# InTouch

KIA NOHO TATA Inclusive | Inspiring | Informative Summer 19 Issue 104


## More power to you

Brennan Massey is at the top of his game

## Never letting anything slow you down

It's a case of mind over matter

## Sailing into the wide blue yonder

And gaining confidence and self-belief

Muscular Dystrophy New Zealand

# InTouch

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Muscular Dystrophy New Zealand

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# Korero with Trevor

An even bigger, better and more profitable Freedom Appeal is planned for 2020.

The past few months have been very busy for the organisation as we near the end of a successful and memorable year.

Thanks to all of our members and supporters who got behind the 2019 Freedom Annual Appeal this September. Fundraising and awareness events happened across the country which you can read more about on page 7.

While raising funds for MDANZ is vital, the Annual Appeal aims to raise awareness and recognition levels and we have big plans in place for an even bigger, better and profitable Appeal in 2020.

We set some ambitious goals for 2019 and as the year ends, it is time to reflect on our successes, identify our priorities and organise our resources around these for the coming year.

I thank all of the governance members, staff, supporters and volunteers who have contributed to another successful year for MDANZ and our four regional branches. I am looking forward to another exciting year ahead leading the organisation.

As we approach the Christmas break, I encourage you to get out in your community, attend a Christmas get-together or coffee group in your region or spend the summer break trying out a new sport.

We hope you enjoy some contemplative time this summer, and that this issue of *In Touch* can add to that experience.

In this issue, the team have compiled some stories about accessible sport options, some great accessible holiday home tips and fostering our youth spirit, which we hope will inspire and motivate you.

May you all enjoy a nice break over summer.

Ngā mihi o te Kirihimete me te Tau Hou.

Season's greetings for Christmas and the New Year.

Warm regards

Trevor Jenkin
*National Executive Chairperson*

## Dates for your diary

**21st December 2019 – 5th January 2020**
National Office closed.

**29th February 2020** – Rare Disease Day.
*Reframe Rare for Rare Disease Day 2020*: Rare Disease Day is entering a new phase, focusing on reframing what it means to be rare for the next decade of the campaign. We need everyone to get involved and join the movement to reframe rare!

Rare Disease Day 2020 is on Saturday, February 29 – a very rare day as it is a leap year.

**14th March 2020** – Ataxia Workshop, Auckland.

**14th March 2020** – National Harley Owner's Group (HOG) Rally "Thunder Mountain". Powderhorn Chateau, Ohakune Junction.

# Big turnout for family camp

The Northern Branch's popular annual family camp was a real success.

The Northern Branch's popular annual family camp in early November, was another great success with more than 50 members attending camp and an extra 10 members coming along for our Christmas lunch on the Saturday.

Santa arrived on a Harley for the kids along with 10 other HOG riders who gave each child at camp a Christmas present. We had three new families at camp who all said they loved the experience, felt very welcome and would definitely come to the next one.

# SMA Reference Group

Do you have Spinal Muscular Atrophy or are you the parent or carer of someone with SMA? Would you like to help direct MDANZ's SMA-related work? If so, please email: info@mda.org.nz with SMA group in the subject line and tell us why you'd like to be involved.

# Getting out there in Northland

Muscular Dystrophy Northern's fieldworker Rachel Woodworth recently attended the biannual Getting Out There Expo held at Forum North, Whangarei, which was hosted by Tiaho Trust.

Rachel says the theme this year was "Enabling Recreation & Leisure" to complement and continue the same theme as the "Getting Out There 2019-2020" publication that was distributed to all households in Northland.

She says the event was officially opened by the local Mayor, Sheryl Mai, and that the expo included about 60 exhibitors showcasing services, equipment and recreation and leisure activities available in Northland for people with disabilities and for older people. The event was attended by members of the Northland DIAS, Government agencies and other community organisations and Rachel says it provided a wonderful opportunity to meet, network and reconnect with members, staff and volunteers working in the sector.

Our fieldworker Rachel Woodworth at the Getting Out There Expo.

# Just a Thought

## Free online mental distress tool launched

The Wise Group, with the support of the Prime Minister Jacinda Ardern and Minister of Health David Clark, recently launched Just a Thought – a free tool that offers evidence-based Cognitive Behavioural Therapy (CBT) courses online.

Just a Thought courses are suitable for people experiencing mild-to-moderate symptoms of mental distress and any one in New Zealand aged 16+ years can use it. All that's needed is an internet connection and a desktop or mobile device.

Our member services manager, Dympna Mulroy, was impressed with the course presentation and felt it was a good resource for MDANZ members and families who are experiencing some symptoms of mental distress. She says the joy of this tool is that it can be accessed in the comfort of your own home at a time that's convenient to you.

You can see the courses offered at https://www.justathought.co.nz.

# A cup of tea and a catch up with Amelia Noyes

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 in October 2018 and was hired as the admin and fundraising assistant. I have been maintaining our website and National Office Facebook page. I have also been very fortunate to work alongside Marty Price and our five Bronze Dukies as a project support person for their Adventurous Journey in December 2018.

Now, I am managing our database – entering in new member details then organising their membership packs to be posted to their addresses.

**What qualifies as a great day at work for you?**

A great day at work for me is coming into the office and seeing all my colleagues. I love coming into a warm and friendly environment and getting to catch up with each staff member as I only work two days a week.

I also like to get all the tasks done that need to be completed and being able to interact with our amazing members whether it's in person, by email or through a phone conversation.

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

From my first experience organising an adventurous journey for our Dukies, I would love to see our members enjoying no restrictions due to accessibility.

It would be awesome for our members to have equal opportunities to leave home and get involved in their community – whether they are going out to catch up with family and friends, do daily chores or to go exploring around New Zealand and the world, having no limits or restrictions on how far, or where, they can go.

**What are you passionate about?**

One of my passions is the art of story-telling. I grew up being read bedtime stories, listening to stories from conversations or on the radio, or even watching television shows and movies.

Every person, place and object has a story. I think it is so powerful to listen to a story or have a story told, I guess that's why I am studying a Bachelor of Communications – majoring in Television and Screen Production.

# Duke of Edinburgh Award update

Our four new Bronze Dukies have some excellent service and skill goals they are setting for themselves, while two of our Bronze Dukies are moving on up to the Silver level.

MDANZ recently awarded our 2017/18 Dukies with their Bronze Awards at the 60th Jubilee in Auckland.

Now, two of our Bronze Dukies, Jack Lovett-Hurst and Dylan Schneider, are moving on to Silver, while we welcome on four new Dukies: Joy Gutschlag, Alisha Mill, Ryan O'Rourke and Camille Peterson.

Marty and Amelia say they are very excited to work alongside these awesome youth members and cannot wait to see how far they go with their goals.


Our Dukies at the 60th Jubilee in August. Ella Mills, Jack Lovett-Hurst, Dylan Schneider, Olivia Shivas. Grace Chapman was unable to attend.

## Bronze Dukies 2019

**Joy Gutschlag, 19 years old, from Todds Valley, Nelson.**

- **Physical Recreation – Swimming:** To swim five to six lengths of Riverside pool without stopping.
- **Skill** – Yet to be decided.
- **Service – Leadership:** To complete six months of service as a Youth Leader at Unite Church.

**Alisha Mill, 15 years old, from Parklands, Christchurch.**

- **Physical Recreation – Boccia:** To gain new skills and get ready for the New Zealand Nationals.
- **Skill – Training a companion dog:** Becoming confident in training my pup on my own.
- **Service – Animal Welfare:** Learning to help assist a dog trainer with their dogs when walking beside a wheelchair.

**Ryan O'Rourke, 16 years old from East Gore, Gore.**

- **Physical Recreation – Pistol Shooting:** To improve my shooting performance.
- **Skill – Acoustic/Electric Guitar:** Learning my pentatonic scale.
- **Service – Photographer for Eastern Basketball Association:** Practice and constantly improve my sports photography.

**Camille Peterson, 16 years old from Mount Albert, Auckland**

- **Physical Recreation – Swimming:** Able to do stretches and swim confidently.
- **Skill – Mobility Dog Training:** Gaining the skills needed to train a mobility dog.
- **Service – Sexuality and Gender Awareness Group:** Assisting others to run this awareness group.

## Silver Dukies 2019

Jack, who is 22 from Newfield in Invercargill, and 16-year-old Aucklander Dylan, are both still deciding on the physical recreation, skill and service goals they will set.

MDANZ news

# Looking for information about disability in New Zealand?

National disability information website, Firstport, has had more than 60,000 visitors since it launched.

Have you visited the national disability information website Firstport yet? If not, make time today to check it out. Replacing the old WEKA site, Firstport has fast become a trusted resource for those searching for information on things like:

- Disability funding streams and how to apply.
- Support available around education, transport, employment, housing and vehicle modifications and more.
- How to find local Disability Information Centres and support services .

www.firstport.co.nz

- Guides and articles on disability equipment and assistive technology.
- Latest news and events related to disability.
- Real life stories and videos.

Firstport has had more than 60,000 visitors since it launched.

It aims to be a welcoming, easy-to-use presence in a busy online world and is completely accessible. Users can use colour contrast, keyboard navigation, adjust text size, and block animations.

Firstport also has an active presence on Facebook with more than 2500 followers.

You can link up with them online at @FirstportNZ.

# DMD study discontinued

The Roche and Genentech Global Duchenne Team has written to the Duchenne community saying it is disappointed and saddened to announce that the clinical development programme studying RG6206 (RO7239361) an investigational anti-myostatin protein, in ambulatory boys with Duchenne Muscular Dystrophy (DMD) will be discontinued.

Earlier it had been reported that MRI and DXA imaging suggested RG6206 had a positive effect on muscle in boys with DMD, however a pre-planned interim data analysis of the Phase II/III SPITFIRE study indicated that RG6206 was highly unlikely to demonstrate clinical benefit and so the decision to close the programme was made.

Dion and Trish Ahern, whose son Harper (pictured above) was in the trial, say that whilst they were disappointed to hear the news, they were also realistic.

"We knew this could happen and hadn't set too high expectations, and we have no regrets of participating in the trial. In fact, we were super grateful and thankful that we even had the opportunity to participate in the trial.

"We learnt that we can manage the logistics, demands, highs and lows of medical trials pretty well. And were so impressed and proud of how well Harper managed the travel, appointments, injections, physio etc while participating in this trial.

"We would love to have another opportunity to participate in other medical trials should any arise that Harper is eligible for," they say.

# Support for MDANZ members from Medic Alert Foundation

The Medic Alert Foundation welcomes the opportunity to support members of the Muscular Dystrophy Association of New Zealand and has discounts available.

The foundation says that existing members of the Medic Alert Foundation can take advantage of discounts available when you purchase online through logging into the website www.medicalert.co.nz

And if you have an unclaimed discount voucher, supplied with your last Medical ID warranty card, you may be able to claim this and make a purchase over the phone.

For anyone that has not enrolled with the foundation, the discount code is MDA999. This code entitles you to a 10 percent discount on the foundation's enrolment fee.

As to the Medical ID, a free Medical ID option is available when enrolling online, or discounted prices are available if you want to choose a Medical ID that is not free.

The foundation's printed enrolment forms can also be used, you just need to write the code on the form and deduct the 10 percent from the enrolment fee specifically.

Either phone: 0800 840 111 or see www.medicalert.co.nz

# Raising awareness and funds

MDANZ members were out and about for our annual Freedom Appeal in September. Here's some highlights.

## Northern

Northern branch members undertook collections at Auckland Airport, Milford Mall and in Tokoroa. At the end of the month the branch hosted a fun Ten Pin bowling event for its members to raise awareness.

## Central Region

The Central Region branch has been involved in a number of member-led events across the region. Thanks to our fieldworker Talitha Vandenberg and Faye Letheridge and The Nikau Foundation, our Wairarapa members spent a fun day together at the accessible Pûkaha, Wildlife Park, Mt Bruce.

During September members and whânau across the greater Wellington region took part in raising awareness and flying the flag for MDANZ with collections at Wellington airport, the railway station, school mufti days and at supermarkets.

Michelle Smith, our Hawkes Bay-based community coordinator, has been energetically engaging with members from Gisborne, Napier, Tamatea and Havelock North who have joined in with a number of morning teas and supermarket collections during our appeal month.

## Southern


As part of its Freedom Appeal, the Southern branch held a sausage sizzle at Bunnings in Dunedin and they were all sold out in record time. Jo Smith (fieldworker) and Andrew (Chairperson) and Matt (Council Rep) Willetts work hard on the BBQ for the sausage sizzle. The region also held a very successful quiz night with raffles. Thanks to everyone involved for their support.

Brennan in action at the 2019 Asia Pacific Oceania Powerchair Football Cup held at Sydney Olympic Park.
Photo credit: Michelle Coles, powerchairfootballimages@gmail.com

# More power to you

## *Brennan Massey is at the top of his game*

Playing at the top level of his sport has seen 17-year-old Brennan Massey's whole attitude to life change, and now the Australians want him for one of their teams.

When *In Touch* magazine called Brennan Massey and his mother Vivienne, the family had just returned from a powerchair football tournament in Sydney competing in the 2019 Powerchair Asia-Pacific Oceania Zone Championship where the New Zealand team had been close to victory and the chance to compete in the world championships.

The eight-person New Zealand national squad came a very creditable third in the tournament but Brennan says third place meant they missed out on going to the 2021 Federation of International Powerchair Football Association's World Cup as only the first and second place-getters in this region qualify.

He says they were so close to getting to the world champs and there was just one point in it in the team's final game against Japan. Vivienne adds that, fingers crossed, they will get there next time.

Viv says the Japanese team was really impressive. They were very dedicated and professional and travelled with two doctors, two physios and a television crew.

The New Zealand team is not quite so well financed, they laugh, saying the Japanese team is really at the next level.

Since Brennan took up the sport, it has become a family affair, as his dad Paul is the co-coach of the national squad and Viv has just recently stepped down from the New Zealand national committee after six years. Brennan's younger brother Cooper, who is eight, didn't go to Sydney this time.

Viv says that unfortunately Cooper didn't get to go to this tournament. "But he has attended most tournaments since he was a baby and has grown up around our wonderful international football family."

Brennan, who has Duchenne muscular dystrophy, was introduced to the sport when he was 11.

"Once he went to have a look and see what it was like, he stepped straight in and joined there and then," says Viv.

She says the introduction to powerchair football came at a very good time for Brennan. He was feeling low about his DMD at the time and the move into the sport saw him "come straight out of that".

As to the benefits of playing powerchair football, Viv points to the fact that it gives kids in powerchairs the chance to get involved in a team sport, it gives them confidence, gets the adrenalin flowing and means they are out and about.

"Playing powerchair football has really helped Brennan's self-confidence and it has changed his whole attitude to life because of the friends he has made."

*Viv says the Japanese team was really impressive. They were very dedicated and professional and travelled with two doctors, two physios and a television crew.*

Brennan agrees with his mum on the benefits of the sport and adds that it has also given him something to do on a regular basis "and not just sit at home". There has been lots of travel involved which is exciting, although Brennan says long trips can be a bit difficult with his DMD.

The travel has included earlier trips to Australia along with training camps in Christchurch and away-games in places like Tauranga and Auckland from their home base in Mangawhai, Northland.

And this year Brennan's North Auckland Football Club won the New Zealand championship.

"We travel every year now, all around the place, and it is a lot of fun," he says.

And there will be more travel to Australia too as Brennan has been asked to play for the Sydney Football Club in their Australian Premiere A league as a marquee player.

When *In Touch* says this must mean Brennan is really good, Brennan doesn't want to comment, but Viv admits he is.

"He is really, really good, he is definitely one of New Zealand's top players and he puts a lot into it."

Asked if you need to be strong to play, they say no. You are strapped into the chair, and the skill comes from the ability to manoeuvre on a pin and your quick response time. Brennan's reflexes are a lot faster now than they used to be, says Viv.

Powerchair football players can be any age and the eight-member national squad that has just returned from the Asia Pacific games were aged from 10 to 60. Four of the team are on the basketball-sized court at any one time and they are subbed on and off as needed.

It is a non-contact sport but Brennan admits it is very competitive on the court, although it is safe as the only thing you can touch is the ball.

While you can tackle at any time, however only two players can be on the ball at one time, unless in the goal area where the defending team can have two players in the box to defend. Otherwise all players must be three metres away from the ball when not engaged, they explain.

You may tackle anywhere on the court and there is a certain area on the guard that a player can accidentally tap when tackling to get the ball, otherwise all contact with another chair results in the player being penalised.

Brennan received his first sports power wheelchair through the Make-A-Wish Foundation. It is a Strike Force Powerchair, which is a pure sports chair designed


Photo credit: Michelle Coles.

*The sports chairs are speed tested for each major game as they are only allowed to go up to 10 km an hour, but that is pretty fast in an area the size of a basketball court.*

specifically for powerchair football and Viv and Brennan say you do need one if you are going to compete seriously. It is low to the ground, has faster turning speeds and a very quick response.

Club documents says if you are playing power football socially, a plastic or metal guard is attached to a person's day chair. This means you can enjoy the sport without an expensive outlay, [as the USA-made sports chairs are expensive].

Viv says the sports chairs are speed tested for each major game as they are only allowed to go up to 10 km an hour, but that is pretty fast in an area the size of a basketball court.

Since getting the dedicated chair Brennan has made the New Zealand team every year.

And it's the team aspect which really appeals to Brennan about the sport, as many disabled sports are not team orientated.

So what would Brennan says to *In Touch* readers who might be wondering if Powerchair Football is for them?

"Get out there and give it a try," he says, even if you are a bit daunted by the idea.

Brennan is also encouraging other friends from MDANZ to come along to the club and says his current New Zealand team members include two people with SMA while others in the team have spinal injuries after accidents.

The travel is great, but takes a bit of juggling, says Viv, and can be expensive. At present each team member covers their own costs of travel, but Viv says both nationally and within their own North Auckland club, they are actively seeking sponsors.

Teams at the 2018 International Day of People with Disability, Australian Powerchair Football Association National Championships in Brisbane. Photo credit: Michelle Coles.

## Powerchair Football

Bronwyn Davies, the national secretary of New Zealand Powerchair Football, points *In Touch* to club documents that say that powerchair football started independently in France and Canada in the 1978 albeit with different rules.

"Today there's an international governing body, Federation International Powerchair Football Association (FIPFA) with a uniform set of rules and criteria. The sport was introduced to New Zealand in 2011 and in 2016 New Zealand joined FIPFA.

"Wheelchair football is played in 27 countries ... Participating countries hope that it will become a Paralympic sport."

Initially there were two clubs in New Zealand, Auckland and Christchurch.

"As awareness has increased we now have clubs in North Auckland, Christchurch, Waikato and Bay of Plenty with interest gaining momentum in other New Zealand regions. For further information go to www.nzpf.nz

New Zealand Powerchair Football

# Mobility Dogs: Life changing loyalty

We have been raising, training and placing service dogs for more than 10 years. Our primary goal is to assist people living with a disability by partnering them with a Mobility Dog.

We recognise that no disability or dog is the same, therefore each Mobility Dog partnership is unique.

Over the years many of our clients with muscular dystrophy have been partnered with a Mobility Dog. Our dogs have full access rights under the Dog Control Act which means they can go into most public places, for example, on public transport, educational institutions, employment environments, restaurants, movies etc.

## The specialist tasks of a Mobility Dog

Each dog is trained to:

- Retrieve and carry items – such as help load and unload the washing.
- Deliver items to a person.
- Open and close doors and drawers.
- Press buttons for elevators and pedestrian crossings.
- Help with payments in shops.
- Assist with daily activities such as dressing and undressing.
- Turn lights on and off.
- And plenty more tasks which are specific for the individual's needs.

## Are you interested in how a dog might work for you?

- Are you over 18 years of age?
- Are you able to care for a dog? Dogs need love, companionship, food and exercise. They are social animals and just want to be with you. It's a big commitment!
- We accept enquiries from all over New Zealand, however our focus at the moment is in the greater Auckland area.

Apart from all the specialist tasks they dogs are trained to do, they also provide emotional support, a sense of security and a connection to the community.

Working with a Mobility Dog can be a life changing experience. We would love to hear from you if you feel a Mobility Dog may be right for you. Please get in touch with applicants@mobilitydogs.co.nz

## *Case Study:* My best mate Lochy is the best thing that has ever happened to me

**Masterton 18-year old Stanley Dickson, who has Duchenne muscular dystrophy, talks about what it is like having a mobility service dog.**

It's easy to see why dogs are often referred to as man's best friend . . . they are so darn loveable.

I'm lucky enough to have two dogs. While one of them is a bit ditzy, the other one is incredible. His name is Lochy, a golden retriever – he is the best thing that has ever happened to me.

Lochy is a "service dog" who has been trained by the Mobility Assistance Dogs Trust. He is with me 24/7, including when I am at school. He can do a heap of things that I really struggle with. He can pick things up off the floor for me, take my socks off, carry stuff, open doors and cupboards, get me my shoes. He's so clever he can even tell the difference between my black school shoes and my casual shoes.He does all these things for me, and all that he asks for in return is lots of cuddles and praise – which I just love doing anyway.

But where he helps me the most is being an incredibly loyal and trusted friend, my best friend. Where ever I go, he comes with me. When I'm feeling a bit grumpy or sad, he is there by my side. I feel very lucky to have Lochy in my life. I am so grateful to the Mobility Dogs team for making this possible. And also my family – mum and dad, and my older brother and little sister – because Lochy is not a pet, he's a working dog and they have all been really supportive keeping me on track."

# Sailing into the wide blue yonder

## *Learning to sail has given a young MDANZ member real freedom and more confidence and self-belief.*

Quinn Heald is a young man on a mission. He wants to be a champion New Zealand sailor and, although he is just turning 12-years-old, he already seems to be heading in the right direction.

Quinn Heald, who has Charcot-Marie-Tooth disease, has already been sailing for three years with Sailability Auckland, a volunteer-based organisation which provides opportunities for people with disabilities to try sailing on very safe adaptive boats called Hansa 303s.

When *In Touch* spoke to Quinn and his mother Michelle, at their Auckland home in Greenhithe, they had just returned from the North Island Championship Regatta for the Hansa 303 class where Quinn was the youngest sailor by quite some way, with some competitors in their 50s and 60s.

The regatta included around 30 boats, in different classes, and Michelle says it was the most boats Quinn has sailed with and there wasn't much leeway given in the competition. It was, she says, a bit nerve wracking for mum, but Quinn loved it.

Earlier this year Quinn won the Waller Cup 303 Doubles at an annual regatta in Auckland where he sailed with a very talented "companion youth sailor", Morgan Lay, from the Royal Akarana Yacht Club. Michelle says these youth sailors help the younger Sailability sailors and, as this was Quinn's third time competing in the regatta, "he was absolutely rapt to win".

Quinn tells *In Touch* that in time he wants to represent New Zealand in the 303 class although he can also sail in other boats, including the Optimist class.

Quinn took up sailing not long after he had had major foot surgery which included tendon transfer and while Quinn had a long recovery period, the surgery has worked well.

And it was his local MDANZ fieldworker who suggested sailing with Sailability Auckland might be something Quinn would enjoy.

Quinn loves being out on the water.

*As this was Quinn's third time competing in the regatta, "he was absolutely rapt to win".*

On the morning Michelle took him down to Sailability, "as soon as I got in the boat, I knew it was what I had to do," says Quinn.

While it was a bit nerve-wracking initially for Michelle and husband Phil, Michelle says the yachts that Sailability use have a weighted keel and are almost impossible to capsize, so are very safe. They are also steered using a joystick and are easy to manoeuver.

"Sailability Auckland is so awesome, it is so well run. It gives the kids the opportunity to go and do something without mum and dad helping, it gives them a lot of freedom and confidence," she says.

She explains too that the way Sailability is set up means that for the sailor your mobility, or lack of mobility, won't stop you taking part.

*They have hoists to help people into the boats and a lot of the sailors are wheelchair users.*

They have hoists to help people into the boats and a lot of the sailors are wheelchair users. When you start out there are two people in the boat, as you learn.

Quinn says that on a recent school camp he took two other kids sailing in a standard dinghy. He had to capsize the boat and right it again and he's proud he was the only pupil on the camp who knew how to sail.

And it will be a skill he will have all his life, says Michelle.

"I say to him, that while other kids can run and jump now, what is important is that when you are 40 [years old] you will still be sailing but your friends won't be doing the high jump."

So why does Quinn like it so much? "I used to be bulled at school because I wasn't fast," but now he has a way of living his sporting dreams.

He loves being on the water and Michelle says you can see this with all the children sailing with Sailability. "When they come in from their turn, they all want to stay out sailing, you can notice the difference in them when they come in off the water."

Real freedom at sea.

Sailability supplies the boats and everything else a would-be sailor might need and although Quinn now has his own equipment Michelle says for those who don't, Sailability can supply it all.

So, what's Quinn's advice to *In Touch* readers thinking this might be for them too?

"Just enjoy it, learn how to sail, don't dream it, do it," noting that his aim one day is to go to the Paralympics [sadly sailing is not currently in the Paralympics but hopefully will make a return in 2028] or Olympics and be the youngest champion.

Quinn has two older brothers, Ashton who is 23, also has CMT although Raymond, who is 25, doesn't. Quinn hasn't yet managed to convince them to try sailing.

Another bonus is that you don't need to be able to swim to take part. Michelle says there is a chase boat and the sailors have a life jacket on. There are more safety boats at Sailability than there would normally be and, because the yachts are almost impossible to capsize, it would have to be extraordinary for someone to end up in the water, she says.

Michelle reiterates that the sailing has done wonderful things for Quinn.

"He is more physically confident now and he wants to stick to sailing one way or another.

"With all the kids you see going out sailing by themselves, that confidence and self-belief picks up.

## Comfort Cough available for purchase or rental

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**www.breathingandmedical.co.nz**

**Phone: 0800 335 333**


breathing medical
RESPIRATORY TECHNOLOGIES

They are doing something their friends can't do, and knowing they can sail a boat gives them real self-confidence.

"It is good for them to do something by themselves, but still be in a nice, safe, controlled situation, while mum and dad are out of the picture."

The other sport Quinn is passionate about is CrossFit, and he trains with Michael Hynard who, the Parafed Auckland website says, has set-up the only Adaptive Athletes programme in New Zealand. Michelle says it is called Functional Adaptive Movement™, and it has helped Quinn with his posture and strength and the programme includes people with many different conditions and strength-levels.

They found out about the CrossFit programme through a friend Quinn sails with and now some of his CrossFit friends are joining him at Sailability.

As Quinn says, if people are scared to try it, they should just do it anyway.

# Never letting anything slow you down

## *For Bruce Knegt it's a case of mind over matter*

A successful businessman, avid skier, outdoors enthusiast, mountain biker, golfer and kayaker Bruce Knegt doesn't let much slow him down. He is a great believer in giving everything a go and, if he can't do it at first, he will still find a way.

At 56 years of age, not all of us are still skiing regularly, heading out on a mountain bike to speed down steep forest tracks or taking the kayak out fishing when possible. But Bruce Knegt is doing all that and more, despite being diagnosed with Charcot-Marie-Tooth before he was 20 years old.

As Bruce sees it very little is going to slow him down. He also owns and runs a very busy and successful membrane roofing and below ground waterproofing company, Auckland Waterproofing Services.

It's a busy work-life and, while his wife Mona takes on all the accounts, he says it's all consuming and he is realising that going forward, he may need a manager to help.

Bruce points out that Charcot-Marie-Tooth is the most common inherited neurological condition in the world, affecting 1 in 2,500 people and while he has never let his diagnosis affect him, he realises it is starting to slow him down.

CMT leads to muscle wasting because it is a neurological condition and it means the message from the brain cannot quite get to the peripheral muscles, i.e. his hands, lower legs and feet.

He says his CMT has come on very slowly and he has learnt to adapt to the physical changes although he is starting to notice more changes happening lately.

CMT is a hereditary condition passed down from the mother's side and he has cousins in Holland with it. Bruce was diagnosed when he was about 18 after he began spraining his ankles and falling over and his sister had said he was walking oddly. So, he went to see a doctor and

Bruce Knegt and his wife Mona at Northstar Skifield by Lake Tahoe in California.

agrees it was a hard diagnosis to take on board at that age, as he had not been aware CMT was in the family.

Over the years there have been physical changes but he has never stopped doing things. He continued with social soccer until continued ankle sprains and falling meant a move into the goal.

He says he began moving to more individual sports as he had something of a mental block about playing in a team because of his condition.

In turn, surfing, for Bruce, morphed into boogie boarding because of balance issues and that was many years before boogie boarding became popular.

He took up skiing in his 20s and he has skied in the USA and Europe. In his 30s he moved to Brunei for some years and it was only on his return to New Zealand that he tried skiing again.

"It was no good, so I gave up for a few years as my balance was gone," but then he saw the Paralympics with the skiing team using 'outriggers'.

The outriggers are elbow crutches with the tip section of a ski pivoted on the bottom of the crutch. Outriggers are used to aid balance and/or to give support. Snow Sports NZ says on its website, outriggers are used by mono-skiers, bi-skiers and standing skiers needing aid with balance.

And Bruce says the outriggers make all the difference. He also points to New Zealand's gold medal winning Paralympic skiers and notes that adaptive skiing can cater for many different abilities.

*The skill with mountain biking is getting downhill as fast as you can.*

There are, he says, always ways around things and that *In Touch* readers should go to Snow Sports NZ's website (www.snowsports.co.nz) which looks after adaptive skiing, noting that every ski-field in NZ has an adaptive ski programme.

When he's out skiing, if he falls over he does need help getting up and usually his wife Mona or his 20-year-son Izaak and 18-year-old daughter, Meisha help out. Bruce says however that he does ski faster than Mona or Meisha, but he cant keep up with Izaak anymore.

When he spoke to *In Touch* the family had just returned from a skiing holiday in Queenstown. Bruce and Mona also skied in northern California last January and he sees skiing as a pretty inclusive sport. "Everybody should get involved. Out of all our friends we seem to be the only ones who still ski."

Skiing is a family event.

But the activity doesn't stop there. Bruce is also a keen mountain biker and tries to get on the steep slopes a few times a year.

He is looking to start using an electric bike as, while Mona can bike up the hills, he doesn't have the strength to pedal up the steep terrain, but can go down the slopes flat out. "The skill with this sport is getting downhill as fast as you can."

Bruce loves the outdoors and the family recently bought a bach at Scotts Landing, north of Auckland, where he takes his kayak out fishing, but he admits this can be frustrating as his hand muscles make it difficult to bait the hooks and he can't retie the lines, but he perseveres.

"I know how to do it, I just can't do it."

On top of this he still plays golf a few times a year, but must use a cart to get around. He jokes that because of the weakness in his hands he has accidently let the club go flying a few times after a swing and he does lose his balance and falls occasionally on the T shots, but he doesn't let any of this faze him. He says just enjoy yourself and laugh about it.

So what would he say to *In Touch* readers about taking up a sport?

"I would encourage people to just look at any sport or activity and if it's something you want to do, give it a go. It is hard enough to know you have a condition that will affect you doing it, but put all that aside, think positive, and if the brain is saying do it, then give it a go." Bruce sees it all as mind over matter.

On the Twin Coast Cycle Trail in Northland.

"You need to think positive and not care what other people think. It is all for me and I am having a good time."

He says perhaps for someone, who may have formerly been able bodied but had an accident, the loss of mobility would be a sudden event and would be a real shock to their system "whereas the condition I have is slow but progressive and you have time to just learn to adapt."

He is also a big advocate for ensuring access to public spaces for people with accessibility problems and ensuring mobility parks are used, and located, appropriately.

*I would encourage people to just look at any sport or activity and if it's something you want to do, give it a go.*

He says the lack of access to some public spaces affects not only people with accessibility problems, but also parents of young children and older people.

"This is personal. I take it to heart and I do speak up about it and, when I see something amiss, I am proactive in trying to get it sorted."

# Mobility Sports: Give it a go

If you have been hankering to try something new
and have some fun, here are a few ideas to get you started.

There are many sports that have been adapted for people with disabilities such as boccia, table tennis, athletics, adaptive snow sports, wheelchair basketball, wheelchair rugby, powerchair football, cycling, swimming and surfing. And that is just a few of them.

And if you are keen to try something new, there are number of Parafed organisations throughout New Zealand which provide sporting and recreational opportunities to Kiwis of all ages with physical disabilities.

All needs and levels are catered for, so whether you're a beginner wanting to give things a go or if you'd like to compete on a national or international level there are pathways for you to achieve your desired outcome.

So do get in contact with Parafed in your region to find out what sporting opportunities are available for you:

- www.parafednorthland.co.nz/
- www.parafedauckland.co.nz/
- www.parafedwaikato.co.nz/
- www.parafedmanawatu.com/
- http://parafedbop.co.nz/
- https://www.parafedtaranaki.co.nz/
- https://www.dsport.nz/ (formerly known as Parafed Wgtn)
- http://www.parafedcanterbury.co.nz/
- https://www.parafedotago.com/

## Try your hand at sailing

Sailability is a volunteer run organisation that has clubs throughout the North Island providing opportunities for those with a disability to try sailing.

The organisation's aim is to get people to experience sailing, whether it is just giving it a go or competing at a world level. Sailing can provide many benefits, both therapeutic and recreational, which in turn give people a sense of freedom and pride through achievement.

Specialised equipment is available for those that need to be lifted into boats and modifications can be made including motorisation (similar to power wheelchairs) depending on your requirements. Measures are put in place to ensure that sailors are kept safe on the water. A power boat patrols the boats out on the water so that everyone can be monitored and helped if needed. Dinghies used in the learn-to-sail courses have been designed so they cannot flip because of a weight used on the keel.

And naturally, the weather is closely monitored and they do not sail in unfavourable conditions.

If you'd like to have a go and get out on the water, below are the details on who to contact in your region.

**Sailability Northland** Chris Sharp, sharpaz@hotmail.co.nz; **Sailability Auckland** Tim Dempsey, sailabilityauckland@xtra.co.nz; **Sailability Tauranga** Rhonda Ritchie, opscommittee.stct@gmail.com; **Sailability Waikato** Rob Greenwood, robbieg@xtra.co.nz; **Sailability Rotorua** Phil Yemon, phil@autosprings.co.nz; **Sailability Taranaki** Dave Allerton, djallerton@xnet.co.nz; **Sailability Hawkes Bay** Katy Kenah, sailabilityhb@xtra.co.nz; **Sailability Whanganui** Bob Davies, bob.w.davies@gmail.com; **Sailability Wellington** Don Manning, info@sailability-wellington.org.nz; **Sailability Nelson** John & Linda MacDuff, macduff@tasman.net

# First ever worldwide LGMD Conference

The aim of the first ever global LGMD conference was to demonstrate to venture capitalists and biotech companies that the LGMD patient community is robust, mobilised and ready to aggressively advocate for effective treatments that are being developed, writes Denise Ganley.

It was a privilege to be able to attend the first ever worldwide conference on Limb Girdle Muscular Dystrophy (LGMD) in August in Chicago. There were 420 delegates from 20 different countries who attended; a mix of people who either had a condition, were family members, health professionals or researchers.

The aim of the conference was to demonstrate to venture capitalists and biotech companies that the LGMD patient community is robust, mobilised, and ready to aggressively advocate for effective treatments that are being developed.

The USA's leading neurologists in Limb Girdle Muscular Dystrophy were present along with major biotech companies on the cutting edge of emerging research.

## What is LGMD?

LGMD is a rare, serious and debilitating form of muscular dystrophy that primarily affects the muscle groups of the hips, arms, and legs. Many subtypes also affect cardiac and breathing muscles which may shorten life expectancy.

Though forms vary, most individuals will use a wheelchair or mobility scooter eventually, due to loss of ambulation. There are recessive and dominant forms but the recessively inherited conditions tend to be the most severe in terms of loss of function.

Prevalence of LGMD is estimated to be 1.63 per 100,000 which would equate to 78 people affected in New Zealand. It is the fourth most common type of muscular dystrophy and 90 percent of people affected have a recessive form (both parents carry the defective gene and have a 25 percent chance of passing the condition on).

The classification for this group of conditions has now changed. Until now the classification was 1 for dominant and 2 for recessive with a letter of the alphabet added as each condition was discovered.

The definition of LGMD required updating because the sub-type alphabetic ordering of the recessive form reached the letter Z (LGMD 2Z). Consensus was reached on a new classification using the letters D and R (dominant and recessive), an assigned number based on the order of discovery, and the affected protein. As a result, for example, LGMD 2B is referred to in the new system as LGMD R2 Dysferlin-related and LGMD 2A is now known as R1 Calpain 3-related. (Source: Treat NMD October 2019 Newsletter).

## Potential treatments

The goal of this first conference was to share information on treatments that are fast, effective, and safe for all forms of LGMD.

The most promising is gene therapy which works to treat the cause of the disease. Gene therapy was first approved by the FDA in 1990 but trials were halted in 1999 due to a patient death (not related to a neuromuscular trial) which delayed progress for around four years.

CRISPR is a new way to change genes and is a type of gene-editing technology that lets scientists more rapidly and accurately 'cut' and 'paste' genes into DNA.

"The basic technology consists of an enzyme that

cuts DNA and a segment of guide RNA that tells the enzyme where to snip. The package may include other components, such as a new piece of DNA code to plug into the edited area.

"The cell's natural repair mechanism completes the edit. Scientists can deliver CRISPR using AAVs (Adeno-associated virus), but that's not the only option; CRISPR can be encapsulated in bubbles of fat, injected directly into cells, or sent through a hole created by an electric current, among other techniques. Editing is meant to occur when the enzyme comes in contact with the target DNA, and only then.

"The hope is that CRISPR technology is a way to programme enzymes to go to exactly the place in the DNA where a change is desired, and nowhere else, and make a precise alteration." See https://www.sciencehistory.org/distillations/the-death-of-jesse-gelsinger-20-years-later

## Gene therapy trials

Gene therapy trials have begun for some of the conditions and are at the pre-clinical stage for R1/2A. The Diamond Sponsor of the conference was Sarepta Therapeutics and it is currently working on therapies for LGMD2E, LGMD2D, LGMD2C, LGMD2B, LGMD2L and the recently added LGMD2A.

These trials will be increasing within the next five years. Trial sites can be anywhere around the world and a benefit for participants is that they may then be granted early access.

Gene therapy still presents with some challenges such as delivery, targeting, immunology, toxicity and cost. However, the cost should be weighed up against the fact that the cost of neuromuscular disease in the US is estimated to be US$46 billion per year.

The goal is to halt the deterioration and break down of muscle to prevent it from turning to fat. An MRI is the best method for measuring this deterioration. Unfortunately for people like me who are more advanced (I have R1/2A) these treatments may be a little late, because although they will halt progression they cannot reverse the damage that is already there.

## Importance of a genetic diagnosis

The key message was that for people to be included in clinical trials they need to have a confirmed genetic diagnosis and ideally have a copy of this that they can

Denise Ganley with Carol Abraham, one of the conference organisers.

supply (ask your neurologist if you don't already have this).

I did not meet anyone who didn't know exactly what sub-type they have, although this doesn't seem to be the case in New Zealand (particularly among the older population).

Genetic testing has advanced a lot in recent years and an accurate diagnosis is critical if you want to be included in any future trials. Not only is it important for you to know which condition you have, it also has direct implications for other family members.

## Standards of care needed

Some of the gaps identified for this group of conditions are the lack of a formal diagnosis and understanding the patient experience. Standard measures need to be developed for muscle strength, mobility, rising from a chair, respiratory, cardiac issues, reach etc. Researchers need to understand more about the progression and gain information from patients in order to measure the impact these conditions have.

Information like this would then help to develop standards of care which we see in the DMD and SMA communities.

Patient registries are very important in this as they collect 'natural history' data, match patients with research studies, identify clinical care needs and document the ways the disease impacts on quality of life. We have a Neuromuscular Disease Registry in New Zealand https://www.mda.org.nz/Our-Research/NZ-NMD-Registry and there are a number of different registries available for each specific LGMD type

https://treat-nmd.org/what-is-a-patient-registry/list-of-registries-by-disease/limb-girdle-muscular-dystrophies/

There is no data available on exercise and LGMD. The best advice is to keep a healthy weight. There is no evidence that diet is related to progression of the condition. Moderate exercise is recommended as this is also beneficial for the heart. Depending on the type of LGMD respiratory function should be monitored every 6-12 months.

## LGMD community

There are a number of different Facebook groups (some are closed groups) for these conditions, either generic or sub type specific, and they are a good forum to learn from others' experiences or discuss issues.

- Limb Girdle Muscular Dystrophy Beyond Labels and Limitations. https://www.facebook.com/groups/29111827568/
- Limb Girdle Muscular Dystrophy Awareness Day. https://www.facebook.com/LGMDAwarenessDay/. The LGMD Awareness Day is the 30th September each year.
- C3 Community for R1/2A. https://www.facebook.com/groups/LGMD2A/
- National Limb Girdle Muscular Dystrophy https://www.facebook.com/groups/NationalLGMDconference/
- Women Living with MD https://www.facebook.com/groups/WomenWithMD/

I loved the opportunity to meet so many people from this rare disease community and to learn much more about the condition I have and the others under this LGMD umbrella.

I am very grateful to the Jubilee Trust and the Lottery Minister's Discretionary Fund for assisting me with funding to attend this conference. The next conference will be in 2021 in the US although the exact location has not yet been decided. I have distributed some information about the conference to members we have listed as having a type of LGMD. If you didn't receive this or you'd like to know anything more, including the new names for LGMD, please email me: Denise@mdn.org.nz.

MDANZ has also put the full list of the new LGMD classifications on our website.

SUPPLIED

# Making your child's wish come true

Make-A-Wish New Zealand helps make the wishes of children and teenagers (from three years to 17-years-old) with critical medical conditions come true.

It all starts with an application form and once that is approved, Make-A-Wish New Zealand will take your child on a unique wish journey towards making their cherished wish come true.

Make-A-Wish NZ has amazing volunteers who will work with your child to IDENTIFY and uncover what their most cherished wish is. We will then DESIGN each journey to create an extraordinary experience that stays true to your child's cherished wish. Wish ANTICIPATION can be as powerful as the wish itself. It builds the excitement and empowers your child to be actively involved in the creation of their wish.

Wish REALISATION and delivering a wish beyond your child's wildest imagination is why we do what we do. The positive IMPACT of a wish lasts long after the wish is granted and spreads to everyone involved in the wish journey.

Every child's imagination is unique, so each journey is designed to create an extraordinary experience that is true to the child. As a parent/legal guardian we ask that you complete and sign the Wish Application Form and return it to Make-A-Wish NZ.

We will contact your child's medical specialist and ask them to confirm medical eligibility. Once the medical specialist has confirmed that your child is eligible, we will assign two wish volunteers. They will arrange to meet the child along with the parents/legal guardians to help determine what their one true wish will be.

Some children know exactly what they want, for others it will take longer. There is no rush or pressure for the wish to be established. Once a wish has been determined the Make-A-Wish team sets out to create a unique experience for your child.

The timing of the wish delivery can vary, depending on what it is and the health of your child. Every effort is made to include you, the immediate family in your child's wish.

## Lachlan's wish comes true

**Young Lachlan who has Duchenne's Muscular Dystrophy had a definite one true wish… he wished for a Lego-themed bedroom makeover.**

Lachlan has a huge passion for Lego, so it was no surprise to find out that his one true wish was for a Lego themed bedroom makeover. Lachlan wished for a special place he could go, to construct Lego models to his heart's content.

With this is mind, Lachlan's entire bedroom was custom built to ensure that he could continue to enjoy and use it in years to come. On the day of the wish delivery, Lachie's bedroom reveal went off without a hitch and it was incredibly special. It was all hands-on deck to get the bedroom ready for Lachlan's arrival. When Lachie arrived home, he was very excited and didn't know what to expect. After a short chat on the driveway, Lachie couldn't wait to go inside and see his new bedroom. He cut the ribbon and opened his door and let out a very loud "wooooahhhh!" He started exploring straight away, looking in the cubby holes, going up top to play, jumping on his bed and opening his Lego presents. The massive smile on his face said it all. He said he would be in his bedroom playing all weekend.

Please visit our website **www.makeawish.org.nz** to download an application form or call the Make-A-Wish office on 09 920 4760 and one of the friendly staff will send you out one.

We LOVE granting wishes! We look forward to receiving your child's wish application.

Make-A-Wish
NEW ZEALAND

# Finding accessible holiday accommodation

There is growing awareness within New Zealand's tourism industry of the need to provide for people with limited mobility – and that includes the accommodation sector.

If you are planning a trip away to see another part of our beautiful country, your accommodation needs will be top of mind.

The tourism industry in New Zealand is increasingly aware of the needs of travellers who have limited mobility, and industry groups actively promote the need for their members to ensure they are fully accessible, so there should be no shortage of accommodation that will suit your needs.

There are a number of holiday accommodation websites which you can search online to find a solution that will suit your personal needs.

Be aware though that it's important to use the full functionality of search options on the webpage to return a list of results that is specific to your requirements, so be sure to check if the webpage has a 'more filters' option.

And do get in contact with the host if you require specific accessibility features and the listing does not detail it. They know the property better than anyone and can give you specific information regarding the accommodation to ensure you are making a booking that meets your needs so you aren't disappointed on arrival.

The tourism.net.nz website has a designated "accessible accommodation" section where you can search businesses throughout New Zealand that have been rated by Be.Accessible. This is managed by the Be. Institute, an organisation working to get all sectors of New Zealand to cater for accessible needs.

Just a few of the many accessible options online that drew our attention were a South Island holiday park, close to shops and the beach, which had three wheelchair accessible units and described itself as spacious, sheltered quiet and safe.

There was also a business offering yurts which had full wheelchair accessibility while a good number of hotels highlighted their accessible accommodation twin share rooms, some of which also had interconnecting rooms. These hotels were also promoting their ground level access with parking outside the rooms.

In many of the accessible properties we saw, support animals were welcome.

And if you are keen on the luxury end of the market, amongst the accessible accommodation options was a stunning luxury house with fabulous waterviews, decks on both sides and lift a to get you to the wheelchair-friendly master bedroom and ensuite.

# Have you used your Discount Card yet? If not, you're missing out!

## How does your Muscular Dystrophy Member Discount Card work?

Simply show the supplier account number on the card to the cashier OR enter the promo code listed on the card when ordering online.

Savings vary per product or service. Below are great comments from two discount card holders.


*"We've had our own business for some years and recently set up an account with OfficeMax – so much easier - great service and best of all, great savings. Thanks so much!"*

*Marian, Discount Card Holder*

*"I love my vehicles and really appreciate the discounts I get from our local Repco store. They always have everything I need and now cheaper with your card."*

*Matt, Discount Card Holder*

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**YOUR DISCOUNT CARD IS POWERED BY:**
You can find out more at www.csc.org.nz

CSC BUYING GROUP
NEW ZEALAND

# The real benefits of exercising

Find a sense of fulfilment and achievement through proactively managing your health.

It hardly needs saying that everyone benefits from exercise, regardless of age, sex or physical ability. But the benefits of exercise are not just limited to that of a physical nature, we can experience many positive mental and emotional outcomes.

Exercise can help prevent or manage health problems such as anxiety, depression, heart function, sleep problems and improve co-ordination.

Taking a proactive approach to your well-being by performing balance and muscle strengthening activities can help prevent falls and reduce recovery time from injuries.

Regular exercise, at a local gym or leisure centre, opens up opportunities to engage socially with like-minded people. Find a local group or team through Parafed in your region.

It pays too, to record your exercise so that you have a measurable achievement to work towards.

A fitness tracker can record your movements, sleep and calories burnt.

Measuring your fitness achievements can clearly demonstrate to you how much you are improving and you can compete against your own statistics.

It is also important to try to get outdoors to do some exercise and soak up some sunshine to get your fix of Vitamin D and take a moment to wind-down amidst nature.

Look up your local council website to see if you have a cycleway or pathway nearby that has a suitable track.

**Five tips for getting started:**

1. Engage in exercise with others.
2. Record your progress.
3. Cater to your individual needs.
4. Don't overdo it.
5. Make it fun!

Before engaging in a specific exercise programme it is recommended that you check with your healthcare provider. They will ensure you are performing suitable exercises for your condition and can refer you to a physiotherapist.

Start slowly and build your way up but know your limits. It is never too late to start fitting some sort of exercise into your week. You will feel a sense of fulfilment and achievement through proactively managing your health.

# Keeping up to date on Duchenne muscular dystrophy

One way to keep up with the vast amount of work being undertaken is to follow the webinar series offered by Cure Duchenne.

At the recent Australasian Neuromuscular Network meeting in Sydney, Australia there were so many clinical trials in Duchenne muscular dystrophy to update the audience on that two key note speakers, Professor Monique Ryan and Associate Professor Kristi Jones had to split the job between them.

How to divide the task? Jones, a clinical geneticist, presented the gene-based therapies currently being trialled around the world and Ryan, Director of Neurology at Melbourne's Royal Children's Hospital described the generic therapies.

With numerous companies now moving into the exon-skipping space we're seeing clinical trials for different chemistries aiming to achieve more efficient exon skipping thus restoring the reading frame in the hope of producing a truncated dystrophin protein – such as that we might see in someone with Becker muscular dystrophy.

An even greater number of companies are working towards ameliorating the downstream effects of a lack of dystrophin.

One way to keep up with the vast amount of work being undertaken in this area is to follow the webinar series offered by Cure Duchenne: https://www.cureduchenne.org/cure/webinars/

And be sure to enrol on the NZ NMD Registry. This will mean you'll be contacted directly should there be research opportunities for you. R

## Treatments for Charcot-Marie-Tooth disease

The fourth annual meeting of the Asian Oceanian Inherited Neuropathies Consortium (AOINC) took place in Sydney with representation from two-thirds of world's population in one room.

Presentations from nine of the 11 countries in the Asian Oceanian region including India, China, Taiwan, Thailand, Malaysia, Australia, Japan, Korea and New Zealand showed the diversity of work happening to progress treatments for Charcot-Marie-Tooth disease in our part of the world. R

There is a diversity of work for treatments in Charcot-Marie-Tooth disease.

# New international DMD trial exceeds target enrolment

US-based Catabasis Pharmaceuticals, Inc. a clinical-stage biopharmaceutical company, has announced the completion of enrollment for the Phase 3 PolarisDMD trial of edasalonexent in Duchenne muscular dystrophy (DMD).

The target enrolment of 125 boys was exceeded due to strong interest from its 40 clinical sites in eight countries and the support of patient advocacy organisations.

The company says the top-line results from the Phase 3 PolarisDMD trial are expected in the fourth quarter of 2020 and the trial is anticipated to support an NDA filing in 2021.

Joanne Donovan, chief medical officer of Catabasis said, in a media release, that edasalonexent has the potential to be a foundational therapy, providing benefit to boys, regardless of their underlying mutation, with the potential to benefit muscle function, as well as cardiac function and bone health.

See www.catabasis.com. R

# CANVAS

Physical examination, vestibular function testing, video-oculography, nerve conduction studies and MRI of the brain are normally conducted to detect signs and symptoms of CANVAS.

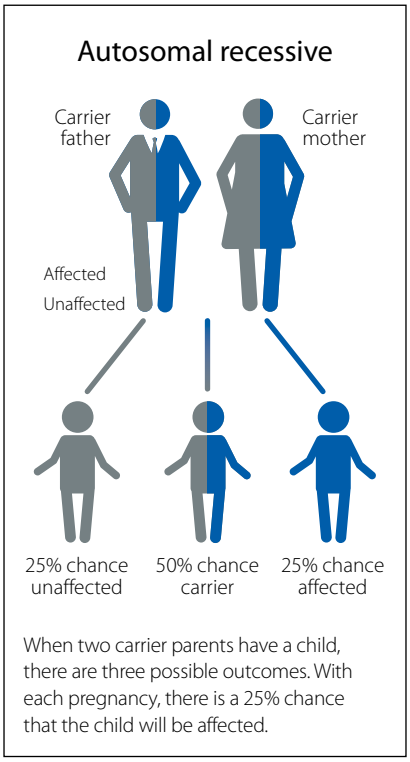
CANVAS is an easy-to-remember acronym that describes an adult-onset slowly progressive neurologic disorder that has an average age of onset of 50-60 years.

People with CANVAS have cerebellar ataxia (coordination problems), neuropathy (peripheral nerve damage), and vestibular areflexia (loss of vestibular function) and combined they form a recognisable syndrome affecting balance and gait, which is progressive, worsening over time.

The vestibular system is a collection of structures in your inner ear that provides you with your sense of balance and an awareness of your spatial orientation (meaning a sense of whether you are right-side up or upside-down). Your brain then integrates that information with other sensory information from your body to coordinate smooth and well-timed body movements.

Common features of this condition include "dolls head reflex" upon examination, which is an impaired ability of the eye velocity to match head velocity when turning the head from side to side. Involuntary eye movements can occur in some individuals with the condition as well as difficulty articulating speech (dysarthria).

Individuals with the condition may have problems standing and will show a positive Romberg test which means they experience loss of balance when the eyes are closed. Loss of coordination of the limbs can also occur.




When two carrier parents have a child, there are three possible outcomes. With each pregnancy, there is a 25% chance that the child will be affected.

Other presenting features can include a persistent cough, dysesthesia (which is an abnormal unpleasant sensation felt when touched, caused by damage to peripheral nerves), oscillopsia (a visual disturbance in which objects in the visual field appear to oscillate), dizziness, and falls. Brain MRI of individuals with CANVAS will show cerebellar atrophy.

CANVAS is a rare but likely under-diagnosed disorder. It is inherited in an autosomal recessive pattern. This means two altered genes are inherited, one from each parent. The parent's health is unaffected as the condition requires two altered genes to occur.

## Diagnosis

Physical examination, vestibular function testing, video-oculography, nerve conduction studies and MRI of the brain are normally conducted to detect signs and symptoms of this condition.

Earlier this year it was established that CANVAS is caused by an alteration in a gene called RFC1 (replication factor C) on chromosome 4. Usually the gene contains a simple tandem pentanucleotide AAAAG repeat of 11 (AAAAG(11)), whereas in CANVAS the repeat expansion is different (AAGGG(n)) and the size ranges from about 400 to 2,000 repeats, with the majority of cases having about 1,000 repeats.

Genetic testing for this pentanucleotide repeat expansion will soon be available.

## Treatment

There is no known cure for CANVAS and treatments are generally to manage symptoms such as chronic

*Individuals with the condition may have problems standing and will show a positive Romberg test which means they experience loss of balance when the eyes are closed.*

cough, pain and dizziness. CANVAS is progressive and a person with this condition may eventually require the use of a mobility assistance device, and may need assistance to perform daily tasks.

Modification of the home with things such as grab bars, raised toilet seats, and ramps will be helpful.

Speech therapy and communication devices such as writing pads and computer-based devices may benefit those with affected speech. Weighted eating utensils and dressing hooks can help maintain independence.

Weight control is important because obesity can exacerbate difficulties with ambulation and mobility.

Individuals experiencing swallowing difficulties (dysphagia) may suffer significant weight loss and will benefit from seeing a speech language therapist and dietician.

People with CANVAS should be followed up by a neurologist regularly with visits to physiotherapists, occupational therapists and other specialists as needed.

Support from Muscular Dystrophy New Zealand is available. ®

# 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. Our postal address is: **PO Box 12063, Penrose, Auckland, 1642**

**Bequests:** You can create a lasting difference through making a bequest. Contact us or visit our website for information on how to include MDANZ as part of your will.

*Thank you. We greatly appreciate your support.*

# Realising you are not alone in this

Glennis Turner, who has CANVAS, says keeping busy is key to her happiness. And, if she comes across something she can't do, she searches around until she finds a way to do what she wants to do.

I knew there was something not quite right when my eyes were giving me trouble. At work the carpet had a chequered square pattern on the stairs, whenever I would come in the door I would get to the point where I just couldn't look at it as it would drive my eyes crazy.

I knew there was something wrong and it got worse and worse. After many doctor's visits I just kept getting the same answer implying that I was imagining things.

Then six or seven years ago a friend in the medical profession got on-board and started asking more questions. He contacted my GP and they had a discussion about my symptoms, they then managed to get me an appointment with a top neurologist.

Within 30 minutes of having some tests the neurologist told me that I had CANVAS. It was a relief to finally know what was going on with me and have a name for the symptoms I had been experiencing. Most people would think it wouldn't be a happy thing being diagnosed with a condition, but for me I finally could put a name to it and start dealing with it.

Prior to my diagnosis I had been getting separate tests done that were time consuming, but now that I had a diagnosis they were able to tie two of the three main problems I was experiencing together; my vision and a cough, for which I had been undergoing asthma tests and chest x-rays.

Unrelated to CANVAS I also experienced painful bloating symptoms. A friend suggested I try going dairy free. I soon discovered that milk and cheese were the main foods causing my bloating symptoms and since then have managed my intake which makes a huge difference to me. Much to my dismay as I love cheese!

***You can always find a way through things, you just have to figure out how.***

Once I was diagnosed I knew I would need to evaluate my work situation as at the time I was travelling from Lynfield to East Tamaki [across Auckland] each day, but with my condition progressing driving long distances was no longer an option.

I managed to get a part-time job four-days-a-week not far from where I live so the commute was much easier to manage.

Not really being able to drive anymore has been hard to accept as it was my independence. I can only drive very short distances and most of the time I rely on my husband to take me places. He is very supportive.

Glennis Turner in her garden.

A year ago my condition worsened to the point I had to give up my job. Initially it was hard to adapt to being at home full-time but I have learnt to keep busy.

The challenge is trying to stay upright and keep my balance. I have a bad back so it has been a lesson in pacing myself and, if my back is giving me trouble, I read.

I have nystagmus which is where my eyes move up and down involuntarily, it makes me feel very dizzy so I save my time in the garden for the afternoon.

I catch up with friends during the week and I find we help each other keep the right mind-set and stay positive and proactive about

overcoming challenges in our lives. You can always find a way through things, you just have to figure out how.

I have always enjoyed gardening but when I was working and raising my family I never had the time. Nowdays my garden is my passion.

I try to get out there most days as I love to see tangible results and it makes me feel good to be achieving something.

It's so visual with gardening you can really see your efforts. I have had to be quite resourceful and find ways to get stuff done without losing my balance and falling over.

I have some rubber knee pads which are great, especially in the winter when its muddy. I also use old pieces of carpet to sit on so that I don't have to maintain my balance. My husband has also bought me a gardening trolley that tips which makes life easier.

If I can't do something I just have to wait until my husband is home and can help in the weekends.

I like to keep busy, I think that is key to my happiness. If I come across something I can't do I find a way how [to do it] whether it's through Google or YouTube about gardening, or getting family to help.

My favourite part of the garden is the archway. I employed my daughter's boyfriend's expertise as a builder to put it together for me and I am looking forward to the pink and white flowers I have planted on either side to grow up, and over, it.

My neurologist Richard Roxburgh is fantastic and always seems to be

A favourite part of Glennis' garden is the archway.

*If you are not getting answers, keep at it and find a way to get people to listen.*

coming up with new research on the condition.

I like to take part in surveys in relation to my condition, if being a part of it means I can help someone else, then I think that's great.

I get regular text "check-ins" from my lovely field worker Rachel which are a real pick-me-up.

Sometimes you feel like you're in this alone but her contact makes me feel like I'm important and that someone genuinely cares.

I like to read the *In Touch* magazine as it helps me to realise that I'm not the only one going through this, it's a good support and resource to keep me up-to-date.

I had a community physio come to see me and she suggested that I start going to the gym and they said it will help me to recover if I have a fall.

A trainee physio at the time was extremely supportive and came and ran through my new exercise programme with me. They're quite simple exercises for my legs, arms and core.

I don't know how long I will be able to keep going but I try to go twice a week. Doing the exercise programme makes me feel good that I am being proactive about my health and it's nice to get out and about and interact with others. It definitely makes a difference.

I would say to anyone going down the same path as me that you really need to be forceful when it comes to getting answers from your medical practitioners and health professionals.

If you are not getting answers, keep at it and find a way to get people to listen. Nobody knows your body like you do so trust your instincts. Find someone that really suits you. I have a really good rapport with my GP and feel that I can discuss anything with them and feel heard, so I think that's really important.

The key to my happiness is staying busy. Find something you really love doing and do it as much as you can, while you can.

If you find you can't do things because of your condition find a way around it. Push those boundaries and be resourceful to achieve what you want to achieve and you will benefit from it.

# A new clinic for neurogenetic research

ASSOCIATE PROFESSOR RICHARD ROXBURGH

CLINIC CO-ORDINATOR KERRY WALKER

People with specific neurogenetic conditions will be invited to enrol in research studies run by the clinic.

We are very happy to announce the establishment of the Centre for Brain Research Neurogenetics Research Clinic, at the University of Auckland. The aim of the clinic is to help people with neurogenetic conditions participate in research and also to improve their health outcomes.

There are approximately 4,000 people in New Zealand who have a rare neurogenetic condition. While the conditions themselves are rare, when grouped together this makes up a significant number of people who have similar health issues and needs.

For most of these conditions, there is currently no medical treatment available to cure, or slow down, the disease processes. However, with expert help from allied health professionals such as physiotherapists, occupational therapists, speech and language therapists, audiologists and orthotists, it is likely that people with these conditions will be able to function better in their everyday lives.

Because each condition is so rare, doctors and allied health professionals do not often see enough of these patients to develop expertise in how best to help them.

The CBR Neurogenetics Clinic was developed to help solve this problem. People with specific neurogenetic conditions will be invited to enrol in research studies run by the clinic.

In taking part in a research study, you will have access to health professionals who are interested in learning more about your condition and the best ways to help you and others who have it.

While the central purpose of the clinic is research, and therefore you may not benefit directly or at all from the research, it may be that the information given to you as part of the assessment will help with your clinical management. The health professionals involved with the clinic are also committed to sharing the knowledge amongst their colleagues throughout New Zealand so that people everywhere with the same conditions can benefit from the clinic. The main benefit in being involved in research at the CBR Neurogenetics Clinic, is that you help to advance the knowledge of your condition.

The more that a condition is researched and the more that is known about it, the easier it becomes to develop treatments and therapies for this condition. Many of the studies run at the clinic have international links and we will be sharing the information we gain with international experts on each condition. In this way we hope to help people in New Zealand contribute to making life a little bit easier in the future for others with their condition.

The first participants we will be enrolling will be people with Friedreich's ataxia as we are now a site for the US National Institutes of Health funded, Friedreich's Ataxia Clinical Outcome Measures Study (FACOMS).

This is the same study which many people will be familiar with from visits to Melbourne and we are undertaking it in collaboration with the Friedreich's Ataxia Research Association (FARA) in New Zealand and the United States. A second study is in collaboration with A/Prof Adam Vogel at the University of Melbourne called SpeechAtax which is a home-based speech therapy course for patients with genetic ataxia.

The clinic is generously supported by the Duncan Foundation and FARA NZ and as time goes on we hope that more MDA members will be eligible for these and other studies. Watch this space!

*Assoc Prof. Richard Roxburgh FRACP PhD is a consultant neurologist at Auckland Hospital and associate professor at the University of Auckland's Faculty of Medical and Health Science.*

*Kerry Walker is the CBR Neurogenetics Clinic Coordinator.*

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.

## Our core team

*Trevor Jenkin*
National Executive Chairperson

*Miriam Rodrigues*
Programme and Service Advisor

*Brian Hadley*
Accountant and Business Manager

*Dympna Mulroy*
Member Services Manager

*Natalie Foote*
Marketing and Communications Manager



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

### Northern Branch


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

### Central Branch

Fieldworkers
Ph: 0800 886 626
Email: info@mda.org.nz

### Canterbury Branch


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

### Southern Branch

Fieldworker: *Jo Smith*
Office Manager: *Vivienne Fitzgerald*
Ph: 0800 800 337
Email: joanne@mda.org.nz

## Council Representatives

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

### Northern Branch

Michael Schneider. Ph: 021 851 747
Email: spider@spider.co.nz

### Central Branch

Bernadette Ingham. Ph: 027 600 3868
Email: members.central@mda.nz

### Southern Branch

Matthew Willetts.
Email: willetts.matthew@yahoo.com

# 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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