



Muscular Dystrophy
New Zealand
Northern

Muscular Dystrophy Northern

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New committee for 2021

Our AGM was held via Zoom on the 17th April and the new committee is as follows: Chairperson—Trevor Jenkin, Vice Chairperson—Michael Schneider, Secretary—Joy Jenkin, Treasurer—Andrea Clive, committee members—Lew Pulman, Debbie Schneider, Yaz Dolbel-Neville and Jessica Anderson.

Introducing new committee member Jessica Anderson:

I am 27 years old and am currently studying full time at the Waikato University working towards my Bachelor's degree in Computer Science, with a major in Data Analytics, which is keeping me super busy.



I'm originally from Christchurch, but moved to Hamilton at the beginning of 2019 for a job. I absolutely love the Waikato region and now call Hamilton home.

I was diagnosed with Char-

cot Marie Tooth (CMT) 1A about 9 years ago, right after I left high school. I am the 4th generation (3rd with a diagnosis) in our family to have the condition that no one's ever heard of.

In my spare time I love watching the V8 Supercars.

I am looking forward to being a voice for our younger members of our branch.

Mid-winter Lunches:

We have mid-winter lunches planned for Auckland, Hamilton and Tauranga.

Dates so far are: Hamilton 10th July at the Hamilton Gardens café, Tauranga 11th July at the Citizens Club, 170

13th Avenue and Auckland 18th July at Phab, Takapuna.

Please keep an eye on our Facebook page as that's where we post all new events along with other information relevant to our membership -

[https://
www.facebook.com/
muscular.northern.](https://www.facebook.com/muscular.northern)

Hamilton Coffee Group:

The Hamilton coffee group continues on the second Wednesday of the month at Palmers Garden Centre café, Rototuna. Next meeting 12th May, 10.30am.

All welcome.



'Wheels on Ice' saw a large turnout of members to Paradise Ice in Avondale.



'Planning for life with a disability is tricky but extremely important'

Can I Help You?

Hello MDN Members! My name is Ryan and I've written this small piece to offer myself as a mentor of sorts to anybody out there who's perhaps a little unsure of what the future may hold. Going through life with a disability can be difficult and sometimes even scary. If I can do it though, I'm pretty sure almost anybody can! It's not always straightforward and I've been very lucky to have a lot of help along the way. It's that help which I now hope to pay forward.

Now that's all well and good but how are you supposed to know if I'm going to be any help to you?

Well, a little about myself: I'm 31 years old and I have Spinal Muscular Atrophy (type 2). For those who don't know, this means I'm pretty seriously physically

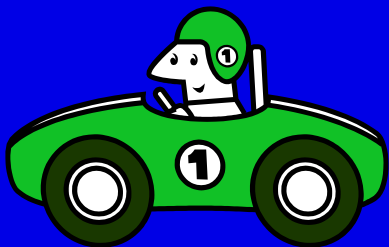
impaired. I've used a wheelchair since I was 2 years old and rely on carers to help me with all my daily needs. This has led to my life being a wee bit different than most, in ways both good and bad. Fortunately, I've still been able to live a reasonably fulfilling life: I've completed an education up to and including postgraduate studies at university, majoring in geography and environmental science; I was able to move out of home in my early twenties and enjoy an independent lifestyle; and I regularly attend live concerts and sports events with family and friends.

As for what I might be able to do to help you: I believe I can offer a unique insight into what it is to live with a physical disability. In particular, I believe I could be

helpful to both young people and young families dealing with neuromuscular conditions. Planning for life with a disability is tricky but extremely important. I can assist by identifying unforeseen issues and lending perspective to important decisions, ranging from what to look for in accommodation to what the best subjects to do at school might be. I've collected a fair amount of knowledge over my life and I want to share it in the most helpful and constructive way possible.

If you think you might be interested in having a chat with me about anything (and I mean literally anything), please contact the MDA and they'll be able to put us in contact with each other.

Ryan Leitch



I.DRIVE

Learner
Licensing
Programme

Available Dates

April 22/23
May 25/26
July 27/28
Sept 28/29

SIGN UP NOW

Contact Josh:

josh@yesdisability.org.nz

027 820 7012

I.Drive

I.Drive allows people with disabilities learn the road code in a more accessible and interactive way, allowing them to gain the knowledge to help them pass their learner licensing test.

Farewell from Darian

It was all the way back in 2010 that my wife, who had been diagnosed with myotonic dystrophy the year before, came to me with a newsletter from MDN and pointed to the job mentioned in it.

“You should do this,” she said. It was a part time Fieldworker role.

So began my time with MDA. A time I have treasured. After two years as a part time fieldworker, I became full time and never looked back.

Over the 11 years I’ve been here,

I’ve met so many wonderful members and feel incredibly honoured to have been welcomed into their lives and be part of their journey with a neuromuscular condition. There have been fun times and there have been sad times. We have lost people along the way – both colleagues who have moved on and members whose journey came to an end. Through it all, this organisation has been like a family. Partly because my wife and I live with her diagnosis ourselves, but partly because I’ve always felt wel-

comed into our members’ homes and lives. I want to thank everyone for that. My time here has been incredibly special.

But all things change and now it is time for a new challenge. I’ve taken on another role with another organisation and, as many of you know, I am also focussed on a writing career. I’m looking forward to both but will miss being an MDA fieldworker very much.

That said, Adrienne and I are still members so I’m sure you’ll see us around! Thank you all so very much and farewell.



I’ve always felt welcomed into our members’ homes and lives. I want to thank everyone for that. My time here has been incredibly special.

From the Chair—Trevor Jenkin

It’s been over 12 months of something none of us would ever have thought we would be a part of, a worldwide pandemic. If I had been told in 2019 that 2020/2021 would bring a worldwide pandemic and create chaos around the world, I would have said no way, how could that happen.

Thankfully with all that is happening around the world the Northern Branch has come out of the pandemic. After a year

of difficult times some fresh ideas on making contact via Zoom have developed.

With the departure of our part time fieldworker the opportunity to rethink how we provide our fieldwork service was something the committee had discussions on. A survey was sent out to members and the result came back quite clear that the face to face meetings were by far preferred by members.

Our Annual AGM was held at

2.00pm on 17th April 2020 thank you to those that attended, the committee nominations were as follows: Trevor Jenkin Chairperson Unopposed, Mike Schneider Vice Chairperson Unopposed, Joy Jenkin Secretary Unopposed. We also welcomed Jessica Anderson from Hamilton to the committee. The other committee members still remaining for another year are, treasurer Andrea Clive, Lew Pulman, Debbie Schneider, and Yaz Dobel-Neville.

Free Face Masks

We have been able to source some N95 face masks. If you would like some please let us know and we can post some out. Otherwise you can collect from our office in Albany.

Great to have for carers or others coming into your home.



Flat available in Botany Downs:

4 bedroom, 2 bathroom accessible flat. Looking for 2 new flatmates to share with two other wheelchair users. Close to shopping centre. Contact our office for further information.

TranzAlpine

In February this year for my birthday I finally got to travel on the TranzAlpine between Christchurch and Greymouth across the Southern Alps. It's something I've wanted to do for years and is noted as one of the world's greatest train journeys.

Access by wheelchair is not an issue as they have a mobility



commodation for the night and the next morning wheeled back into town for the return journey to Christchurch.

Our motel in Christchurch where we stayed before getting on the train was very close to the railway station which made everything easier and meant we didn't need to



are spectacular taking in the Canterbury Plains and following alongside the Waikakariri River before moving into the Alps region.

Being there in summer meant there was only a sprinkling of snow on the top peaks but a trip in winter time would be most picturesque.

We stopped at Arthur's Pass for around 10 minutes and the very helpful Kiwi Rail staff assisted me to get onto the platform along with everyone else.

The reason to stop there is a practical one as they need to attach an extra engine and have additional engineers on board



hoist to get you into the dining cart where there are two tables set up (one on each side of the train) for people in wheelchairs and their companions. The dining cart is obviously where all

order a mobility taxi.

I would really recommend this trip and the Northern Explorer (Wellington to Auckland) which we did a few years ago.



the food and drink is available and there is a large accessible bathroom here as well.

The trip is 223kms which takes just under 5 hours. The views

for the descent (and climb on the return journey) through the Otira Tunnel which is 8.5kms long.

Once we arrived in Greymouth we wheeled/walked to our ac-

The next one we'd like to do is the Coastal Pacific which goes from Picton to Christchurch along the very beautiful Kaikoura coast.

Denise Ganley