InTouch

KIA NOHO TATA Inclusive | Inspiring | Informative Autumn 20 Issue 105

All in a day's work

Inspiring ideas to fuel your best work

Exploring true work-life balance

+

Finding the right workplace for you

+

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+

Discover workplace support and resources

Muscular Dystrophy New Zealand

InTouch

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

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

Design: The Artset
the.artset@gmail.com

Cover photography:
Hamish Melville
hamishmelville.com

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Korero with Trevor

A new year is the perfect opportunity to look at where your future is taking you and to be inspired by our members' stories of their work and careers.

Christmas and New Year has come and gone, so too the holidays, and our long, summer days already feel like they are fading away.

Were you one of the many that made a list of resolutions for 2020? While there are many common goals for people, such as exercise regimes or taking up a new hobby, have you considered focusing your energy on career development, a complete job change or perhaps even re-training?

A New Year brings new change and now is the perfect opportunity to look into where your future or career is taking you.

Helen Keller said: "I cannot do everything, but I can do something. I must not fail to do the something that I can do."

I encourage you to focus on what you CAN do, just like our members featured in this issue of *In Touch* magazine who share their stories around employment and training.

This may be the very motivation you need to get your own resolutions underway.

We have worked through our planning and budget cycles for 2020 (MDANZ's version of resolutions) and I can assure you that we have another massive year ahead and we hope to deliver many more benefits and services to our members, whilst building the capability of our organisation.

I am looking forward to continuing in my role as the National Executive Chairperson, helping to make a difference for our members. I'll be the first to admit it can be a challenge with a few frustrations, but it is extremely rewarding meeting and working with people in the MDANZ community.

If your resolution includes staying healthy and fit as we head into winter, it is timely to urge you to seek advice about the pneumonia vaccine as MDANZ subsidises the fee for the Pneuomvax 23 vaccine. For more information please email info@mda.org.nz.

I also encourage you to seek advice or support from your fieldworker if you need assistance or guidance; they are there to help you ensure you focus on what you can do.

Hei konā rā, Bye for now.

Trevor Jenkin
National Executive Chairperson

Our beautiful cover

Meet 10-year-old Tana Heke, who is generously fronting our Bake a Difference fundraising campaign (see all the details on page 15).

Tana goes to Te Awamutu Primary School and has three brothers, Nathan, Karehana and Dante. He's the only one in his family with DMD and he loves playing on his scooter or, when he is tired, a bit of PS4 gaming. Tana tells *In Touch*, he loved being a part of the campaign shoot and thought it was cool that he got to be famous. Thank you Tana.

Spinraza in New Zealand: Nearly there

A positive recommendation from PHARMAC may mean treatment for SMA is now in sight for some of those who need it.

All around the world families with spinal muscular atrophy (SMA) are gaining access to treatment with Spinraza. Here in New Zealand the road to funded treatment has been tortuous but a positive recommendation by Pharmac's Rare Disease Subcommittee may be the first sign that treatment is now in the sights of some of those who need it.

In September last year Pharmac's Rare Disease Subcommittee reviewed a resubmission from Biogen for nusinersen (Spinraza) for the treatment of SMA that included revised eligibility criteria and updated clinical trial data.

The recommendation will be reviewed and endorsed (or otherwise) by the Pharmaceutical Therapeutics Advisory Committee (PTAC) in February 2020.

The subcommittee recommended nusinersen be given a high priority for funding, for the treatment of pre-symptomatic infants and children with SMA, subject to certain Special Authority criteria.

This recommendation was based on the absence of funded alternatives, the high health need of these individuals, longer-term evidence of survival gain and meaningful clinical benefit with nusinersen, and that patients with pre-symptomatic SMA had the greatest potential to benefit.

The Special Authority criteria for initiation, and subsequent continuation, of the treatment in pre-

symptomatic infants and children are that the application needs to be made by, or in consultation with, a specialist medical practitioner experienced in the diagnosis and management of SMA associated with a neuromuscular clinic of a recognised hospital in the management of SMA.

All of the following criteria must be met:

1. Genetic documentation of 5q SMA homozygous gene deletion, homozygous mutation, or compound heterozygous mutation, identified via newborn screening;
2. Patient must be pre-symptomatic;
3. Patient must have only two or three copies of SMN2;
4. Treatment must be given concomitantly with standard of care for this condition;
5. In the first 12 months treatment must not exceed four loading doses;

Continued on page 4 ...

Defined signs and symptoms of SMA

Type 1 SMA	i) Onset before 6 months of age; and ii) Failure to meet or regression in ability to perform age-appropriate motor milestones.
Type 2 SMA	i) Onset between 6 and 18 months; and ii) Failure to meet or regression in ability to perform age-appropriate motor milestones.
Type 3a SMA	i) Onset between 18 months and 3 years of age; and ii) Failure to meet or regression in ability to perform age-appropriate motor milestones.

Continued from page 3 ...

6. Patient must be 18 years of age or under;
7. There has been demonstrated maintenance of motor milestone function (as assessed using age appropriate scales: the HINE Section 2, CHOP INTEND, or HFMSE) since treatment initiation;
8. The patient does not require invasive permanent assisted ventilation, which means ventilation via tracheostomy tube for greater than or equal to 16 hours per day.

The subcommittee also recommended nusinersen be funded with a medium priority, within the context of the rare disorders therapeutic area, for the treatment of symptomatic patients with type I, II, and IIIa SMA.

This recommendation was based on the same factors as for the presymptomatic patients as well as the evidence of survival gain for infantile onset SMA and meaningful clinical benefit for all of the symptomatic subgroups considered.

Again, the initiation and continuation of treatment for children with symptomatic type I, II and IIIa requires an application from, or in consultation with, a specialist medical practitioner. Re-assessment is required every 12 months and the same criteria apply as for pre-symptomatic infants and children except that the patient must have experienced the defined signs and symptoms of SMA type I, II or IIIa prior to three years of age.

We will report on PTAC's endorsement in the next issue of *In Touch*.

By Miriam Rodrigues

A real plan of action

The Disability Action Plan will ensure every government agency assesses what needs to be done to close the gap between the outcomes for disabled people and everyone else.

Here at MDANZ we are all proud to have been part of the development of the important Disability Action Plan 2019-2023 and to have had the opportunity to work directly with government to ensure that our members get their rights as citizens upheld.

The plan, which was launched in November by the Minister of Disability Issues, Hon. Carmel Sepuloni, was co-developed by government agencies and the Disabled Persons' Organisation Coalition, of which we are one of seven member-organisations.

This is a plan for all New Zealanders – He waka eke noa (We are all in this together). It will ensure every government agency assesses what needs to be done to close the gap between the outcomes for disabled people and everyone else.

The plan sets out the two main things that will make a difference in the lives of all disabled New Zealanders – the need to collect data and evidence that shows what work needs to be done, and a requirement to engage with disabled people to find the solutions that will lead to the necessary improvements. See https://www.odi.govt.nz/assets/Uploads/R-Cabinet-paper-Disability-Action-Plan-2019-2023.pdf

There are new actions being planned by agencies as part of this Disability Action Plan and there's room for further actions to be added. This is not a closed list of actions to be ticked off over the next four years; it is a framework for making Aotearoa-NZ better.

MDANZ Representatives on the DPO Coalition Dr Tristram Ingham and Bernadette Ingham.

We have thanked all the agencies which have committed to work with our representatives on implementing these actions over the next few years and particularly Minister Sepuloni for her leadership in championing the release of this important milestone.

An eLearning module for GPs

MDNAZ hopes a new online course for GPs will lead to more people getting faster referrals to neuromuscular specialists.

Neuromuscular disorders are rare and most GPs will have very few patients with these conditions. Members have indicated that their GP does not understand their condition well and that they need to be experts in their own condition.

However, people affected by muscle-wasting conditions know that their GP plays an important role in their care. A delayed diagnosis of a neuromuscular condition can be particularly devastating for families and can also mean that people are not able to access the optimum care at the earliest opportunity. It also prevents families from adapting and planning ahead from an early stage.

MDANZ, in conjunction with Muscular Dystrophy UK, has developed a new online eLearning module for GPs. The purpose of this module is to provide helpful information on the presentation and primary care management of muscle-wasting conditions.

This module is case-based and covers how to recognise and manage some of the more common muscle-wasting conditions. It focuses on:

- Duchenne muscular dystrophy (DMD).
- Becker muscular dystrophy (BMD).
- Facioscapulohumeral muscular dystrophy (FSHD).
- Spinal muscular atrophy (SMA).
- Myotonic dystrophy (DM).
- Charcot-Marie-Tooth disease (CMT).
- Myasthenia Gravis.
- McArdle Disease (acute rhabdomyolysis).

MDANZ hopes that this online course will lead to more people getting faster referrals to neuromuscular specialists. Earlier diagnosis will also ensure families get access to the therapeutic approaches currently in clinical trial or development.

The material is presented by the Goodfellow Unit (GFU), an accredited continuing medical education/ continuing professional development (CME/CPD) provider for the Royal New Zealand College of General Practitioners and functions under a tripartite agreement between the Goodfellow Foundation, the College and the University of Auckland.

The unit can be found under e-Learning courses and is titled Neuromuscular conditions at www.goodfellowunit.org. We are working hard to ensure as many GPs as possible are made aware of this course and encourage all our members and supporters to discuss it with their own GPs.

By Dympna Mulroy

Bye Marty and Joanne, hello to Jackie

The MDANZ team is sad to see Canterbury Fieldworker, Marty Price and Southern Fieldworker, Joanne Smith, leave. Marty has been with us for seven years and Joanne for three and a half years.

Marty serviced the top and west of the South Island and will be sorely missed by many members.

We are fortunate enough to be keeping Marty with us as the Duke of Edinburgh Award Leader so our lucky Rangitahi members will still see him around. Thank you for all your incredible work and service Marty. The Canterbury branch will remain in the experienced hands of Fieldworker Paul Graham.

Jo has also been a truly dedicated and loved Fieldworker. Thank you for all your incredible work and service Jo.

But the good news is that in early March Jackie Stewart joins the Southern branch as the Fieldworker. Jackie comes to MDANZ with lots of experience and can't wait to get out and meet the members.

Shave for MDA

Nic Brockelbank celebrated his 18th birthday on February 8 and to mark the occasion, his mother Chrissie and brother Toby both had their hair shaved off to raise money for MDANZ, a cause that Nic has fundraised for since he was 10. By mid-February they had already raised just over $2,000 through a Givealittle page (https://givealittle.co.nz/fundraiser/shave-for-mda) called Shave for MDA and there may well be more to come with the page open until April 8 and the café where Nic works part-time planning to donate their tip-jar for all of February.

Chrissie explains on the Givealittle page that Nic, who has muscular dystrophy, has been raising money for MDANZ since he was at primary school. When he was 10 he had his first cookbook published by Scholastic (*Nic's Cookbook*) and a second book published the following year (*Nic's Lunchbox*).

Nic donates half of the royalties he earns from the sale of these cookbooks to MDANZ.

Chrissy wrote at the time that she wanted to do something to support "this great cause" so to celebrate Nic turning 18 she was shaving off her hair and both she and Toby would have a number zero. "Please help us support this great cause and donate if you can," she wrote.

Toby, Nic and Chrissie Brockelbank.

Central's new team

Michelle and Talitha are both MDANZ members.

The Central Region branch advocates for members supporting other members so they can achieve their goals and Branch Secretary, Bernadette Ingham, says the branch is fortunate to employ a Community Coordinator and a Fieldworker who are both MDANZ members from the region.

Michelle Smith is Central Region's new Community Coordinator (East Coast District) while Talitha Vandenberg is the new Fieldworker for Taranaki/Manawatu.

Michelle moved from Auckland to Hawke's Bay in 2018 for a quieter more balanced life. She has FSHD and uses a power wheelchair and has "the love and assistance of a fantastic husband and a super-smart mobility dog".

She was MDANZ Northern Branch Chair while in Auckland and has also worked for the organisation.

Talitha says her new role is her dream place to be. She is loving meeting members and she says she knows what it's like to have a body that doesn't work like her mind does.

"My body is restricted by the neuromuscular condition known as myasthenia gravis however my heart/determination isn't," she says.

Contact details for Michelle or Talitha are on page 29.

Save the date

The Annual General Meeting of MDANZ will be held on Friday 24th April at 6pm at the National Office, 419 Church Street East, Penrose, Auckland.

Join us for an evening of interesting speakers, and mix and mingle with your National Council, staff and other MDANZ members.

Branch AGMs

Northern: Saturday 21st March, 2pm at National Office.

Wellington: 2pm, Saturday 19th April at Naenae Bowling Club, 25 Vogel Street, Naenae.

Canterbury: Saturday 4th April, 2pm at the Christchurch Community House, 301 Tuam Street, Christchurch.

Southern: Saturday 28th March, 2.00pm at the Cargill Enterprises, Dunedin.

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Annelize Steyn currently works as a diversional therapist in Wellington and loves her job.

Finding true work-life balance: You have to work at it

For Annelize Steyn work-life balance means dealing with the very natural grief and denial that comes as a condition progresses.

Learning to deal with her grief and denial as her condition progressed has meant that Annelize Steyn has focused on a true work-life balance and on accepting that she needs help.

Annelize Steyn, who is now in her 50s, was diagnosed with facioscapulohumeral muscular dystrophy (FSHD) when she was 17. She had been playing netball for her high school's top team and began struggling with shoulder weakness. She says that, in a way, she is a text book case of deterioration.

"I have gradually used aids along the way in a progressive manner. First a walking stick, then walking frame, a wooden trolley, various other aids, a manual wheelchair and then into an electric one."

She says she struggled for a long time, dragging her wooden trolley around. "I would hold onto it for my dear life. It need not have been that way. It was like a ripple effect of thinking that I was coping, when I was not."

She says she used to stretch herself too far at work. "As a result, I would return home at the end of the day completely mentally and physically exhausted. Weekends were spent needing lots of time resting in bed instead of with my family."

Annelize eventually got an electric wheelchair which she says changed her life, at home at least. She still didn't take the chair to work "and continued to live in denial".

Annelize currently works as a diversional therapist for Enliven in Wellington, which offers Presbyterian support for those living with a disability. And she loves her job.

But while she was persevering without the electric chair at work, she had a fall one day which proved to be a turning point.

"I had to speak to my manager about my needs [which] I had been avoiding for a long period of time. Even though they had always been very supportive, I had pre-conceived ideas as to what they were going to say.

"After 13 years being employed there, I thought I wouldn't be able to work there any longer."

But that thinking didn't last five minutes. She and her husband, Herman, met with management who immediately said it was fine to bring her wheelchair into work. Being in a rest home meant that the common areas were set up for wheelchair access.

"In terms of staff areas, I needed easier access to the staff room and my desk height had to be adjusted. I have changed a few things around and I have put my folders down low. I don't 'feel' my wheelchair anymore, I don't let it define me."

And she says she knows she could have done better in the past in terms of reaching out for help from health professionals.

"I was in denial for many years and it didn't help my ability to cope. I really want to emphasise how important it is to maintain a healthy work/life balance. I realised that I had to get to the point where I was forced into making changes rather than managing my needs."

Throughout her life, Annelize says that she was functioning really well up until her FSHD progressed to the point where weakness in her legs meant she started tripping and then falling.

"I really didn't deal with my grief and denial in terms of the progression of my condition. If I had reached out earlier then I may have got an electric wheelchair and not gone through that period of gruelling struggle.

"MDANZ has options for funded counselling which I would highly recommend. In terms of denial, spending time with my fieldworker was really helpful. Dympna was so very supportive. She sat through hours of tears with me and was such a professional when assisting me. I am very thankful for her help."

Annelize also says it is important to surround yourself with others with disabilities.

Annelize is a proud grandmother of six.

If I had reached out earlier then I may have got an electric wheelchair and not gone through that period of gruelling struggle.

"Reach out to your local community, spend time with others with disabilities, join a support group. I was also on [National] Council for a few years, I had the opportunity to meet so many amazing people. I learnt so much from them all."

She has also adjusted her diet to help manage her fatigue.

"I believe that it is all elements of your health that you need to reflect on. It's a full circle, your spiritual, emotional, physical [aspects] all come into play.

"Adapt your life, where you can, to work for you. We are so individual and our coping mechanisms are so different, you need to find what works for you on your own journey."

In 2018 Annelize had the opportunity to do the Be.Leadership course which she says was incredibly beneficial.

"I have gained so much courage. It has changed my 'faulty thinking'. Through discussing my grief and denial I have grown a lot stronger."

She is now looking forward to doing the More to Life Organisation's More to Life course which she says examines the relationship between mind, body, and spirit, and the way our habitual beliefs and unconscious fears conspire to stop us from becoming our most authentic and creative selves.

And her advice about work?

"Whether you're in work or not, look into studies and online courses. Gain as much knowledge as you can. In terms of proactively managing your existing career see other avenues within your career path, that offer an office or computer- based role.

"I am in a fortunate position now that I am a team leader that I have a team around me that can fill in the parts that I cannot physically do myself. It's a real team effort and I am grateful for that."

She has also just started to tap into funded support at work through Workbridge, where you can have someone come in for an hour or two a day to help with any part of your role that you can no longer do.

"There's support out there that we don't always know about it. Stay in the system and reach out. I feel very lucky to be part of MDANZ."

Originally from South Africa Annelize moved to Auckland in 2000 as she fell in love with a man in New Zealand. Herman has four children ranging in age from 28 to 40-years-old and she says she's very proud to call them her three daughters and one son and is a proud grandma of six.

"I am proud to be part of such a supportive and amazing family that are so accommodating."

All that said she doesn't want anyone to think she is super woman.

"There are different layers of coping, one moment you can be on top of the world and then we can come crashing down. The goal posts are constantly shifting," she says.

Annelize at work.

Annelize's employment journey

Annelize Steyn started her working career in office administration and later moved to study counselling full time at Manukau Institute of Technology.

She told *In Touch* that she chose counselling as her career path and that she loves group facilitation.

"Work with your fieldworker and identify what you can cope with in terms of considering your career path. There are funding options for study too, don't let that be a barrier to enrolling."

When her husband was transferred to Rotorua Annelize began working with community mental health services, specifically with elderly people with mental health challenges.

Herman's later transfer to Wellington, saw her apply for the job at Enliven which included good training options.

She is currently completing her diversional therapy papers, noting that diversional therapists work with people of all ages and abilities to design and facilitate leisure and recreation programmes.

Asked about advice for those who might be finding it hard to find employment, she says there are many technical institutes that offer training. "Once you have a job take up in-work training such as Careerforce in-work training (www.careerforce.org.nz).

"Always look for ways to upskill and actively manage your career path to allow for possible progression of your condition. There is also volunteer work available and get involved in your community. There are lots of community programmes available at low cost," she says.

A flexible and supportive work environment

Finding the right workplace for you

For young job seekers it's a matter of not giving up at the first hurdle, says Latifa Daud.

Finding work for any new graduate is not always not easy, but it can be even more challenging if you are managing a neurological condition.

Twenty-six-year old Latifa Daud, who lives in Auckland, has Charcot-Marie-Tooth disease (CMT) and has used a wheelchair full-time since she was 14-years-old.

But that hasn't stopped her from working in jobs she enjoys and where she feels supported by organisations that are prepared to be flexible enough so she can manage her condition.

Latifa started university after high school and completed a Bachelor of Arts majoring in English literature before going on to do a post graduate diploma in communications at Auckland University of Technology.

But after graduating it took her about a year to find employment.

She agrees that it was a long process and it was very frustrating.

"I knew that I wanted to be in an industry that wasn't toxic and would give me the flexibility I needed in order to manage my condition."

She had been following developments at Be.Accessible (now renamed to Be.Lab) for some years and when a job advertisement popped up, she applied and was successful in gaining an administration role with the organisation.

She tells *In Touch* that once she had been with Be.Accessible for about six months, she also took on the marketing and communications role and says it was a very supportive organisation to be a part of.

Latifa was with Be. for about two years before moving on to a project co-ordinator role at a public sector organisation.

Latifa Daud's day-to-day tasks involve finance, communications and "quite a bit of co-ordination behind the scenes".

"It made me feel valued and inclusive. They want me for my skills and that feels great."

Her day-to-day tasks involve finance, communications and "quite a bit of co-ordination behind the scenes".

When she first started at the organisation a year ago, there were a few adjustments that needed to be made to her workplace.

"Because my office is located upstairs, they put in a water cooler for me so that I didn't have to try and venture back down to ground level."

Other small things needed adjusting too.

"The door of my office always needs to be kept wide open so that I can get in and out more easily."

So how she did she feel about the organisation making the adjustments required and their workplace flexibility?

"It made me feel valued and inclusive. They want me for my skills and that feels great.

"In terms of managing my condition the work hours are very flexible.

"This makes it easier for me to manage my fatigue. It's a case of, as long as I complete the required work and the hours outlined, they are happy.

"If something needs repairing on my wheelchair then I can work from home. My manager is very understanding and great to work with."

But Latifa isn't sitting on her laurels.

In 2018 she completed the Be.Leadership programme which she says was a valuable course that has given her a lot of confidence.

"The year-long programme gets you thinking of leadership in a different realm. It makes you challenge the rest of the world as it is. You obtain the skills to deal with different situations you may come across when it comes to accessibility. It teaches you a lot. It teaches you to be quite perceptive."

She completed the course with the help of funding from MDANZ's (now renamed) Bradley Jenkin Discretionary Fund.

So, is there anything she's learnt from her employment career so far that would be helpful to other MDANZ members seeking employment for the first time?

"Just keep at it," she says. "It can be incredibly frustrating, but something will come along. Don't give up."

An incredibly enriching experience

Study as an adult has changed Stephen Jones as a person

Access and resource difficulties haven't stopped Stephen Jones from succeeding at both full-time work and in his studies.

Fifty-four-year-old Stephen Jones, who was diagnosed with limb girdle muscular dystrophy in his late teens, has just completed a law degree, returning to university after many years working as an accountant.

And while returning to study has been far from straight-forward, Stephen would encourage anyone to find a way to do it.

"It's not all plain sailing, it is going to be hard, but it's incredibly enriching. The stress you get when an essay is due and then the adrenalin from submitting an essay you've worked so hard for, is so rewarding," he tells *In Touch* from his Wellington home.

"I had the honour of being asked to be the only graduate speaker at my graduation [in December last year]. To be in the presence of incredibly intelligent young people every day was really a privilege."

But he is not stopping there. Once he gets his professional papers done he would like to do a Masters' degree, although there are still a few barriers to overcome.

"Typing is a big issue for me," he says of having to type long essays, noting he will need to get a voice-activated configuration set up. Car parking can also present problems.

But he feels more mentally invigorated than he has in 20 years.

"It really has changed my outlook on life. My daughter is my main support, she is amazing. She is currently studying early childhood education and we have some great discussions when it comes to social justice.

"I really feel that the having the opportunity to study as an adult has changed me as a person. It has made me a more understanding and respectful parent and grandparent."

Stephen Jones had the honour of being asked to be the only graduate speaker at his graduation. Photo credit: Te Herenga Waka, Victoria University of Wellington.

While he has just graduated in law, Stephen started his working life as an accountant. And the seed for that may have been planted when he was very young and was given a Monopoly set for his birthday.

His parents said, at the time, that the way he played the game and chased up the payments meant he would been an accountant one day.

That comment must have resonated and when the time came to decide whether he was going to follow his passion for woodwork and become a cabinetmaker or go to university, it was university he chose.

"I was diagnosed in my final year at college with limb girdle muscular dystrophy and made the conscious decision to go down the academic path."

He graduated with a commerce degree specialising in accountancy in 1988 at a time when a disability service was pretty much non-existent.

"There were limited services available for me at the time I studied. You could have a 15-minute break for a cup of tea in the middle of your exam, that was about it," he says.

"I was diagnosed in my final year at college with limb girdle muscular dystrophy and made the conscious decision to go down the academic path."

"I made the decision to specialise in business advisory services rather than the auditing side of things as this would require me to move from place-to-place too much. At the time I was using a walking stick as an aid."

He won a position at a chartered accountancy as their first graduate and worked there for many years.

"At the time I worked there I had an electric armchair made especially for me through another MDANZ member. It had an air compressor fitted so that it made it easier for me. I also had supportive work colleagues who would help me getting up off the toilet."

He jokes that sometimes they would forget he was there and he would get left for a while.

In 1998 Stephen took on a role as a commercial manager at another organisation and had to make a decision in terms of his mobility.

"I had to decide whether I was going to take my armchair with me and have to be dependent on others picking me up, or giving me a hand to stand up, or to get an electric wheelchair.

"This was a time of me re-carving out my support network and establishing people I would call on for help."

The organisation built new accessible toilets while he was there but "it amazes me that they didn't ask for my opinion or to provide any insight. They didn't use my knowledge".

A restructure in 2011 meant a move into a different area within the organisation and before he took the new role any issues in terms of accessibility were discussed.

"In the three years I worked there they didn't put any of the things they had promised into place. In saying this my boss at the time was great to work with," he says.

Another restructure meant an opportunity for Stephen to decrease his workload to 20 hours a week so that he could start his law degree and he says a six-month adjustment period moving from full-time paid employment was a great way to manage his finances and work towards his goals.

He admits starting to study again brought challenges around having the right desk to work at and the first couple of times he sat an exam were quite daunting.

But he would encourage anyone wanting to study to find a way to do it and he emphasises the very real personal and professional rewards it brings.

Muscular Dystrophy
New Zealand

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Workplace support and resources

There's a range of support measures to help you get into work. By Dympna Mulroy.

The following information has been taken from the Employment New Zealand website https://www.employment.govt.nz/ and FIRSTPORT www.firstport.co.nz

Supported employment agencies are located across New Zealand and help people with a disability to find and keep a job.

Workbridge: Workbridge is the largest supported employment agency in New Zealand that gives employers access to a wide talent pool of people with a disability, injury, or illness. They can help you develop job searching skills and find the most suitable employment for you. They also administer government funding schemes to support a person with a disability undergoing a period of assessment, work experience, training, or education as part of their plan to gain open employment. https://workbridge.co.nz/

New Zealand Disability Support Network (NZDSN): On the NZDSN website there is a list of supported employment agencies such as Workbridge which you can search for by region or by disability. They can help put you in touch with an agency in your area. www.nzdsn.org.nz

Workwise Employment Agency: Supports people with mental health conditions to return to work and to stay in work. It has several offices in the North Island, and one in Christchurch. www.workwise.org.nz/

Be.Employed: One of the services provided by Be. Accessible. It is a career pathway programme, designed specifically for New Zealand's tertiary qualified access students. Be.Employed facilitates 12-week paid employment opportunities for undergraduates and graduates looking for meaningful work experience in their areas of study and/or aspiration. Applicants must be living with an access need or disability, have completed study in the last 12 months and be in either penultimate or final year of tertiary study. https://www.belab.co.nz/be-employed

Be. Leadership: A programme through Be. Accessible that offers participants a unique opportunity to realise and develop leadership potential, self-awareness and the skills and attributes needed to create meaningful change. It is not directly associated with employment but can help people grow and develop skills that may influence their work performance and employability. https://www.belab.co.nz/be-leadership

The New Zealand government funds a range of employment and employment related services and support for people with disability, including training and apprenticeships. Help is available for preparing to look for work, looking for a job and, if needed, ongoing support once in a job.

There is a list of all government-funded or supported services and support, including those provided by contracted private or NGO groups on the Employment New Zealand website https://www.employment.govt.nz/ under "Resources and government support for disabled employees and jobseekers".

Other things to consider

Benefits while working: The income a person earns from their job can affect their benefit amount. Work and Income may grant an exemption for severe disablement. See more information on the Employment New Zealand website under "Financial help and wages" or from your local Work and Income office.

Sustainable employment trial: If you receive the Supported Living Payment and would like to see how you feel going back to work, you can try it out through a sustainable employment trial. You can work 15 hours a week for half a year to test how you feel and you don't lose any of your benefits.

Employment Transition Grant: This is a weekly payment which helps some people who have completed a sustainable employment trial.

Work Bonus: Work Bonus is an incentive payment available if you choose to work even though you don't have work obligations as a condition of your benefit. You may be able to get Work Bonus if you were getting a Supported Living Payment because of poor health, an injury or disability.

Working with a neuromuscular condition

People living with a neuromuscular condition remain under-represented in our labour market

A new study explores the rates of employment of people with myotonic dystrophy and identifies the factors that influence their work performance. By Dympna Mulroy.

Seeking and maintaining suitable work is a challenge for many people with a neuromuscular condition. In my capacity as a fieldworker for many years I have listened to many stories of the difficulties in obtaining and maintaining work.

I therefore decided to explore the rates of employment and identify what factors influence work performance for people with myotonic dystrophy. This condition was chosen as it is one of the most common neuromuscular conditions in New Zealand, however some of the findings can be considered with other groups of neuromuscular conditions. [A total of 202 people took part in the study of whom 69 were employed at the time.]

The importance of paid employment is central to an individual's self-worth. It creates a sense of identify and purpose, contributes to economic self-maintenance, home and family maintenance, personal development and can represent our contribution to our community, workplace, or society.

Yet people living with a neuromuscular condition or disability remain under-represented in the New Zealand labour market.

Findings from the 2013 New Zealand census showed that only 45 percent of people living with a disability are employed on either a part or full-time basis compared with 72 percent of non-disabled adults.

Importantly 74 percent of those who were not employed said they would like to work if a job was available (Stats NZ Tatauranga Aotearoa, 2014).

Employment rates

The results of my study indicate that the employment rate for people with myotonic dystrophy was significantly lower at 34.2 percent in comparison to the national rate at 45 percent of all disabled adults employed in New Zealand.

In this study more than half of the participants felt that their genetic condition directly affected their employment at some stage, often due to difficulty working the required number of hours or withstanding the physical demands of the job.

Some unemployed participants expressed their desire to work but faced difficulties in looking for jobs to suit their capabilities. Those that had secured a job appeared to be performing well, which is encouraging from an employer's perspective and for people seeking work.

Work performance factors

Work performance was broken down into four demand levels - physical, time management, mental-interpersonal and output. The main factors influencing work performance were pain, depression, fatigue, sleep, physical and cognitive functioning. Of these pain and fatigue had the most impact on a person's ability to perform at all four levels – time management, output, interpersonal-mental and physical.

The biggest impact these factors had was on the physical demands of the job. This was mainly due to symptoms of fatigue, functional limitations, and pain.

Mental-interpersonal demands in a job were also affected due to the impact of cognition, mental wellbeing (depression/ anxiety), pain, fatigue and sleep on work performance.

Fatigue was found to be the most debilitating factor in work performance. Higher levels of fatigue were associated with poorer work outcomes and performance. Thus, focusing on treatment strategies for fatigue may have a knock-on effect on many performance areas.

Adaptations

Some of these physical demands could be minimised with the correct support, intervention, and equipment such as environmental adaptations or flexible work conditions.

Work environments that are flexible to employees' needs and adaptable to alternative ways of working e.g. changes to work schedules, remote working, flexible work hours, and ergonomic assessments may enable more people to remain in employment for longer and were beneficial for people in the study.

Supporting individuals in these work adaptations or seeking alternative work opportunities would reduce the occurrence of early retirement when people were no longer able to perform the demands of their current job but wanted to maintain a career.

For this to happen people need to feel supported and safe to disclose their condition and have a good relationship with their manager and colleagues.

Participants experience

The participant narratives highlighted mixed experiences of disclosing information about their condition to an employer.

Support from employers and colleagues and their attitudes and understanding of the person's needs were key factors for some people in maintaining their job.

However, the disclosure of their condition was a barrier for others who felt they would be confronted by their ability to perform and thus continued to hide their concerns and learnt to adapt to new challenges.

As per the policies and legislation, employer expectations and employees' needs should be considered to supply adequate provision of support, as necessary.

This was not always the case as one participant stated:
"If I make or ask for changes, they will ask questions. I am currently managing most of the time at work."
(Female 61 years.)

A small percentage of participant's employers were aware of their limitations and did not expect them to do work that was too demanding.

Support from colleagues was also important for some participants to help them overcome physical work challenges.

People who were no longer able to meet demands in their role struggled to seek new employment due to their condition or lack of experience in other fields. Societal acceptance and prejudices of living with a long-term disability were perceived as an employment barrier. Previous work experiences led to feelings of rejection, lack of confidence and self-esteem to apply for future jobs.

"I feel employers do not want to hire me as my condition may affect how I work. When I told them about my condition, they stopped giving me work. This

happened on two occasions. It knocked my confidence and self-esteem." *(Male 21 years.)*

As a result of these experiences and difficulties maintaining work, many participants sought early retirement or discontinued work from an early age (before the age of 50).

Some never achieved work status due to perceived or environmental barriers and past negative experiences trying to secure a job. Access to vocational therapists at an early stage could help alleviate some stress for the employer and employee by implementing timely strategies and adaptations to the work environment.

Exploring work challenges and available supports is an important conversation starter that should be revisited throughout the person's work career.

Future practice

Forward planning and timely input are valuable. Early intervention is key for physical, mental, and cognitive issues such as fatigue management, pain management, and cognitive training.

This support should be ongoing with vocational rehabilitation oversight as their condition changes. More than half the people in this study had not made work adaptations but expected that they would need to in the future.

Therefore, people may only need input at various stages of their career due to the slow progressive impact of symptoms, especially in midlife (30-40 years of age).

Knowing who to go to for support may empower individuals to reach out for assistance and overcome work demands. Exploring work challenges and available supports is an important conversation starter that should be revisited throughout the person's work career.

Educating employers about the skills a person can offer and initiating an early conversation about adaptations and modifications to enhance work performance is important. Ongoing monitoring from a vocational therapist, employer or employment support agency should occur to ensure timely intervention when required.

People diagnosed at a younger age are in a position to make career choices that are less physically demanding and more sustainable to their long-term needs.

Education was a significant factor in determining rates of employment in this study. Even if a significant disability is present those with a higher level of education have an increased chance of employment *(Madej-Pilarczyk, 2014)*. The provision of career counsellors for teenagers, or adults at an early stage in their diagnosis, may help them make realistic and sustainable career choices. Supporting young people to gain an education and understand the long-term benefits this can have on their employment opportunities is important.

A range of strategies such as volunteering, internships, work placements, and approaching organisations in person for a work trial, might enable a person to re-enter the workforce and build up their work experience and résumé.

Since the introduction of individualised funding in New Zealand, and more recently Enabling Good Lives and system transformation, people with disabilities have more flexibility and choice in how they utilise their allocated funding from the government.

Providing choice and control to disabled people may enable more of them to utilise funding to source out employment and volunteering opportunities in their community.

A positive outcome of this study was that most of the participants who are employed are performing well. It indicates that with suitable environmental conditions, and support, a paid occupation could be achievable for others.

MDANZ fieldworkers are available to support you when seeking work or to advocate with you when meeting employers to discuss your condition, adaptations, work limitations and strengths.

SMA counts

The only prevalence and incidence study of spinal muscular atrophy in New Zealand is currently underway.

How many people in New Zealand have spinal muscular atrophy? How many children and adults get diagnosed with spinal muscular atrophy in New Zealand every year? Which types of SMA do they have?

The only prevalence and incidence study of spinal muscular atrophy in New Zealand is currently underway.

Clinician researchers Associate Professor Richard Roxburgh, Dr Gina O'Grady and genetic counsellor Miriam Rodrigues are seeking to answer these questions with the help of paediatric neuromuscular nurse specialist Sharron Meadows and a team of researchers from the University of Auckland.

They're measuring the incidence of SMA, which is the rate of newly diagnosed cases over a period of time such as one year.

They're also describing the prevalence of SMA - the actual number of people (children and adults) alive, diagnosed with the condition at a particular date in time.

The NZ NMD Registry is the major source of ascertainment for the study so if you have SMA and want to be counted please ensure you're enrolled on the NZ NMD Registry – check with your MDA fieldworker or email nznmdregistry@adhb.govt.nz (R)

NZNMD REGISTRY

Pregnancy in NMD

A highlight of the TREAT NMD conference held in Leiden, Netherlands in December was the session dedicated to pregnancy in neuromuscular disorders.

A patient, a clinician, and a researcher each shared their knowledge and experience of pregnancy in NMD with all three emphasising the overall lack of knowledge and expertise in this area.

The main things women with neuromuscular conditions seek advice on when considering pregnancy are:

Fertility; genetic risk and disease severity for the baby; pregnancy course; mode of delivery; anaesthesia and medications.

And most importantly; the course of their own condition after pregnancy.

And yet there is very little valid information for most neuromuscular conditions.

Physicians rely on their personal experience (if they have any) but tend to be very conservative and most of the existing information available is based on retrospective studies.

There is a call to include pregnancy data in the existing TREAT NMD registries. If you'd like a copy of the full report *Pregnancy in NMD* please email info@mda.org.nz (R)

Calpain 3 – what's that?

If you have limb girdle muscular dystrophy type 2 A (now known as LGMD R1) calpain 3 is the missing or defective protein that lies at the root of your progressive muscle weakness.

How? This is unknown and is the subject of a research grant awarded by the Coalition to Cure Calpain 3 (C3) to Dr Antoine DuFour, Assistant Professor of Physiology and Pharmacology at the University of Calgary.

His project, titled *Unbiased Systems-wide Investigation of Calpain 3 in Patients with LGMD2A/R1 Using Mass Spectrometry*, aims to better understand the biological role of calpain 3 in skeletal muscle.

Calpain 3 belongs to a class of proteins called proteases. Proteases have the ability to cleave other proteins. Dr Dufour's project aims to identify the proteins cleaved by calpain 3.

To do this, his team will use a technique called mass spectrometry to screen all of the proteins present in muscle cells to identify which are cut by calpain 3.

Muscle samples from not only LGMD2A/R1 mouse models but patients as well will be analysed. Screens will also be performed to identify changes in protein expression and the role of calpain 3 in signalling to other proteins.

This project has the potential to help us more fully understand the biological function of calpain 3 and how its dysfunction leads to LGMD2A/R1. (R)

Friedreich Ataxia

Friedreich Ataxia is a rare condition, yet is the most common form of inherited ataxia, with one-in-50,000 people affected. Compiled by Miriam Rodrigues.

Friedreich Ataxia (FA or FRDA) is a slow, progressive disorder of the nervous system and muscles, which results in an inability to co-ordinate voluntary muscle movements (ataxia).

This condition is caused by the degeneration of nerve tissue in the spinal cord and of nerves that extend to peripheral areas such as the arms and legs. FA affects the upper and lower limbs as well as the head and neck. There is a loss of sensations in the arms and legs, but mental capacity is not affected.

The onset of symptoms of FA usually occurs in childhood between the ages of five to 15 years, however may appear as early as 18 months or as late as 40 years of age.

It is a rare condition, yet is the most common form of inherited ataxia, with one-in-50,000 affected. FA affects males and females equally.

FA reduces normal life expectancy of the individuals, usually due to associated conditions, such as heart disease and diabetes. However, some people with less severe symptoms of FA often live through into their 60s or 70s.

What are the features of Friedreich Ataxia?

The first symptom to appear in FA is usually difficulty walking (gait ataxia).

This gradually worsens and eventually spreads to the arms and the trunk.

Individuals may over- or under-extend the leg when it is brought forward in walking, and feet may be lifted higher than necessary and brought down too hard. The use of a cane or other walking aids may be required.

Over time, muscles begin to weaken and waste away, particularly in the feet, lower legs, and hands. Frequent falls and difficulty controlling the hands will result in increased clumsiness. It may become increasingly difficult to perform tasks such as writing, getting out of chairs and climbing stairs.

FA affects the upper and lower limbs as well as the head and neck.

Foot deformities such as club foot, involuntary bending (flexion) of the toes, hammer toes (curled toes), or foot inversion (turning inward), high arches of the foot (pes cavus) may develop. These usually do not pose a problem in themselves, though if problems do arise, bracing or surgery can be beneficial.

Although progression varies from individual to individual, the ability to walk is often lost within eight to 10 years from the onset of symptoms, making it necessary to get a wheelchair. Options can be assessed by an occupational and/or seating therapist.

Other symptoms include loss of tendon reflexes, especially in the knees and ankles. There is often a gradual loss of sensation in the fingers and toes, which may spread to other parts of the body.

The muscles controlling speech can be affected, resulting in slow and slurred speech (dysarthria). Speech therapists may provide beneficial support for this.

Rapid, rhythmic, involuntary movements of the eye (nystagmus) can also be common.

Scoliosis, an abnormal curvature of the spine, can become an issue and can impair respiration. Spinal bracing may be required, and in more severe cases spinal fusion surgery. An

orthopedic specialist is essential in monitoring the scoliosis.

Conditions associated with Friedreich Ataxia

There are conditions associated with FA that do not result from the degeneration of nerves.

Cardiac problems are common and are present in approximately 80 percent of FA individuals and arise from various forms of heart disease that often accompany FA. These include cardiomyopathy (enlargement of the heart), myocardial fibrosis (formation of scar tissue in heart muscle) and heart failure.

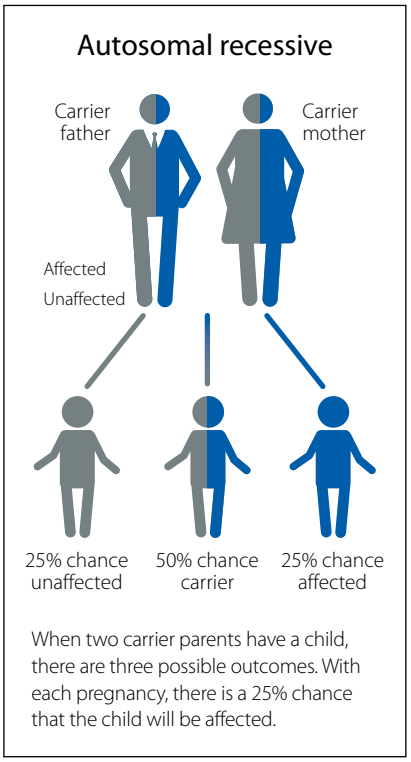
Symptoms can include chest pain, shortness of breath, and heart palpitations. Other heart rhythm abnormalities may be present, such as a fast heart rate (tachycardia) or a heart block, which is the impaired conduction of electrical impulses, necessary for the contraction of the heart. Cardiac problems can be treated with medication, though severe forms of heart disease can be fatal.

Diabetes mellitus is a condition characterised by abnormally high blood and urinary sugar levels. About 10 percent of individuals will develop this and will experience increased thirst, hunger and urination. This can be managed with diet and medication, such as insulin.

What causes Friedreich Ataxia?

FA is an autosomal recessive disorder.

Humans have 46 chromosomes made up of genes. Each chromosome, which is a tightly coiled chain of DNA (deoxyribose nucleic acid) contains millions of chemicals called bases. The four bases are adenine, thymine, cytosine and guanine (A, T, C and G), which pair together in sets of three to form coded messages. These messages are instructions for producing proteins that make the body function.



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

In FA, there is a defect in a gene on chromosome 9. In 98 percent of cases there is a triplet repeat expansion of the GAA sequence of bases. A greater number of repetitions is related to earlier onset and faster progression of the disorder.

The corresponding protein that is altered due to this repeat is called frataxin and is produced in diminished amounts. Frataxin is found in energy-producing parts of cells called mitochondria. When frataxin levels are low, cells (particularly in the brain, spinal cord, and muscle cells) cannot produce energy properly and the build-up of toxic by-products leads to "oxidative stress", which has the potential to destroy cells.

In FA, this "oxidative stress" affects nerve cells in the spinal cord and the peripheral nerves, which connect the spinal cord to muscles and sensory organs. This results in failure to stimulate some muscles, which will eventually weaken and waste away (atrophy).

There is also damage to the cerebellum, which is a small structure at the back of the brain which helps to plan and co-ordinate movements. Combined, these problems lead to the progressive losses of muscle strength, sensation, balance and coordination that characterise FA.

Diagnosis of Friedreich Ataxia

Diagnosis usually commences after the identification of key characteristics of FA. Several tests are available to confirm diagnosis of FA and associated conditions:

- Physical examination – test of reflex and sensory responses.
- Electromyography (EMG) – observes the electrical activity of muscles and its consistency with activity typical of individuals with FA.
- DNA testing – can identify the presence of the abnormal gene in the individual with FA as well as carriers.
- Nerve or muscle biopsy – can confirm diagnosis.
- Nerve conduction studies – measure the speed with which nerves transmit impulses.
- MRI (magnetic resonance imaging) or CT (computed tomography) scan, which maps the brain and the spinal cord. ®

Finding the many different ways to reach your goals

Joseph Boon, who has Friedreich Ataxia, believes it is important not to give up on what you want to do. He says just know that there are many different ways to get there and that you'll have to strategise and you'll have to think.

Joseph Boon really isn't letting anything stand in his way. Not long before *In Touch* went to press Joseph was selected as the Green Party's candidate for the Rangitīkei seat. He says he is looking forward to meeting the challenge of campaigning in such a large, rural electorate.

Here is his story.

My parents started to really notice when I was showing the same symptoms as my older brother. I kept losing my balance, I couldn't throw a ball very far or hold a drink.

In the beginning our parents thought that things would improve with time and that maybe it was dyspraxia. But the symptoms were getting worse and occasionally I would lose my balance completely and not know why.

That is when a family friend, who was a GP, did some research and arranged an appointment for us to see neurologist Richard Roxborough.

I travelled up to Auckland from Palmerston North with my parents and my younger sister and brother and met with Richard who conducted a series of clinical tests. He was pretty sure he knew that it was Friedreich Ataxia (FA).

The diagnosis was confirmed with a genetic test. It was a complete shock, it seemed to change everything. I was 17-years-old at the time. It was devastating for us all as my sister and brother also received the same news. [Joseph is now 29.]

The diagnosis was confirmed with a genetic test. It was a complete shock, it seemed to change everything. I was 17-years-old at the time.

Mum wanted to protect us so she really didn't want us to go on the internet and start looking things up. But our millennial tendencies kicked in and my sister and I jumped online when we were at school.

We started researching and breaking it all down, to try and understand what it all meant. After being diagnosed we felt very much on our own, but this soon changed when we became members of MDANZ.

Joseph Boon

We have somewhere we feel like we belong and can contribute to help others with neuromuscular conditions. It's so much better now because when someone receives a diagnosis they are directed to MDANZ for support straight away and the FA clinic is up and running.

The reality is that there is no cure and it is going to keep getting worse but there is lots of research going on and we will beat it at one point or another. Being with MDANZ means you can be a part of that.

Back in early days it was things like losing my balance, staggering and not

be able to hold things like a cup of tea that were problematic. I then started to develop scoliosis which was very painful and physically obvious.

I underwent surgery to have my spine fused. Post-surgery I went on to live in Wellington so that I could attend university. I walked with a cane and had to really try and manage my fatigue.

By the time I got to my third year I had to drive to uni, I then had to walk from my carpark to my lectures but I would fall asleep in the middle of them as I was thoroughly exhausted.

That was the point where I decided that I really needed to see about getting a manual wheelchair. It was a weird thing to see an occupational therapist and they are saying things like "but you're still walking".

The point is I am so glad I didn't wait until I could no longer walk. The whole process took so long to get the chair, 18 months in fact!

Since completing my Bachelor of Film and Political Science degree, I have moved back home and have been in various jobs, along with an unpleasant experience working for one organisation.

I have since realised how passionate I am about social issues especially those surrounding disability services. I am also very focused on advocating for the arts and live theatre and making this more of a focus in our community.

I have been a member of the Green Party for a year now and see that I can really make a difference. [At the time of writing his story Joseph had put his name forward for nomination as a candidate and was "eagerly awaiting the results".]

When I was 17 and thinking about what I might do with my life I thought I might make movies or go into Parliament. But things that happened in my early 20s meant I lost sight of that a bit, although I have since come back to the knowledge that I still really can put that goal in place.

Having a mobility dog has opened-up lots of possibilities for me. I would love to be one of the first to have a mobility dog in Parliament. Now that would be something.

Due to the nature of FA you must accept things will always be changing.

I recently attended a Mobility Dogs training camp where I was united with my dog Shelby for the first time. She really has been a game-changer. Funding through the Bradley Jenkin Memorial fund has enabled me to provide care for Shelby's needs and I am very grateful for that.

Having a mobility dog has opened-up lots of possibilities for me. I would love to be one of the first to have a mobility dog in Parliament. Now that would be something. I'm going to have a good crack at it!

People with FA learn to adapt, it's the nature of our condition so we are used to constant change, but it's about not walking away when you are presented with a barrier.

I recently went to an event where there was access via stairs only. I got friends to carry my wheelchair up and I proceeded to crawl up the stairs. I didn't hide away, I confronted it. Strangers carried the chair on the way back down.

Just before Christmas I fell out of my wheelchair and dislocated my shoulder, I spent seven hours in the A & E department in extreme agony. It was a terrible experience. If there's anything to take from that I think that you need to voice your needs.

I consider myself to be a mild-mannered person. I don't like to be verbal and put pressure on people, but when it comes your health, don't be afraid to utilise your resources and speak out.

Contact your friend who is a GP, ask for help, call in favours, ask for someone more experienced. Understand who your advocates are and they will fight for you. You need to get people on your side.

The important thing is that you figure out how to achieve your goals. Don't give up on what you want to do.

Just know that there are many different ways to get there.

You'll have to strategise, you'll have to think, but you can make it!

Keep your head up and just keep moving forward

Dean Finch says that talking to your children and family about your condition will help them understand what is going on.

I found out nearly 12 years ago when I was 26-years-old that I had Friedreich Ataxia (FA). My brother was diagnosed first and soon after, when I went for a genetic test in Dunedin, I was also diagnosed with FA.

As to how he felt about the diagnosis Dean says: "What can you do about it. It is what it is, you just have to keep going, moving on".

Dean, now 38, says that the most obvious thing to him before being diagnosed was that he was "no good on my feet, after I'd had a few drinks".

There was nothing else major that was obvious to him but after being diagnosed it made sense and explained why his balance had been so off.

Dean has worked full time for a local timber yard for the past 14 years and has had to adjust a few things about his job.

"My day-to-day tasks at the yard used to involve quite a bit of manual labour. I've changed roles to a slightly different part of the yard so it involves more forklift driving."

Dean, who lives in Milton, just south of Dunedin, has three children who are 11, seven and five and Dean says they keep him busy.

When he spoke to *In Touch* he'd just been bike riding with his oldest son. They are beginning to be a good help and understand more about his condition.

"FA is pretty unknown in New Zealand I guess. It's good that they are starting a clinic in Auckland.

The funded counselling sessions, available through MDANZ, were very beneficial.

"I have been taking part in a drug trial and have been backwards and forwards to Australia for the past 18 months for that. I've taken two of my sons over with me on my trips. They were asking questions about what was going on so I decided to involve them.

"If you have young kids help them to understand so they have the right information."

Dean says the funded counselling sessions, available through MDANZ, were very beneficial.

"It was good talking to someone to get another perspective, not just on my condition, life in general really.

Dean Finch with Jasper, one of his three children.

"Also knowing you have a fieldworker to talk to is great, there's someone there to support you if you need it.

"We're all so different, everyone's experience is different with FA. Just keep your head up, keep moving forward.

"The more you talk to your family and friends about it, the more they will understand.

"People are so quick to judge. I'm probably not the best walker but people see you and they don't know what is wrong with you and presume different things," he says.

Ask the **PANEL**

Help grow a better understanding of FA

CLINIC CO-ORDINATOR
KERRY WALKER

Anyone affected by Friedreich Ataxia is eligible to be part of an international study which is an important step in moving towards getting treatments which will change the course of the disease.

The CBR Neurogenetics Research Clinic is very pleased to now be a site for the Friedreich Ataxia Clinical Outcomes Measures Study (FACOMS). This study has been ongoing in the USA and Australia for many years now, and many New Zealanders have been travelling to Melbourne to take part in the study and be seen at the Friedreich Ataxia Clinic there.

There are several reasons we are excited to be participating in this study. Firstly, New Zealanders with Friedreich Ataxia (FA) are often not seen in the public system as regularly as they could be, and when they are seen by a health professional, this person is not often an expert on FA.

However, the main reason is that this study is an important step in moving forward with the work of getting treatments which will change the course of the disease.

The aims of the study are to gather specific clinical data on an annual basis, so that we can better understand the condition and how its changes in symptoms can best be measured.

Treatments which affect the course of the disease may be small at first and knowing how to measure small, but real, effects may be important in making progress in disease treatment.

Secondly, the doctors (led by A/Prof Richard Roxburgh) and the Rehab team (led by neurophysiotherapist, Julie Rope) will be developing further local expertise in FA and be able to pass that knowledge on to other health professionals around New Zealand.

This will also enable each participant to have a plan which they can implement through their medical and rehab teams.

Taking part in the study involves a yearly visit to the clinic at The University of Auckland Medical School campus in Grafton. Each visit takes approximately two to three hours, with the first being the longest.

At each visit, participants see a neurologist or a study doctor, neuro-physiotherapist and an occupational therapist.

The doctor goes through a thorough medical history and neurological exam. The neurophysiotherapist and occupational therapist assess mobility and physical symptoms through some standardised assessments and tests.

Participants will also be asked to complete some questionnaires about how FA affects them, which can be done online before, or after, the clinic appointment.

We also encourage participants to ask any questions about Friedreich Ataxia or their current symptoms, treatments, or any tests they may have had done.

The neurophysiotherapist and occupational therapist will provide information about treatment going forward, and how to access that in the area the participant lives in.

If you have been participating in Melbourne and would like to continue this, you do not need to move to the

(L to R): Kerry Walker (senior clinical research coordinator), A/Prof Richard Roxburgh (neurologist and lead investigator), Miriam Rodrigues (NZ Neuromuscular Disease Registry), Julie Rope (neurophysiotherapist and co-investigator), Barbara Croawell (FARA NZ) and Dianne Boon (FARA NZ).

Ask the **PANEL**

Auckland site. However, if you would like to participate in Auckland from now on, please let us know.

If you have not participated at the Melbourne site, but would like to enrol as a new participant in Auckland, we would also love to see you.

We will be contacting anyone who is eligible using the NZ Neuromuscular Disease Registry, so if you are enrolled, we will be in touch directly.

If you are not enrolled, but would like to be, please visit: https://www.mda.org.nz/Our-Research/NZ-NMD-Registry

Anyone who is affected by FA and who lives in New Zealand is eligible. We are currently only able to see adults but are looking to enrol children in the future.

To help with travel for those people who live outside of the Auckland area, FARA New Zealand has generously awarded funding to allow all New Zealanders to attend.

For further information phone 09 923 8652 or email cbr.nrc@auckland.ac.nz

We acknowledge the funding provided by the Duncan Trust for the Rehab team.

Kerry Walker is the senior clinical research coordinator at the CBR Neurogenetics Research Clinic.

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Muscular Dystrophy New Zealand

Muscular Dystrophy New Zealand

About us

MDANZ is a trusted source of specialist information and provides a range of free services and practical support for individuals, families and whānau with lived experience of rare neuromuscular conditions.

The Muscular Dystrophy Association of New Zealand Inc., commonly known as MDANZ, began in the late 1950s. Since then MDANZ has broadened its scope to support many other neuromuscular conditions. We are proud to have Judy Bailey and Dame Susan Devoy as our longstanding patrons.

Our unique governance structure ensures leadership of the organisation by individuals and family members with lived experience of a neuromuscular condition. We have four regional branches that are supported by the National Office based in Auckland.

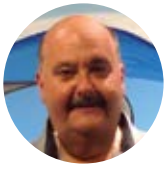
We want New Zealanders with lived experience of neuromuscular conditions to experience freedom of choice in a responsive society.

To achieve this mission, we provide;

- Free information and advice, through our website, an 0800 info line and in paper booklet form
- A nationwide fieldworker service for personalised support
- Free loan of resources, such library books, recreational beach chairs and cough assist machines
- Funded support for counselling
- Discretionary funding for life enhancing resources not covered by government
- A high quality quarterly magazine to inform and inspire our membership and broader communities of support
- Funding for neuromuscular research and a mechanism to help New Zealanders to access clinical trials and new treatments
- Education workshops for members, health professionals, schools and others
- Advocacy and lobbying at a community or national level
- A platform for support groups and peer to peer networking

MDANZ is a registered charity and relies almost entirely on donations from the public, trusts and other businesses/ organisations to continue its work in the community.

Our core team



Trevor Jenkin
National Executive Chairperson

Miriam Rodrigues
Programme and Service Advisor

Brian Hadley
Accountant and Business Manager

Dympna Mulroy
Special Projects Coordinator

Natalie Foote
Marketing and Communications Manager

Anita Giordani
Marketing Assistant

Amelia Noyes
Fundraising & Admin Assistant

Shelley Butler
Accounts Assistant

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

Northern Branch


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

Central Branch


Fieldworker: *Talitha Vandenberg* (left)
Community Coordinator
(East Coast District): *Michelle Smith* (right)
Ph: 0800 886 626
Email: members.central@mda.nz

Canterbury Branch

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

Southern Branch

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

Council Representatives

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

Northern Branch

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

Central Branch

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

Southern Branch

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

Conditions covered by MDANZ

Muscular Dystrophies:

Becker Muscular Dystrophy
Congenital Muscular Dystrophies and Congenital Myopathies
Distal Muscular Dystrophy
Duchenne Muscular Dystrophy
Emery-Dreifuss Muscular Dystrophy
Facioscapulohumeral Muscular Dystrophy
Limb-Girdle Muscular Dystrophy
Manifesting carrier of Muscular Dystrophy
Myotonic Dystrophy
Oculopharyngeal Muscular Dystrophy

Diseases of the Motor Neurons:

Spinal Bulbar Muscular Atrophy (Kennedy's Disease and X-Linked SBMA)
Spinal Muscular Atrophy - all types including Type 1 Infantile Progressive Spinal Muscular Atrophy (also known as Werdnig Hoffman Disease)
Type 2 Intermediate Spinal Muscular Atrophy
Type 3 Juvenile Spinal Muscular Atrophy (Kugelberg Welander Disease)
Type 4 Adult Spinal Muscular Atrophy

Hereditary Spastic Paraplegias (HSP)

- all types:
Also called Familial Spastic Paraparesis

Leucodystrophies

- all types.

Metabolic Diseases of muscle *- all types including:*

Acid Maltase Deficiency (also known as Pompe's Disease)
Debrancher Enzyme Deficiency (also known as Cori's or Forbes' Disease)
Mitochondrial Myopathy (including MELAS, MERRF, NARP and MIDD)
Phosphofructokinase Deficiency (also known as Tarui's Disease)
Phosphorylase Deficiency (also known as McArdle's Disease)

Diseases of the Peripheral Nerve:

Charcot-Marie-Tooth Disease (CMT) (Hereditary Motor and Sensory Neuropathy) - all types
Dejerine-Sottas Disease (CMT Type 3)
Hereditary Sensory Neuropathy

Inflammatory Myopathies:

Dermatomyositis
Inclusion Body Myositis
Polymyositis

Diseases of the Neuromuscular Junction:

Congenital Myasthenic Syndrome
Lambert-Eaton Syndrome
Myasthenia Gravis

Myopathies *- all types:*

Andersen-Tawil syndrome
Central Core Disease
GNE Myopathy
Hyperthyroid Myopathy
Hypothyroid Myopathy
Myofibrillar myopathy
Myotonia Congenita (Two forms: Thomsen's and Becker's Disease)
Myotubular Myopathy
Nemaline Myopathy
Paramyotonia Congenita
Periodic Paralysis

Inherited Ataxias:

CANVAS
Friedreich Ataxia (FA)
Spinocerebellar Ataxia (SCA)

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

Central Cavernous Hemangioma
Neurofibromatosis Type 1
Neurofibromatosis Type 2
Schwannamatosis
Tuberous Sclerosis
Von Hippel Lindau Syndrome

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

Spinal disorder - Mobility impairment - Walking impairment - Arthritis - Multiple sclerosis - Cerebral palsy
Neurology - Muscular dystrophy - Amputation - Parkinsonism - Back pain - Stroke - Restricted growth

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