InTouch

KIA NOHO TATA Inclusive | Inspiring | Informative. Autumn 18 Issue 98

Freedom beyond limits

How the right mobility aid gives independence

Talking it over

Counselling does help

Choice vs risk

Views on the End of Life Choice Bill

Get ready now

Banning winter bugs

Muscular Dystrophy New Zealand

InTouch

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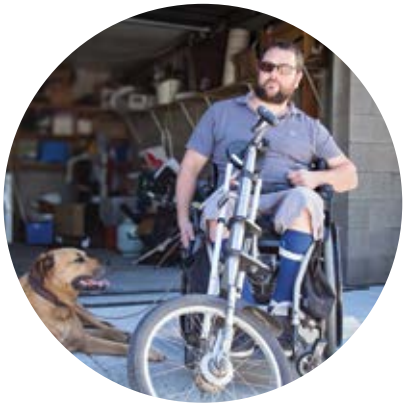

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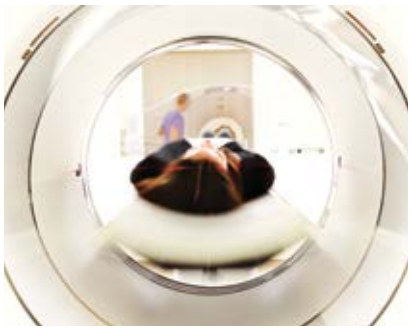

YOUR CONDITION IN REVIEW

GUEST SPEAKERS

ASK THE PANEL

We would also like to acknowledge our corporate sponsors:

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Also thanks to Allied Medical, Biogen and Sanofi Genzyme, the ARA Lodge No 348 IC Charitable Trust, the Clyde Graham Trust, NZ Post Community Post, Auckland Council, Richdale Charitable Trust and the Independent Living Service for their continuing support.

Korero with Ken

Ngā mihi nui ki a koe arā me tō whānau hoki.
Greetings to you and your family also.

Christmas has come and gone, so too the holidays, and our long summer days are fading away and getting shorter and cooler. What did Santa bring you? He was extremely generous to MDANZ and its members this year. At a very low cost to us, and with the help of a dedicated supporter and donor, Hyundai NZ provided MDANZ with two near-new vehicles for use in our fieldworker service. These vehicles have been deployed to maximise their contribution to our members, as well as reduce operating costs. I am extremely thankful for the generosity of all those involved.

In fact, I am continually humbled by the kindness and dedication of all of the supporters of MDANZ who contribute to make it such a wonderful organisation – they are our lifeblood. Whether it be monetary donations, giving of much limited time, or simple thoughts and words of encouragement – all are valued and appreciated. Thank you, arohanui, your contributions and efforts are reflected in our accomplishments.

So as another year has dawned and our AGMs roll around yet again, I encourage everyone to think about how they might get involved and make a contribution.

I am looking forward to continuing in my role on National Council helping to make a difference for our members. I'll be the first to admit it can be a challenge with a few frustrations, living with FSH not the least of them. But, it is extremely rewarding meeting and working with people in the MDANZ community.

As winter approaches, I have checked my diary to schedule the flu vaccination, and it is timely to urge our members to seek advice about the pneumonia vaccine as MDANZ subsidises the fee.

Ma te Atua koe e manaāki e tiaki.
May God bless and keep you.

Ken

Ken Green
MDANZ Chairperson

Hyundai NZ General Manager Andy Sinclair hands the car keys to Ronelle Baker who acknowledged the amazing impact this support will have.

In touch with Ronelle

Kia ora koutou, hello everyone.

I wish that, like the Prime Minister, I could have a jaw-dropping announcement for 2018. I'm not expecting, but am proud to say that MDANZ is my baby at present, and I love nurturing this organisation, its people and watching it grow.

Having worked through the planning cycle for another year, I can assure you we have a massive year ahead and hope to deliver many more benefits and services to our members, whilst building the capability of our organisation.

Thomas Edison once said, "*Opportunity is missed by most people because it is dressed in overalls and looks like work.*" The context of a new government and transformational change occurring in the disability support sector offers many opportunities for MDANZ. It was exciting to meet with the new Minister for Social Development and Disability Issues the Hon. Carmel Sepuloni, and to describe our organisation as intelligent, tenacious and ready to take a seat at the table and explore any opportunity for input at a policy level.

I explained to the Minister that, because we have progressive conditions, our needs are different to many other disability-related groups. We want the interface between health, disability and community services to be strengthened, and for resources to increase and move flexibly with us, as our needs change over time. We want to be well, live well and have resources that support our independence and help us contribute our talents in ways that matter. I feel it was a genuine conversation and I'm looking forward to many more.

In this issue, I want to acknowledge Conal Alexander who appears on our front cover, for the cool and inspiring attitude he has to life. I can really relate to the article about mobility aids and the experience of dealing with changes in strength and stamina. In my early 20's, I started out having a fold-up walking stick in my bag, for times when I felt unsteady. I leaned on the supermarket trolley a lot at shops, and used a mobility scooter to get around my university campus.

I remember the first time I tried a wheelchair and the freedom and fun I had using it – which was okay in the big picture because I could still get out and walk around. By the time I got to my late 30's things had changed dramatically. There is no way to dress up the fact that moving to a power chair was hard. It is, and will always be, like Thomas Edison's metaphor – an uninteresting pair of overalls and hard work! But I have more opportunities and experience as a result of using it, and that makes it worthwhile.

Hope you enjoy this issue of *In Touch* and look forward to sharing more opportunities with you as the year progresses.

Hei konā rā, Bye for now.

Ronelle Baker
Chief Executive

A cup of tea and a catch up with … Adam Bouman

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 January 2018 as the executive assistant to our CE Ronelle Baker.

What qualifies as a great day at work for you?

Solving problems I didn't expect to come across.

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

Apart from all the resources and support people need to live well and enjoy their day-to-day lives ... I'd like to see a free holiday for everyone once a year, to anywhere they would like!

What's the perfect morning tea for an office shout?

Pie – sweet or savory. Preferably both!

What are you passionate about?

Society being more inclusive and embracing of all people.

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 MDA as part of your will.

Thank you. We greatly appreciate your support.

Save the date

The Annual General Meeting of MDANZ will be held on Friday 20th April at 7pm National Office, 419 Church Street East, Penrose, Auckland.

Join us for an evening of interesting speakers, and mix and mingle with your governance, staff and other MDANZ members. Free parking.

Branch AGMs

Northern: Sunday 15th April, 2pm at National Office.

Wellington: Saturday 7th April, 1pm at Petone Community House, 6 Britannia St.

Canterbury: Wednesday 28th March, 12pm at the Papanui Library, 35 Langdons Rd, Papanui, Christchurch

Southern: Saturday 10th March, 11.30am at the Cargill Enterprises, Dunedin.

Funds for Freedom 2017 year in review

It's been another great year for the Members Discretionary Fund.

The response from our members to this initiative continues to be phenomenal, and we know this is making a positive difference in many lives.

Seventy-six members from all over the country applied throughout the year for funds to assist them to achieve their goals and dreams. We were able to make a contribution to 48 members throughout the year, which is a significant increase on the previous, our first, year.

A number of people attended conferences both in New Zealand and overseas, and also did University study, training and leadership programmes.

Members Bonny Stephens and Talitha Vandenberg received assistance with their airfares to attend the Myasthenia Gravis Conference in Australia.

Bonny said it was wonderful to have six New Zealand members at the conference - along with their spouses - and a great experience hearing from neurologists and meeting some of the 200 other conference attendees.

"I would like to thank MDANZ for its support in making it possible for me to attend, and hope that I can be of support to members in the Canterbury area and beyond".

A number of members were given assistance with equipment purchase, including a variety for health and home, such as medic alerts, body supports, assistive and device technology, and back-up batteries.

We were able to assist with the placement cost of three Mobility Assistance Dogs this year.

Debbie Fenton was one of these recipients, with her two-year-old Labrador Retriever Jackson. She wrote; "I have just had the most fantastic experience in my life thanks to the MDANZ Discretionary Fund.

"I have spent the past two weeks in Mobility Dog training camp to bond and learn commands that Jackson knows. Jackson has already made such a difference in my life, helping with daily tasks. He has an amazing personality, just waking up to a beautiful face looking at me in the morning starts my day off on the right step."

Also pictured below is Tommy, who is enjoying greater independence and companionship with his fluffy friend Sammy.

We were pleased to assist Brendan to purchase an uninterrupted power supply unit, to give him peace of mind at night after recent power outages in his area.

Our Member Services Manager Miriam Hianna enjoys being part of the assessment panel that reviews all applications. "We would love to assist everyone each round, however we have finite funds, so this is not always possible". She encourages those who aren't successful not to be dismayed. There are four rounds a year. You can try again, as long as your application meets the criteria.

For more information about the fund, please see our website.




Left to right: Bonny Stephens and Talitha Vandenberg; Debbie Fenton and Jackson; Tommy and Sammy; Brendan Hope.

Muscular Dystrophy New Zealand

Help us raise money without spending a cent.

You have the power!

Community Power is a new power company that wants to make a difference to the lives of New Zealanders.

To do so, it shares a portion of its profits with charities such as the Muscular Dystrophy Association of New Zealand (MDANZ).

By switching your power company to Community Power, you will stay on your current rates, or pay less – you won't pay any more for power. And by simply paying your power bill, Community Power will donate a portion of their profits to MDANZ and acknowledge you for this donation. It won't cost you a cent more and you won't have to dip into your own pockets.

This is the most powerful fundraising initiative we've ever launched. We don't need your money, we just need your power!

I've made the switch. Will you make it too?

Ronelle

Ronelle Baker
Chief Executive

Yes I will! How do I switch?

1. For a free, no obligation quote, email a copy of a recent electricity bill to: **support@communitypower.co.nz**
2. We will let you know how much your donation will be and if there are any savings for you.
3. Then just say "Yes" to start donating at no cost to you, we do the rest.
4. Your electricity supply will not be interrupted, we will take care of everything.
5. If you receive a network company dividend or rebate you will continue to receive this.
6. If you receive a prompt payment discount you will continue to receive this.
7. We will advise you on each monthly invoice of the amount you have donated and of your total donations made since joining us.
8. **Remember, your donations come from our profits, not your pocket. Thank you for helping.**

In partnership with COMMUNITY POWER *Power of Together*

www.communitypower.co.nz/md

Dr Silmara Gusso (left) discusses bone mass.

Investigating whole-body vibration training

Study funded by the trust.

Dr Silmara Gusso, Exercise Physiologist and researcher at the Liggins Institute, has been successful in obtaining a research grant to part-fund a study investigating whole-body vibration training (WBVT) for children and young people (aged 4-16 years) with congenital myopathy.

WBVT is a novel therapy that has proven beneficial effects on muscle function and bone health in previous studies in children with motor disabilities such as cerebral palsy. By maintaining muscle mass and bone mineral accrual during growth, WBVT has the potential to improve mobility and bone strength, leading to improved quality of life. There is limited evidence on the safety of this therapy for children and young people with Duchenne muscular dystrophy.

However previously published studies have focussed solely on assessing the safety of this therapy, demonstrating that short-term WBVT in children and adolescents with DMD is generally well-tolerated and does not lead to worsening muscle function. These studies were not powered to detect changes in efficacy outcomes, due to small numbers and short duration of the trials.

Dr Gusso's proposed study will look at outcomes from prolonged duration (20 weeks) of WBVT with frequent sessions (9 minutes 4 x weekly), measuring mobility, muscle mass and function, and bone health, in children and adolescents with congenital myopathy. The study will also investigate the effects on: lean mass, bone mineral density and bone mineral content as well as quality of life measures. A key aim is to document treatment guidelines for WBVT with this population.

Introducing…

Leigh Hale, PhD, FNZCP

Neuromuscular New Zealand Trustee Professor Leigh Hale is the Dean of the School of Physiotherapy / Centre for Health, Activity, and Rehabilitation Research at the University of Otago, and the Editor of the New Zealand Journal of Physiotherapy. She graduated as a physiotherapist from the University of Cape Town (South Africa) and went on to attain her MSc (Neurorehabilitation) and PhD from the University of the Witwatersrand (Wits)(South Africa).

Professor Hale worked as clinical physiotherapist in all areas of physiotherapy before pursuing an academic career. After teaching neurorehabilitation at the Department of Physiotherapy at Wits for 10 years, she moved to the University of Otago in 2000. Professor Hale primarily researches in the area of community-based physiotherapeutic rehabilitation for people living with disability and with neurological conditions, such as multiple sclerosis, stroke, and Parkinson's disease.

Leigh Hale

BRANCH news

Catching up with news
from around the country

A great get-together in Gisborne.

Wellington

Christmas was a big event for the branch with several celebrations held during the season. A big shout out goes to the amazing owner and staff at Roll In Cafe in Gisborne. The cafe was accessible and welcomed the group with a large bowl of delicious afghan cookies on the house. It was a great opportunity to stop, relax, and allow members to connect in the friendly, spacious cafe. Members were impressed with the ramped entrance at front, a new ramp at the rear, and plenty of handy parking close to entrances.

A members' Christmas dinner was held on the 16th of December at Bellevue Hotel and Gardens in Wellington. Those who attended enjoyed a scrumptious Christmas meal and entertainment. Many thanks to the branch committee, including our chairperson Annelize, for organising this event.

The branch AGM is at Petone Community House on 7th April. Check Facebook and the branch newsletter.

office.mdawgtn@xtra.co.nz

Northern

Ripper rugby, paddle boats, swimming, group jigsaw puzzles and the usual Saturday night quiz were all highlights of the branch camp help in the second weekend of December at Ngaruawahia Christian Camp. But of course nothing quite compared to the visit from Auckland HOG (Harley Owners Group), who brought presents for all the children, and Santa Claus himself. The kids also went home with a new teddy bear each, thanks to the Wilson Home Trust.

support@mdn.org.nz

Congratulations Marty.

Canterbury

Congratulations to Fieldworker Marty Price who received a community award for the work he does in the Nelson area coaching sports teams and helping out with community patrol.

From March, the Branch office will be relocated to Christchurch Community House, 301 Tuam Street, Otautahi, Christchurch.

The Canterbury branch has been chosen to partner with The Warehouse Riccarton as part of the 'Bags for Good Neighbourhood' programme from February to July 2018. Please support us when you shop at this store.

mdacanty@xtra.co.nz

Southern

Bikers Rights of NZ (BRONZ) is one of Southern Branch's ongoing supporters and make a generous donation each year. On the 10th December, Fieldworker Jo Smith joined branch member Stanley and his family in the Octogen to receive the donation. Stanley and his brother loved having the chance to sit on one of the bikes and hanging out with the bikers. It truly made their day.

This year Jo will continue to work in the community providing personalised support and education in the area of neuromuscular conditions to both new and existing members. Building relationships with other healthcare professionals is a significant part of the fieldworker role. Community education may include talking with teachers or disability support staff to improve their understanding of rare, progressive neuromuscular conditions, which will help them to provide even better services and support for members.

Keep Saturday 10th March free for the branch AGM. It will be held at Cargill Enterprises, Dunedin. Further details to come on Facebook.

joanne@mda.org.nz

Thanks to BRONZ for a donation and giving our young members a great experience.

Three wheels have given Conal Alexander freedom.
Photo credit: Gemma Foulds.

Freedom beyond limits

How to keep doing the things you enjoy

Wellington Fieldworker Dympna Mulroy explains how finding the right mobility aid can be the key to independence.

Asking for and accepting support can sometimes be difficult. Nobody wants to lose their independence or appear weak. In my experience, one of the comments I often hear is, "Getting a walking stick or wheelchair is giving in". There is this feeling that you must battle against muscular dystrophy for the rest of your life. Change and acceptance can be hard, and you can never force someone to take support when they are not ready. However, once someone takes that leap and receives physical support in the form of a mobility aid, they often realise how much freedom and independence they have with it. Many even wish they had gotten this support sooner.

Another common concern is, "My muscles will become much weaker if I use a scooter or wheelchair". There is a very fine line between continuing to move around without support, and the risk of falling. Safety should

always come first, and if you begin to notice any of the following I advise you speak to your fieldworker, GP, physiotherapist or occupational therapist. The process to get some physical supports can be lengthy, and it is best to start the conversations early. Things to look out for include:

- Reduced balance
- Falling
- Tripping
- Fatigue when walking, moving around and standing e.g. getting tired while shopping or standing at the bench to cook a meal
- Reduced energy to go distances

There will be times when a physical aid will be more helpful. For example, on uneven surfaces, in unfamiliar environments and if you are going to be out for a long time as it can help fatigue management and give you confidence and support. An aid can also be of benefit to members of the public. It makes them aware you may have balance or mobility issues, so they don't bang against you or walk too close. It alerts them that you may not be able to save your balance or change direction quickly. Walking sticks and some walkers are very portable, and easy to keep in the back of your vehicle in case you decide to use one, or have an emergency situation.

Some people are not at the stage of needing a wheelchair to get around but may feel restricted as they can't do all the things they want to, such as going on walks with their family, or going to the local shops. As a result, they lose confidence when going out, end up doing less and spend more time indoors. Mobility scooters have become a common solution for these situations, and have enabled a lot of members to regain their independence and freedom, allowing them opportunities to go out with their family and friends and attend events. The use of scooters in the general public has also grown, with some malls, zoos, museums, supermarkets and councils providing them free to hire while you're there.

There are a range of different physical aids available and it can be very confusing to know which ones are best and how to access them. Occupational therapists specialise in wheelchair provision and seating, while physiotherapists concentrate on walking aids like walking sticks and frames. Depending on the DHB, some therapists can provide both services.

Occupational therapists specialise in wheelchair provision and seating, while physiotherapists concentrate on walking aids like walking sticks and frames.

If you require a mobility assessment, you should speak to your GP, an occupational therapist or physiotherapist (if you have one). Alternatively, you can contact your local fieldworker who can refer you to a therapy service, and support you through the process. Depending on your level of priority, you may have to wait a while for your mobility device. Wheelchair provision requires a few stages including measurement, ordering and trialling.

The Ministry of Health funds walking sticks, walking frames, wheelchairs and sometimes buggies for young children, following an assessment by an accredited therapist. Funding for mobility scooters is a little harder, and many people apply to the lotteries grants board for funding assistance. Your fieldworker can help you with this process. Some people choose to purchase folding walking sticks or other mobility aids from pharmacies and disability retail outlets. Take care to ensure the sales people have enough training to advise on correct height and technique to avoid injury.

Transport can be a major consideration when using a wheelchair or scooter. Wheelchairs are allowed on buses, though not all buses will be accessible. With scooters, it's up to whoever runs your local bus service whether they are permitted. Others rely on accessible taxis for local transportation. Many people also self-fund or apply for public funding to modify a vehicle to transport their wheelchair or scooter. If you decide to self-fund a vehicle, seeking advice from an occupational therapist experienced in vehicle assessment is highly

recommended, to ensure you choose one that is best for your current and future needs.

Mobility in whatever form – foot, car, wheelchair, walking frame, scooter, pram, bike - is important for everyone. It means we can go to places, see and do things, and be part of our community. But how we look, and what people will think is sometimes a concern that can hold us back. The stigma that aids are for 'old people' still resonates for some. Looking beyond this, all shapes, ages, sizes and types of people use mobility aids in our communities.

Ultimately, your freedom and independence are more important than anything else.

Members have shared stories with me of how some people stare at them in public, and this can deter them from using an aid. In moments like this, it is worth remembering that other people are usually more consumed by their own lives and they don't know you, or usually dwell on the fact that someone has a mobility aid once the moment has passed. Hopefully this stigma will continue to diminish as societal attitudes shift toward a more positive and inclusive view of physical differences and access needs.

Ultimately, your freedom and independence are more important than anything else. If you feel a physical aid may benefit you and help you to keep moving more safely and with ease, talk with your fieldworker, a support network member, or health care provider. It may be the start of a new journey in your life.

Conal Alexander had a third wheel made for his manual wheelchair.

Freedom is … three wheels

Being known as a third wheel isn't usually a compliment, but Conal Alexander's third wheel is a ticket to freedom.

Thanks to the third wheel he had made for his manual wheelchair about 15 years ago, he can travel nearly anywhere he chooses from his Christchurch home. He often makes the five kilometre round trip into town to go to the movies, or enjoy a nice meal out. Conal catches up with his mother Lyn nearly every day for a coffee, and to visit the park with his much-loved dog Bob. A few years ago he rode the 11 kilometre rail trail from Hornby to Lincoln to raise funds for FARA (Friedreich Ataxia Research Association).

The extra wheel fits into a small hole under his chair and lifts the front wheels off the ground, turning it into a giant pedal car, with the hand-operated pedals at shoulder height. This gives Conal a comfortable riding position in his 'tricycle', and he is able pedal along at an impressive speed.

He also has a power chair that he prefers to use inside when he needs to, and also has an electric third wheel. But he enjoys his manual chair because it helps keep him fit.

Conal has lived with Friedreich Ataxia since being diagnosed as a young child and has been a wheelchair user since he was 18.

The bike is helping him get stronger and more confident and the whole family is enjoying going on bike rides together.

Freedom is … special tyres

Like the other kids in his street, seven-year-old Bradley Carter loves riding his bike to school with his friends and going on outdoor adventures with his family.

But living with Charcot-Marie-Tooth Disease was making it difficult for him to keep up with others. After speaking to the owner of the local cycle store who recommended a 'fat tyre' bike, Bradley's mum Kaye applied to the MDANZ Members Discretionary Fund to get some financial help.

His application was successful and Bradley is loving the freedom his new bike gives him.

It is a mountain bike with extra fat wheels which help him keep his balance and make it easier for him to reach the handle bars and compress the brakes. It also has gears, so once he gets more confident and learns to use them, he will be able to manage a few hills.

The bike is helping him get stronger and more confident and the whole family is enjoying going on bike rides together.

Bradley Carter loves his new bike.

Olivia's wheels give her the freedom to go to new places.

Freedom is … e-Motion wheels

Olivia Shivas lives life at full speed. She has a busy job and loves to travel as much as possible in her spare time.

Thanks to e-Motion wheels (power-assisted wheels that are attached to a manual wheelchair) she's able to get to places that might have been difficult previously.

"I heard about them from another wheelchair-user who had them and then I chatted to my OT about getting them too. I was about to start uni and I needed an extra boost to help me up hills in the city campus," says Olivia, who often compares the technology to an electric bike because users still have to propel the wheels with their arms for the power-assist function to work.

"I'm able to be fully independent and safe going out and about. There are lots of steep streets around my work, so even the simple things like getting lunch with workmates is something I can do more easily with the e-Motion wheels. The wheels really suit my needs and lifestyle, and they look like regular wheels."

They are particularly useful on hills, grass and gravel. While Olivia often recommends the wheels, she points out they are heavy. Her ones weigh 10 kgs per wheel, although newer ones are slightly lighter.

Let's talk about it

Chatting with a counsellor can play an important role in looking after yourself

Our guide to knowing what to expect from a counselling session.

Mental health is increasingly under the spotlight in New Zealand as there is a growing awareness that our emotional, psychological, and social well-being needs to be cared for and nurtured in the same way as our physical health does. It affects how we think, feel, and act and also helps determine how we handle stress, relate to others, and make choices.

Coping with change, stressful situations and the associated feelings they bring may have once been something we were expected to do on our own, but it's now universally acknowledged that professional help can make a huge difference.

MDANZ is well aware of this and offers free counselling sessions to members throughout New Zealand. We believe that the impact of living with a progressive neuromuscular condition sometimes raises feelings or issues that can be helpful to talk about with an independent professional.

We have partnered with EAPworks, a nationwide professional support service that offer solutions-focused counselling, and resources for managing personal, work or life issues. EAPworks counsellors work in the community and in workplaces with adults, young people, couples, or families on all sorts of issues, such as grief and trauma, addictions, interpersonal conflict and family or workplace stress.

Going to see a counsellor can feel like a big step for some, so with the help of EAPworks, we have prepared some answers to commonly asked questions.

How can I be sure my counsellor has a reputable qualification?
All counsellors are are part of a national network of professionals contracted to EAPworks. Each counsellor is required to be tertiary trained, registered with a professional body, and has to have a minimum of five years experience, so you can be sure of the validity of the counsellor.

How can counselling help me? I don't have a mental illness and am not depressed, but recognise it's helpful to talk to someone about some big changes that are happening in my life. Will it just be me answering questions, or will I be given specific direction and strategies?
Each person can use the counselling sessions for any reason that impacts on their wellbeing. Sometimes it is just having someone independent, confidential and professional to talk about what you are going through, or you might need strategies to manage a situation of concern. Counselling can give you a different perspective on a situation or a new lens to look through.

What is important is that you make it clear what you would like to get out of the sessions so that the counsellor can help ensure your needs are met. No one is there to pry into your life or tell you what to do – they are there to assist you with what it is that you are needing at that time.

How many sessions am I allowed?
Up to three per person per year are funded by MDANZ and more by approval if you and the counsellor believe there is a need for more, and funding is available. Many counsellors work privately as well if you want to self-fund.

I'm a caregiver. Will counselling benefit me as well as my child?
Having the role of caregiver is such an important role with its own joys and challenges. Being able to off-load to someone who understands, or to discuss any issues you are having can be really helpful. We all need a break to renew our batteries and to do some self-care things for ourselves and this can be one of them!

The sessions are also very valuable for those whose lives are directly impacted by the condition – managing the day-to-day frustrations and just being able to share what it is like with an independent person who has no agenda other than listening to you and supporting you.

No one is there to pry into your life or tell you what to do – they are there to assist you with what it is that you are needing at that time.

What sort of things will we discuss?
You can discuss anything you like! The sessions are just for you to discuss your situation generally or you may have specific things you want to talk about like things that relate to managing the physical, emotional or mental aspects of life. Relationships can be an important topic to discuss too if you need to. Grief and loss and life transitions are also common topics chatted about.

Can I be made to talk about things I don't want to talk about?
No – no one is there to make you talk about anything that you do not want to! It is your time to get what you want out of the sessions and if a question was asked that you preferred not to answer, just say so and your wishes will be respected.

How often will I need to see the counsellor?
It varies – some people just need one session – others several – this programme offers up to three funded sessions per person per year without question. If more are needed, you can discuss this with the counsellor. MDANZ will assess any additional requests based on need and funding available. Your name won't be shared with MDANZ, when requests for more sessions are made.

Will anyone else find out about what we talk about?
The counselling sessions are completely confidential between you and the counsellor. The only exception to this is if there was a safety issue where someone was likely to be harmed, then the New Zealand law requires confidentiality to be broken.

Comfort Cough available for purchase or rental

Comfort Cough has been designed to assist people to clear bronchopulmonary secretions.

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Feedback from our members

"Everything went smoothly. Easy to access. Counsellor met our son's needs, he clicked with her and picked up some good tips to manage his issues."

"It has been helpful for acceptance of reduced ability and reality of how things are. Encouragement to accept assistance including using mobility card, elbow crutches etc. to improve the quality of life. Also good for managing stress, and vocational and social issues."

"Really good service. Very valuable. Good sounding board. When first time accessed didn't know what to expect but proved very valuable, validated that my thoughts and feelings were ok and normal. Extremely worthwhile." (from a caregiver)

How do I get started?

MDANZ funds up to three counselling sessions per year to eligible members. Your counsellor can request more funded sessions from us and we will consider these requests on a case by case basis depending on the need, and our available funding.

To receive this funding, you must be a registered member of MDANZ and either have a neuromuscular condition covered by MDANZ, or provide close care/ support for a member with a neuromuscular condition. This service is also available for immediate family who have experienced a bereavement.

Making an appointment

It's quick and easy to access this counselling programme.

Freephone 0800 SELF HELP (0800 735 343) and give your name and MDANZ membership number. You will be asked what your main concern is and be referred to a professional, accredited and experienced counsellor in your area.

If you have any other questions about this programme, or do not know your membership number please contact us at the MDANZ National Office or talk to your Fieldworker.

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Gene therapy for DMD

Early in January, the first dose of microdystrophin gene therapy for Duchenne muscular dystrophy was given at the Nationwide Children's Hospital in the USA. The aim of this therapy is to improve the muscles of those with DMD. It provides systemic delivery of a microdystrophin gene construct that targets both skeletal and cardiac muscle through one intravenous injection, a protocol approved by the FDA. It is thought that it takes five days for the virus vector to deliver the therapy and to fully integrate into heart and muscle cells. Some early results will be discussed at PPMD's annual End Duchenne Conference in Arizona, June 2018. R

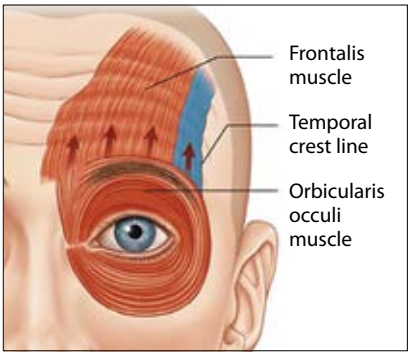
OPMD treatment given orphan drug status

Slowing the breakdown of muscle.

The U.S. Food and Drug Administration (FDA) recently granted the gene therapy BB-301, produced by Benitec Biopharma, orphan drug status for the treatment of oculopharyngeal muscular dystrophy (OPMD). OPMD is caused by a mutation of the *PABPN1* gene that results in faulty protein associated with muscle weakness.

Benitec Biopharma published a study last year using cells from OPMD participants that showed a particular molecular biology strategy might be used to shut down and replace the faulty protein and reverse impaired muscle strength and slow the breakdown of muscle.

The FDA's orphan drug status follows the European Medicines Agency's (EMA) decision to grant orphan designation to BB-301 one year ago, in January 2017.



Muscles affected around the eyes.

Orphan drug status enables the company to receive incentives such as hastened approval processing time and less expensive filing fees.

Benitec is currently conducting preclinical and safety studies of BB-301, and plans to advance it into human clinical trials by the end of this year. R

HSP expert visits New Zealand

Professor Evan Reid.

November 2017 saw Professor Evan Reid visit New Zealand from the United Kingdom for the first time. Evan's work in Cambridge centres around hereditary spastic paraparesis (HSP) and his ability to turn information available from the genetics of HSP into a greater understanding of the molecular biology behind the condition. Prof Reid came as the keynote speaker at New Zealand's Neurological Association's annual conference and whilst in the country he also gave a talk at the University of Auckland's Centre for Brain Research. His research is complex and works right across from molecular biology looking at alterations in DNA sequence through cellular mechanisms to larger body systems to the whole person. He sees many people with HSP in the UK and is involved in their care and management.

There are more than 80 known loci in around 50 known genes (these numbers are constantly being revised upwards) that cause HSP. Every one holds a key to unlocking the door to understanding more about cellular health in particular axonal health. Evan's strategy is to take cell biology, animal models and human studies centred around HSP and fully elucidate the areas of cross over.

Insufficiency of a protein called spastin is the most common cause of HSP – what does spastin do? It appears to drive a cellular mechanism called endosome tubule fission, which is basically involved in moving things about the cell. The cells that become damaged in HSP are the long axons supplying the lower limbs and when they're unable to work properly because of not enough spastin protein we see the signs and symptoms of HSP developing. Ⓡ

Significant results in DMD trial

Summit Therapeutics has announced positive 24-week interim data from PhaseOut DMD, their Phase 2 clinical trial of the utrophin modulator ezutromid. The data showed that there was a significant reduction in muscle damage and an increase in utrophin in muscle biopsies.

This is in line with the expectation that utrophin modulation maintains utrophin production in mature muscle fibers, enabling utrophin to replace the need for dystrophin in DMD muscles. It is unknown yet whether ezutromid will be able to produce long term functional or other clinical benefits, but this is a very exciting step for this class of drug. Importantly, ezutromid has been well-tolerated to date by all people in the PhaseOut DMD. The results from the full 48 weeks of the trial expected in the third quarter of the year. Ⓡ

$2.5 million for US research into LGMD treatment

Myonexus Therapeutics has announced that it has secured $2.5 million to advance limb girdle muscular dystrophy (LGMD) gene therapies into the clinic. This will enable them to initiate a phase 1/2 clinical trial testing MYO-101, the company's LGMD2E gene therapy, in early 2018. Ⓡ

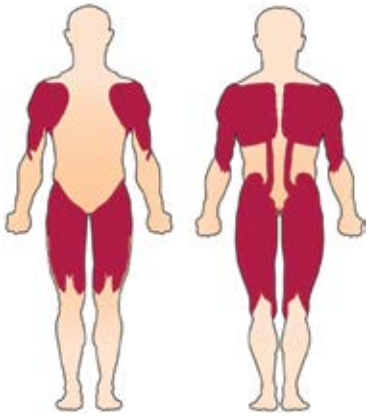


Image credit: mda.org

Trial data for new SMA investigational drug

Cytokinetics, an American based pharmaceutical company, recently announced the publication of results from three early clinical trials in healthy volunteers that evaluated safety, tolerability, metabolism, excretion, and mode of action of the molecule "CK-2127107".

The data supports the ongoing Phase 2 trials of the drug in people with spinal muscular atrophy (SMA). The results showed that muscle force generated was increased with this drug in response to nerve stimulation. Single doses were well-tolerated in healthy volunteers at doses up to 4000 mg and no serious adverse effects (SAEs) were reported and adverse effects (AEs) were all mild or moderate. Ⓡ

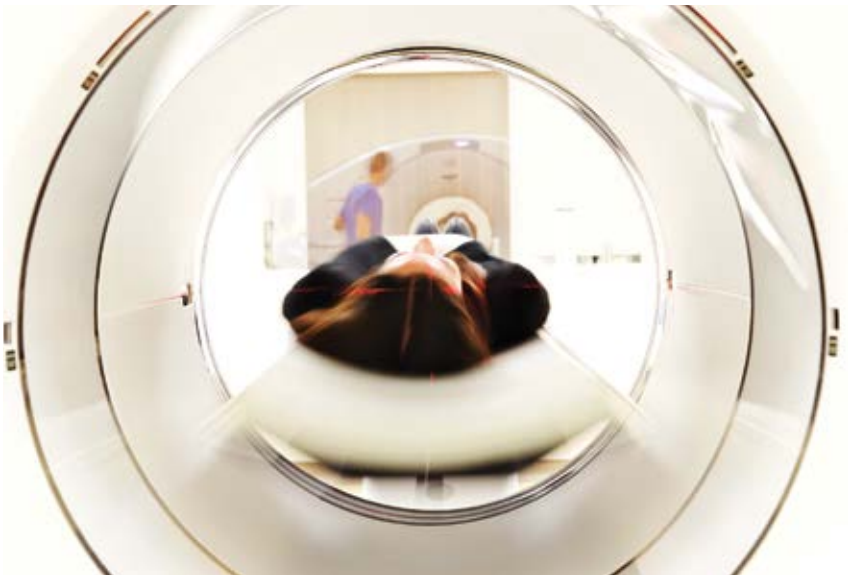
MRI to diagnose muscular dystrophy

An easier way to identify symptoms.

Different types of muscular dystrophy (MD) are caused by different genetic mutations, and a proper diagnosis can involve a range of tests, such as blood tests, functional tests, muscle biopsies, and magnetic resonance imaging (MRI). An MRI is a rapid, non-invasive diagnostic technique using a magnetic field and radio waves to produce detailed images of the organs and tissues (such as muscle, fat, and bone) within the body. It works to spot muscles affected by a condition, show the degree of damage, and to guide physicians in choosing tissues to biopsy.

MRI currently is the best method to evaluate the shape, volume, and physical appearance of voluntary muscles, and distinguish between types of muscles in a muscle group. MRI can identify MD in asymptomatic patients and is useful in early disease detection, as it is able to spot inflammatory changes in muscle and the presence of edema and fat infiltration. MRI can also be used to track the disease progression, in conjunction with methods such as ultrasound, in determining the degree of muscle tissue being replaced by fat or fibrous connective tissue.

When used with methods such as magnetic resonance spectroscopy (MRS) and diffusion-weighted imaging, MRI scans may aid in bringing a better understand of the biology of MD to researchers and clinicians. Ⓡ



The MRI scanner is a short tunnel which is open at both ends. You lie on the scan table while the image is taken.

Revised clinical care guidelines for DMD now available

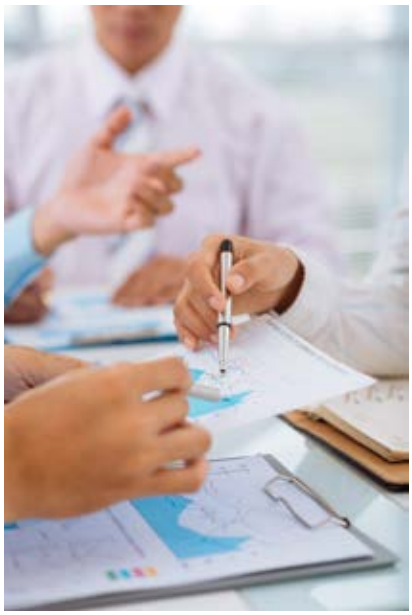
Working towards improved care.

The revised three part clinical care guidelines for Duchenne muscular dystrophy (DMD) have now been published and are available through the Lancet Neurology. In 2014, a steering committee of experts from a wide range of disciplines was established to update the 2010 DMD care considerations, with the goal of improving patient care. The new care considerations aim to address the needs of patients with prolonged survival, to provide guidance on advances in assessments and interventions, and to consider the implications of emerging genetic and molecular therapies for DMD. The committee identified 11 topics to be included in the update, eight of which were addressed in the original care considerations. The three new topics are primary care and emergency management, endocrine management, and transitions of care across the lifespan.

Diagnosis and management of Duchenne muscular dystrophy:

Part 1: diagnosis, and neuromuscular, rehabilitation, endocrine, and gastrointestinal and nutritional management.

These guidelines reflect a shift to more anticipatory diagnostic and therapeutic strategies, with a renewed focus on patient quality



of life. In part 1 of this three-part update, the care considerations for diagnosis of DMD are covered, and neuromuscular, rehabilitation, endocrine (growth, puberty, and adrenal insufficiency), and gastrointestinal (including nutrition and dysphagia) management.

Part 2: respiratory, cardiac, bone health, and orthapedic management.

This presents the latest recommendations for respiratory, cardiac, bone health and osteoporosis, and orthopaedic and surgical management for boys and men with DMD. Additionally, guidance is provided on cardiac management for female carriers of a disease-causing mutation. The new care considerations acknowledge the effects of long-term corticosteroid use on the natural history of DMD, and the need for care guidance across the lifespan as patients live longer. The management of DMD looks set to change substantially as new genetic and molecular therapies become available.

Part 3: primary care, emergency management, psychosocial care, and transitions of care across the lifespan.

In part 3 of this update of the DMD care considerations, the focus is on primary care, emergency management, psychosocial care, and transitions of care across the lifespan. Many primary care and emergency medicine clinicians are inexperienced at managing the complications of DMD. This provides a guide to the acute and chronic medical conditions that these first-line providers are likely to encounter. With prolonged survival, individuals with DMD face a unique set of challenges related to psychosocial issues and transitions of care. This guide discusses assessments and interventions that are designed to improve mental health and independence, functionality, and quality of life in critical domains of living, including health care, education, employment, interpersonal relationships, and intimacy.

Hereditary Spastic Paraplegia / Familial Spastic Paraparesis

Understanding this group of inherited disorders.

What is Hereditary Spastic Paraplegia?

Hereditary spastic paraplegia (HSP), also called familial spastic paraparesis (FSP), refers to a group of inherited disorders caused by various genetic alterations. Although there are various presentations of these conditions they all share common symptoms of weakness, spasticity (stiffness) and reduced ability to sense vibrations in the legs. Often the initial symptoms are mild difficulties in walking style (a spastic gait) due to leg stiffness. HSP tends to progress (get worse over time) quite slowly but, may eventually result in the person requiring the assistance of a cane, walker, or wheelchair. The number of people who have HSP varies from population to population ranging between 1.3 to 9.6 per 100,000 people. HSP affects both males and females similarly.

Types of HSP

HSP can present as "pure" with progressive lower limb spasticity and weakness or with other symptoms of a systemic or neurological nature (complicated HSP). These additional symptoms can include ataxia (lack of muscle coordination), epilepsy, impaired vision due to cataracts,

A walking stick is helpful for maintaining balance.

problems with the optic nerve and retina of the eye, cognitive impairment, peripheral neuropathy, and deafness.

Symptoms may begin in childhood or adulthood, depending on the particular HSP gene involved. When symptoms begin after childhood they usually progress slowly and steadily. If symptoms start in very early childhood they may not progress and therefore resemble spastic diplegic cerebal palsy. The severity of the condition varies widely with some people being severely disabled and others only mildly. Life expectancy for "pure" HSP is not affected.

Causes of HSP

Numerous genes are responsible for several forms of HSP, with more than 80 genetic causes of HSP identified to date, and many more will likely be identified in the future. HSP genes are designated "SPastic parapleGia, loci ("SPG") and numbered in order of their discovery (for example, SPG1 through SPG80). These genes generally encode proteins that normally help maintain the function of axons (which conduct nerve impulses) in the spinal cord. Loss of the conduction of information in these cells causes the symptoms experienced in HSP.

Inheritance

HSP has several forms of inheritance. Not all children in a family will necessarily develop symptoms, although they may be carriers of the abnormal gene

Depending on the specific gene defect that is causing the condition it is inherited in three ways which are described below:

X-linked recessive: The sex chromosomes X and Y determine if a baby will be a boy or a girl. X-Linked HSP is caused by defects in genes present on the X chromosome.

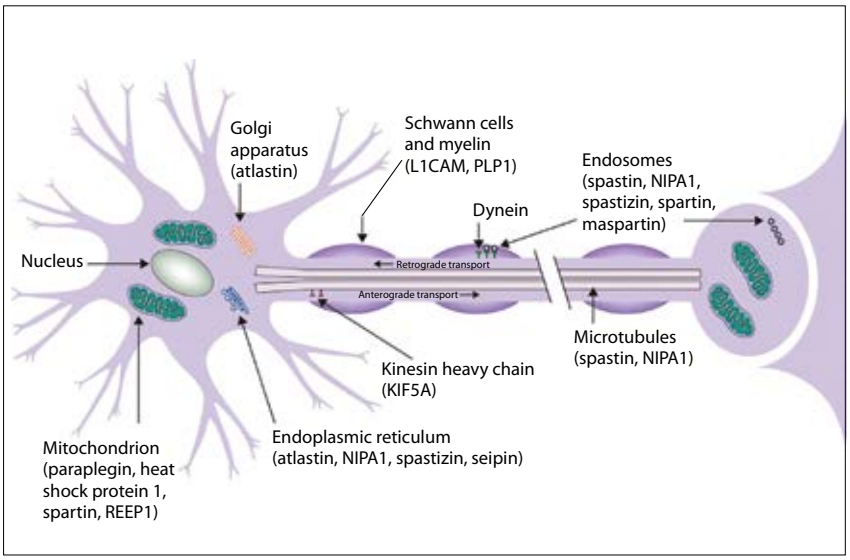


Diagram of nerves and transmission of signals. Photo credit: thelancet.com

One functioning copy is enough to prevent X-Linked HSP. Girls receive an X chromosome from mum and an X chromosome from dad and are described as XX. Boys receive an X from mum and a Y chromosome from dad and are described as XY. As boys have only one X chromosome if they inherit an X chromosome with a defective gene then they will have that condition. The mother is described as a 'carrier' and with one functioning gene is usually unaffected. A carrier mother has a 25% chance in each pregnancy of having an affected male child.

Autosomal dominant: This means that one defective copy is enough for the disease to present. The gene with the defect is found on one of the 22 pairs of chromosomes not involved in sex determination. Men and women are equally likely to be affected. A person with an autosomal dominant condition has a 50 percent chance in each pregnancy that their child will also be affected.

Autosomal recessive: This means that both copies of the abnormal gene must be defective for the disease to develop fully. In this situation each parent is a carrier of the same defective gene. Each child they have has a 25% chance of inheriting the disease.

If symptoms start in very early childhood they may not progress and therefore resemble spastic diplegic cerebal palsy.

Genetic counselling is available to families who have had a diagnosis of hereditary spastic paraplegia (as there are several different inheritance patterns it is important that the diagnosis is correct). This service provides information, helps families understand inheritance patterns and what this means for their family, as well as enabling people to make more informed family-planning decisions. You can access the free NZ genetic counsellor service via your GP, self-referral or talk to an MDANZ fieldworker who can assist you.

Diagnosis

The diagnosis of HSP is primarily by neurological examination and observation of a spastic gait as well as testing to rule out other disorders. Family history, genetic testing, laboratory tests, neurophysiologic testing, and neuroimaging can also help confirm a diagnosis.

MRI abnormalities, such as a thin corpus callosum (largest midline structure of the brain), may be seen in some of the complicated forms of HSP.

Management

There are no specific treatments to prevent, slow, or reverse HSP. There is a multidisciplinary team approach to management of the symptoms that present during the course of this condition and to improve balance, strength and agility. A neurologist, physiotherapist, occupational therapist, and a dietitian may all be needed at some point.

Current recommendations are:

- Daily physical therapy and exercise aiming towards improving cardiovascular fitness and maintaining and improving muscle strength and gait and reducing muscle tightness.
- Referral to an occupational therapist to make sure any assistive walking devices or ankle-foot orthotics are used if appropriate.

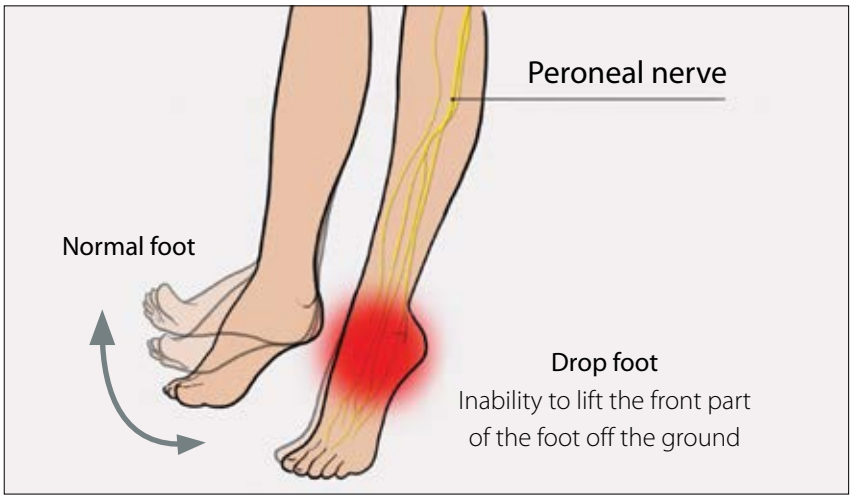


Diagram showing drop foot. Illustration: www.bodyorganics.com.au

They may have some practical suggestions that have worked for others to offer as well.

- Drugs to reduce muscle spasticity (including Botox injections) and reduce urinary urgency.
- Annual or as needed evaluations by a neurologist and physiotherapist to monitor any progression of the condition and to make sure treatment programmes are relevant.
- Avoid exposure to medications or chemicals that cause neuropathy if possible.

During Pregnancy

HSP symptoms generally do not change significantly during pregnancy, unless a medication treating symptoms is stopped during the course of the pregnancy. In general, uncomplicated HSP does not pose increased risk for pregnancy, labour, or delivery. In general, having uncomplicated HSP does not increase risk associated with obstetric anaesthesia.

Research

Current research is looking at the following methods of treating HSP:

- Gene therapy: a mechanism for supplementing defective genes with healthy genes in the tissues affected by neuromuscular disease;
- Gene silencing: turning off genetic instructions that cause the production of toxic proteins.

Support

Our fieldworkers are available for support. They have in-depth knowledge of a range of neuromuscular conditions, and will have an understanding of your needs and challenges. Have a chat over the phone or they can come to you for a kanohi ki te kanohi/face-to-face visit. They may have some practical suggestions that have worked for others to offer, as well as providing general support and a referral to health professionals. This service is offered free of charge to MDANZ members and is funded through donations and grants. See contact information at the back of *In Touch* to find a fieldworker.

Our Support Network facilitates people with similar circumstances or challenges to connect so they can share their experiences, and provide each other with emotional support, as well as practical advice and information. By bringing together people with common experiences, support networks can provide an invaluable addition to medical care. Our Support Network currently has over 600 members throughout New Zealand who want to be in touch with others livings with neuromuscular conditions. Please contact info@mda.org.nz more information.

Useful Websites

http://sp-foundation.org/

http://rarediseases.org/

References http://www.ninds.nih.gov/disorders/hereditary_spastic_paraplegia/hereditary_spastic_paraplegia.htm

https://umaine.edu/edhd/research/acc/what-is-agenesis-of-the-corpus-callosum-acc/

http://www.ncbi.nlm.nih.gov/books/NBK1509/ ®

Making the most of now

Sonia Hooper shares her journey with HSP, and explains that while she doesn't know exactly where it will take her, she is making the most of where she is now.

My name is Sonia, but I am also known as Mum, Sona, Sonic, Nurse, Sister and Moa. I was born and raised in Christchurch, moving to Wellington for some years before returning to Christchurch. I have raised a son and trained as a registered nurse, my job for 24 years.

My journey with Hereditary Spastic Paraparesis (HSP) has been a long one. I was officially diagnosed in about 2012. In hindsight, I had been experiencing symptoms for years. At first I struggled to get a referral to a neurologist. When I finally did, I was pleased, but also nervous. Denial is a way of managing to get on with life and I didn't know what was going to happen.

At the appointment, I did all the standard tests. With my poor gait and strong reflexes, it was decided I most likely had Hereditary Spastic Paraparesis, even though I didn't have any relatives with it.

Receiving a diagnosis was actually a relief. I had entered my symptoms into Google several times and HSP was on the list, so I had some idea of what it was and at least knew what I was dealing with. Being philosophical and accepting helped, and having people in my family with mobility issues meant I had positive role models of people who lived with difficulties, and got on with life.

I have done lots of research to help me understand HSP. Many things I had ignored, or pushed to the back of my mind over the years, started to make sense after my diagnosis. For years I had been told I walked on my tip toes, my balance was poor and I seemed to be constantly tired. I'd had falls due finding it difficult to pick up my feet. This got better when I lost some weight.

I get pain at times, partly due to HSP symptoms, but also secondary pain as a result of the way I walk, and using my muscles for tasks they are not designed for.

Managing the fatigue is the main problem I have. I only have half a bucket of energy, so have to use it well. That means using a dishwasher instead of standing at the sink for a long time, having rest days in holiday itineraries, keeping to a regular routine to ensure adequate sleep, and using a mobility card to prevent a long trek. Occasionally, I use an elbow crutch if I am walking a long way, especially on uneven surfaces. It helps me lift my feet, prevent tripping, and conserves my energy.

Meeting other people with HSP has been awesome. It's great to be able to talk with someone with the same experiences of fatigue, and knows about coping with the reactions of others.

My mother has mobility problems due to arthritis, but it seems that covered up co-existing HSP symptoms similar to mine. It puts paid to any doubts about my diagnosis, and it is helpful for both of us.

A diagnosis was a long time coming for Sonia. Photo credit: Gemma Foulds.

MDANZ has been great. Paul Graham is a gem and has been a listening ear and source of information. The counselling sessions funded by MDANZ have been helpful in acceptance and dealing with the grief issues I have.

These days I lead a full, if quiet, life. I am looking for another job without shift work as that affects my energy levels. I enjoy work, and being a mum. I enjoy my wonderful family and friends, keep tropical fish, study and write books on genealogy and am active politically. HSP restricts me, which frustrates me, and I don't know what is going to happen next. But I plan on making the most of what I have today.

Part of my story is missing

An HSP diagnosis has made Jonathan Morris ask questions about his biological mother, and he hopes she will make contact one day.

I was born in Oamaru, in December of 1964 and originally named Andrew. When I was very young, my birth mother gave me up for adoption. I was adopted by a wonderful family and have always got on well with my adoptive parents Doug and Jean Morris.

We moved to Nelson, and my mum laughs that I didn't much like school from the day I started until the day I left! I had a learning disability and suffered from Epilepsy; having to deal with both of these was very difficult at times.

Well into my adult life, roughly about ten years ago, I started noticing that I was walking around on my tip toes, and having frequent falls. I had completed an apprentice through Nelson City Council Parks and Reserves and was then mowing lawns. I didn't think much of it to start with, but after some time I saw my GP about it, who then referred me to a neurologist. It has been a long journey, however I finally got a diagnosis roughly a year or two ago through genetic services in Wellington Hospital, when I was referred to MDANZ.

I didn't know anything about HSP when I received the diagnosis, and didn't know anyone with the condition. I finally managed to connect with someone in Christchurch who had HSP, but they were not as advanced as I was, I was at a different stage. I met two others at the MDANZ Camp, one with a very similar condition, and we stay in touch.

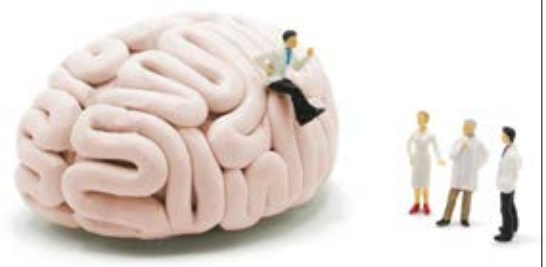
I initially could drive which was great, but had to give it up recently after I was told at the hospital following a serious fall that I shouldn't. I sold my car and found a mobility scooter that was suitable instead. The scooter is great as I get to most places locally and still manage to maintain my independence. When I get off the scooter, I use a walker to get around.

I think about my biological mother a lot and would like to take this opportunity to reach out to her.

I now live in Stoke and attend MDANZ coffee mornings once a month in Nelson, I look forward to those as it's a chance to connect and socialise with others. I still try to keep going as normal, I like my gardening, and although I am unable to mow the lawns anymore, I still garden as I enjoy that. I volunteer with Stoke Senior Services, and am there three days a week and try to stay as active as I can. My biggest piece of advice for others with similar conditions is don't give up, keep going even though it gets hard at times. There are no limits to what you can do, you have to find what you like doing and what you can do. Grab the bull by the horns and get into it.

Jonathan is very active in the community.

I think about my biological mother a lot and would like to take this opportunity to reach out to her. I'd like to know if anyone in her family has the same condition. I don't have any animosity to her at all, and completely understand how different things were when she had me at the age of 16. It's a chapter in the book of my life I know very little about, and would like to be able to fill it in.



A day in the life of a neurologist

DR. RICHARD ROXBURGH

A peek into the average day.

Traditionally, a neurologist's main job is to see new patients and try to make an accurate diagnosis. In recent times, as our knowledge has improved, neurologists have become more involved in treatment and management of the conditions that people have. A neurologist's day generally reflects these two priorities.

In Auckland we have our days split into half days, each of which will usually involve a different activity. Some of these activities involve seeing inpatients at either Auckland, Middlemore, North Shore or Waitakere Hospitals.

We take turns to be the consultant on the Neurology ward at Auckland City Hospital. Often that's very challenging as only the most difficult management cases are usually kept under our care. There is often a lot of reading around rare conditions.

We also take our turn to be the Stroke Neurologist .

A typical outpatient's clinic has a mixture of new patients and review patients. Typically, a new patient clinic appointment is assigned 45 minutes and a review 25 minutes. In that time we listen to the patient's problem, examine them, come to some conclusion about what the diagnosis is, try to explain this to the patient and maybe prescribe medication or request tests, or both. We then follow up with letters – summarising our findings and suggesting the right plan of management, referring to other specialities and to relevant support organisations and/or research opportunities like the NZNMD Registry. We let the referring doctor know the results of our tests and explain what they mean.

Thrown in there are group radiology sessions where we discuss 'interesting' scans and learn from each other's cases, or put up scans that we are puzzled by and need each other's help with. Once a week we discuss all the Neurology inpatients at Auckland City Hospital and the Stroke unit. We discuss cases where we got things wrong and try to understand how we could do things better. Once a month we also review our financial situation – to make sure we are not wasting money – and check our waiting lists.

Like everyone else in the world, we are struggling with the issue of email. This might be from the hospital telling us that a lift is broken, or from the University reminding us of a talk coming up or (my least favourite) ACC asking for a report on a patient we saw months ago.

Thrown in there are a group radiology session where we discuss 'interesting' scans and learn from each other's cases or put up scans that we are puzzled by and need each other's help with.

All of us do some teaching as well and some of us try to do research on top of this – a few have specific roles at the University.

There are perks, such as study leave and attending conferences to keep up to date with other doing similar work. The biggest perk though is working with people and their amazing, interesting, fascinating, nervous systems!

Dr. 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.

GUEST speakers

For me it's about risk

DR HUHANA HICKEY

Let's make sure we are well-informed.

The End of Life Choice Bill is interesting for disabled whānau, particularly for those of us who have progressive conditions that can often lesson our quality of life. I am personally a believer in freedom of choice.

However the Bill does not sufficiently protect those of us with significant impairments, from being euthanised if it is considered we are "suffering" or a "burden" on the family and society.

The difference with an End of Life Bill is that instead of you committing suicide yourself, you have someone else do it for you. The current Bill being considered by Parliament does not only apply to terminal cases, it extends the opportunity to disabled, elderly, and anyone else not deemed to have any quality of life by a society that still doesn't value disabled people and consider them as equals.

...disabled people may, when in terrible pain, consider taking steps to be euthanised. Yet, when their pain is managed, evidence shows many don't want to die before their time.

Nobody wants anyone to live in pain or have poor quality of life. The reality is many disabled experience both of these things and ignorance and negative attitudes from society can make it difficult to find acceptance for who we are. Liz Carr, a disabled actor in the UK has good insight. This link will lead you to one of her many discussions on you tube. https://www.youtube.com/watch?v=sRE6Zwq62vc (or you can just search her name).

The risk that sits with the Bill if it becomes law, is that disabled people may, when in terrible pain, consider taking steps to be euthanised. Yet, when their pain is managed, evidence shows many don't want to die before their time.

I don't want to tell you what to think one way or the other. But I do want to encourage you to be well-informed - do some reading and watch some clips of people telling their stories. In particular, look at disability, euthanasia and Belgium. It is insightful. It will also help you to understand why many disabled oppose the Bill, and why many Māori are also opposed.

There are many others who have concerns about the risk to disabled people. If you want to know more and use Facebook, consider going to the Not Dead Yet Aotearoa page, which is a group of disabled advocating for the rights of disabled people in this proposed legislation.

Dr Huhana Hickey MNZM has a background in human rights and disability law, she is currently a post doctoral research fellow at AUT where she is studying the health and disability needs of whānau hauā. She remains committed to ensuring all persons with disabilities and their whānau know of and have access to their rights.

For me, it's about choice

PHILIP PATSTON

I believe in choice, quality of life and dignity.

These are freedoms I value so greatly that I support the End of Life Choice Bill of New Zealand, I am a life member of the End of Life Choice Society of New Zealand (eolc.org.nz) managing its website and social media.

The bill has provoked much discussion in all sectors of New Zealand life, and particularly among the disabled community. I recognise that some people fear the consequences the legislation will have for people with disabilities. Their concern is it might make them feel obliged to end their own lives so as not to be a burden on family, friends and society.

I do not share these views. In fact, I find them a little bit patronising. They imply that I may have such a low sense of worth, that I need to fear being coerced into choosing to die early to avoid being a burden.

I believe disabled people have the same rights to dignity and autonomy as non-disabled people. Disabled people can also suffer from terminal illness. I am disabled and I want the right to PAD (physician-assisted dying) should I reach a point where I am suffering from a terminal illness that is expected to end my life within six months, or have a grievous and untreatable medical condition.

My impairment, or unique function and experience as I prefer to refer to, has nothing to do with PAD. Any bill passed in Parliament would have safeguards to ensure that I myself could not decide, nor could anyone coerce me, to end my life because I was tired of being disabled.

As a staunchly active disabled person, I value equally my right to live and my right to choose to end my life in the case of acute suffering.

I don't think combining the issues of disability discrimination and assisted dying is useful. As a staunchly active disabled person, I value equally my right to live and my right to choose to end my life in the case of acute suffering. If I were to be in a position where my suffering was intolerable, and assisted dying was available, I would want the right to choose to end my suffering.

We as a society should not deny one right by promoting another. I believe that complex issues such as voluntary euthanasia need to be approached on a case-by-case basis, and with love not fear.

Philip Patston is Managing Director of Diversity New Zealand Limited and Chair of Auckland Council's Disability Advisory Panel. Some parts of this piece have been published previously.

GUEST speakers

Taking a break on a big day out.

Lessons learned on Conical Hill

OLIVIA SHIVAS

One of the most memorable parts of my holiday was the few days my family and I spent in Hanmer Springs.

There were eight of us staying in a holiday home, including my dad, brother and a cousin who have a mild form of muscular dystrophy (I'm the only one in my family who uses a wheelchair).

My cousin had the 'brilliant' idea that we should all climb Conical Hill, a one kilometer hike zig-zagging up over bark, stones and tree roots. The first few hundred meters were tough! I needed at least one person pushing from behind and another pulling from the front to stop my wheelchair tipping forward over the tree roots. At every corner my cousin would say, 'We're halfway to the top!' and it seemed impossible at times. We stopped for water breaks often and made sure everyone had a moment to catch their breath.

We had a quarter left of our climb to reach the summit when a group walking past offered their help. Without hesitation, my mum said, 'Yes please!' Two of the guys started pushing me in my chair, but then one of them asked if he could piggyback me because it would be easier than two of them pushing a wheelchair. So I was carried the rest of the way up and plonked onto one of the benches to enjoy the view. The guys waited around so they could carry me back down. The journey was much more relaxing going down as I was able to look around and appreciate the trees without worrying about steering a wheelchair and falling out! I got to know the guys quite well as we chatted on the 20 minute trek; one was a police officer and the other a high school teacher.

When we reached the end of the trail, I thanked them for their help and kindness. They will probably never fully understand the difference their help made to me and my family. I can also say that I've been rescued up Conical Hill by the Police!

I learnt a few things from climbing Conical Hill.

- Firstly, it's okay to ask for help. I'm very independent and can do most things by myself. But every now and then, I do need an extra hand with carrying a heavy object or reaching something from the top shelf of the supermarket. I like to prove to others (and myself) I'm independent, however asking for help doesn't make me less independent. I also think people actually like helping others and want to do so, but just don't know how.
- Secondly, no matter how much of a pickle of a situation you think you are, it will work out in the end. As we were climbing up Conical Hill, I was worried about the trip down. However, I didn't need to stress about that.
- Thirdly, there were times when I thought it'd be easier to just turn around and go home. It was a lot of work for myself and my family pushing the wheelchair; I didn't want them to hurt their backs! But I'm glad we pushed on (literally!) as the view was incredible. I actually thanked my cousin for encouraging (or forcing!) us to climb the hill because it turned out to be a positive experience for everyone.

If you ever want to get in touch, email me at olivia.shivas@gmail.com

Olivia is the Rangatahi representative on National Council. She lives with central core disease and has a passion for seeing young people reach their full potential. Olivia has a Bachelor of Communication Studies and works at Attitude Pictures, a TV production company that promotes the stories of people with disabilities.

Fighting the bugs this winter

MIRIAM HANNA

Q: What can I do now to make sure I stay as healthy as possible this winter?

As we head towards the cooler months, it is important to start thinking about how you are going to keep well when winter bugs descend.

As with any illness, the prevention of winter ails is better than a cure. There are things you can do now to ensure you come out the other end of winter feeling healthy and energised.

Consider getting the flu vaccine. Although sometimes myths do the rounds saying the vaccine may cause illness rather than prevent it, only a very small percent of the population notice any symptoms when given it. It is also important to note that the vaccine changes every year, and if you've had a reaction in the past, you may not have one with the next vaccine.

So, why does the vaccine changes every year,or every other year? Influenza is caused by a virus that mutates (or changes its structure) over time. The World Health Organisation monitors influenza illness throughout the year and makes recommendations on which three influenza types are likely to cause the most illness in the Northern and in the Southern hemispheres during their respective influenza season. Based on this information, pharmaceutical companies develop vaccines that protect against those types. This it's recommended you have the injection each year.

Some people get worried about the vaccine's effectiveness when they still get sick even though they had it. It is important to note that getting a flu shot doesn't mean you won't get sick at all, but it means you won't be as sick as those who are unprotected. Vaccination also helps prevent secondary complications, hospitalisation and even death. That's right, influenza can be deadly. For more information, check out the website www.fightflu.co.nz.

It's also worth considering a pneumococcal vaccine, alongside your flu shot. This prevents inflection with pneumococcal-pneumonia causing bacteria, again preventing severe complications and hospitalisation.

Another medication to add to your cabinet is Buccaline. It's available from your pharmacist and is recommended at the start of every winter. It protects against secondary bacterial complications of influenza and colds for approximately three months.

Boosting your natural immunity is also important. Take plenty of Vitamin C, Zinc, ginger, horseradish, echinacea and Manuka honey to name a few. There are many high quality supplements available from your local pharmacy or health store. Melzest is a cold-busting product newly launched in New Zealand and produced by local company Honeylab. We have a small number of samples available for trial, if you would like to receive one, please get in touch with us by phoning 0800 800 337 or emailing info@mda.org.nz

... if you've had a reaction in the past, you may not have one with the next vaccine.

Now is also the time to start thinking about your home, and whether you need to make any changes to stay healthy during winter. It should be dry and insulated so it is warm over the winter months. If you are asthmatic, ensure you always use your preventer inhaler, and have a reliever close by.

Miriam Hanna is Information and Resource Coordinator at MDANZ and is a practising and registered community pharmacist.

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 1950. 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

Ronelle Baker
Chief Executive

Miriam Rodrigues
Programme and Service Advisor

Brian Hadley
Accountant and Business Manager

Miriam Hanna
Information and Resource Coordinator

Adam Bouman
Executive Assistant

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

Northern Branch


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

Wellington Branch


Fieldworkers: *Dympna Mulroy and Penny Piper*
Office Manager: *Elizabeth McCallum*
Ph: 04 5896626 or 0800 886 626
Email: elizabeth@mda.org.nz

Canterbury Branch


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

Southern Branch

Fieldworker: *Jo Smith*
Ph: 03 486 2066
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

Trevor Jenkin. Ph: 021 267 4380
Email: trevor.jenkin@gmail.com

Wellington Branch

Annelize Steyn. Ph: 021 480 108
Email: kilmarnock.annelize@gmail.com

Southern Branch

Robbie Verhoef. Ph: 021 044 9437
Email: robbie.verhoef@yahoo.co.nz

Canterbury Branch

Warren Hall. Ph: 03 329 4390
Email: warrenjh@xtra.co.nz

Conditions covered by MDANZ

Muscular Dystrophies:

Becker Muscular Dystrophy

Congenital Muscular Dystrophies and Congenital Myopathies

Distal Muscular Dystrophy

Duchenne Muscular Dystrophy

Emery-Dreifuss Muscular Dystrophy

Facioscapulohumeral Muscular Dystrophy

Limb-Girdle Muscular Dystrophy

Manifesting carrier of Muscular Dystrophy

Myotonic Dystrophy

Oculopharyngeal Muscular Dystrophy

Diseases of the Motor Neurons:

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

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

Type 2 Intermediate Spinal Muscular Atrophy

Type 3 Juvenile Spinal Muscular Atrophy (Kugelberg Welander Disease)

Type 4 Adult Spinal Muscular Atrophy

Hereditary Spastic Paraplegias (HSP)

- all types:

Also called Familial Spastic Paraparesis

Leucodystrophies

- all types.

Metabolic Diseases of muscle *- all types including:*

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

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

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

Phosphofructokinase Deficiency (also known as Tarui's Disease)

Phosphorylase Deficiency (also known as McArdle's Disease)

Diseases of the Peripheral Nerve:

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

Dejerine-Sottas Disease (CMT Type 3)

Hereditary Sensory Neuropathy

Inflammatory Myopathies:

Dermatomyositis

Inclusion Body Myositis

Polymyositis

Diseases of the Neuromuscular Junction:

Congenital Myasthenic Syndrome

Lambert-Eaton Syndrome

Myasthenia Gravis

Myopathies *- all types:*

Andersen-Tawil syndrome

Central Core Disease

GNE Myopathy

Hyperthyroid Myopathy

Hypothyroid Myopathy

Myofibrillar myopathy

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

Myotubular Myopathy

Nemaline Myopathy

Paramyotonia Congenita

Periodic Paralysis

Inherited Ataxias:

CANVAS

Friedreich Ataxia (FA)

Spinocerebellar Ataxia (SCA)

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

Central Cavernous Hemangioma

Neurofibromatosis Type 1

Neurofibromatosis Type 2

Schwannamatosis

Tuberous Sclerosis

Von Hippel Lindau Syndrome

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

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