical and Scientific Advisor

Brian Hadley
Accountant and Business Manager

Fiona Tolich
Member Reference Group Coordinator

Natalie Foote
Executive Assistant

Shelley Butler
Accounts Assistant

Chris Stichbury **Manager for Research, Development and Monitoring**

Our branches

Central Region

Community Coordinator – East Coast District: *Michelle Smith (above)*
Community Co-ordinator – Wellington Region: *Pip McLean*

Fieldworkers: *Talitha Vandenberg* and *Raygaana Naidoo*
Ph: 0800 886 626 Email: members.central@mda.nz

Northern Region

Fieldworkers: *Darian Smith* and *Rachel Woodworth*
Office Manager: *Denise Ganley*
Ph: 09 415 5682 or 0800 636 787 Email: support@mdn.org.nz

Canterbury Region

Fieldworker: *Paul Graham*
Office Manager: *Vivienne Fitzgerald*
Ph: 03 377 8010 or 0800 463 222
Email: mdacanty@xtra.co.nz

Southern Regions

Fieldworker: *Jackie Stewart*
Office Manager: *Vivienne Fitzgerald*
Ph: 0800 800 337
Email: southern@mda.org.nz

Contact centre

Development Leader:
Dene Benham.

Supervisors:
Maatuakore Wirihana-Tawake, Samuel Boyd.

Senior Customer Service Representatives:
Kelly Williams, Melissa Jamieson, Simone Wareham.

Customer Service Representatives:
Ashia Porteous, Annette Glasglow, Carlos Bennett, Jaime Kilmister, Joelle McCulloch, Rawiri Clarke, Tamara Sergent, Vicky Ferguson.

Administrative Assistant:
Janine Gardner.

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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