



Muscular Dystrophy Northern

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<http://www.facebook.com/#!/profile.php?id=100000800815656>

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**Bowtie Week
22nd—30th
March 2014**

Christmas Party 1st December

Our Christmas party this year is on Sunday 1st December, 11am at the Papakura RSA, Elliott St, Papakura.

A Christmas buffet with ham on the bone, roast chicken, vegetables, salads and sticky date pudding is \$22.50 for adults with children \$1 per year of age up to 12 years (jelly and ice cream for their dessert).

Otherwise there is an a la carte menu to choose from.

Santa will be arriving at 11.30am with presents for the younger children.

Please RSVP 28th November.

Office Hours:

Our office will be closing on Friday 20th December and re opening on Monday 13th Janu-

ary. MDN staff and committee members would like to thank all



of our members, funders and others who have supported us so generously over 2013. We

look forward to being of assistance to you with our Fieldworker service in 2014.

Our two Fieldworkers, Darian and Kristine are here to help members and their families with any issues they may be experiencing.

It might be assistance with Winz benefits, accessible housing or housing modifications, information relating to a specific condition or just general disability information.

Please make use of this service that is provided free of charge for our members. We are here to help in whatever way we can.

Wishing you and your families a very Merry Christmas and a safe New Year.

Short Story Competition

Last year's short story competition was very popular so we've decided to do it again!

Deadline: January 17th 2014

Fee: \$5 per story (all proceeds go to MDN)

Open to everyone. All topics/themes welcome. Win-

ner published in In Touch Magazine

For details and an entry form, contact Muscular Dystrophy Northern Branch:

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Making the Most of a Health Passport



“Quality
medical service
delivery comes
down to
remembering
human
experiences and
having empathy
for them”

Medical people sometimes forget. They forget every patient is different. They forget to listen when the patient tells them his or her needs. They forget to pass on the message, that they don't know everything they need to, and that they will need to go beyond “normal procedure” for somebody with a neuromuscular condition. Sometimes it can feel like they forget the patient is human! But the reality is, medical people sometimes forget because they are human too. And they are busy and overworked and often inexperienced with neuromuscular conditions. So what do we do about it?

Well, the Armageddon Expo organisers were kind enough to give us free passes recently and some of our members did make friends with the Daleks... but wheeling through hospital halls shouting “Exterminate!” in a full frontal assault might not be the best approach.

As individuals, we can ensure that we plan for any hospital stay with information, support people, and equipment organised well in advance.

Even if you don't intend on

a hospital stay any time soon, make a plan for in case of emergency.

We can also make use of the Health Passport programme. The idea of this is that you keep all your relevant information in one “passport” that you take with you. This provides a source of information for medical staff when you're unwell and unable to deliver it yourself.

Check out www.hdc.org.nz/about-us/disability/health-passport for more info.

Recently, MDN member Tegan Morris and I delivered lectures at the University of Auckland's School of Nursing.

I've been fortunate enough to be invited to speak to nursing classes there for a couple of years now, and I consider it a hugely valuable opportunity.

We get to catch nurses at the start of their careers, while they're still learning, and teach them about neuromuscular conditions in a way that will inform their work habits later on.

We talked to these student nurses about MDA, neuromuscular conditions, the fieldworkers service,

how to work with people who have neuromuscular conditions, and – most importantly – what it's like to have one. Then we opened the floor to all the questions they might have but might not be comfortable asking a patient.

There have been some curly questions! For Tegan about what it's like to live with her condition and for me about management details and about how being married to someone with a condition affects our relationship. We answer them as best we can.

I believe that hearing about these things and understanding the challenges of neuromuscular conditions from a human perspective – not just from a textbook – will help them remember when it counts, later on.

Because, in the end, quality medical service delivery comes down to remembering human experiences and having empathy for them. And that human might be you.

Darian Smith

Thank You!

ASB Community Trust

Bay Trust

Bluegrass Trust

COGS

HOG Auckland Chapter

JM Thompson Trust

Lion Foundation

Lottery Grants Board

LW Nelson Trust

Newmarket Rotary

NZ Community Trust

Outsource IT

Pelorus Trust

Southern Trust

Trillian Trust

Trust Waikato

Wel Energy

Accessible Gardening

“Sunshine on my shoulders makes me happy”, sang John Denver. I expect most of us can relate to that. Sunshine also makes going outside much more pleasant (as long as it isn't too hot, that is). Which brings me to gardening.... What better way to spend one's spare time?

The benefits range from exercise right through to stress relief. A flower garden will bring joy and beauty to your life and if you have a vegetable garden you get the added benefit of being able to eat

what you grow.

I recently checked out four retail outlets (Bunnings, Kings Garden Centre, Mitre 10 and Palmers Garden Centre) and found that Kings and Mitre 10 stocked a range of hand tools from Finland suitable for those with reduced hand strength.

Some of these tools have a power gear which makes them up to three times as easy to use—secateurs, pruning shears and extending loppers.

They are certified for ease of use and are a design award winner. True, they are a little bit more expensive than some other brands but with a full lifetime warranty you would expect that.

If you were to combine such easy to use hand tools with a raised garden bed of at least 60cm in height and hard surfaced garden paths of at least 1m wide, gardening could easily become a productive hobby of yours. I recommend it.

Kristine Newsome

“A flower garden will bring joy and beauty to your life”

News and Events

North Shore Coffee Group:

Next meeting Wednesday 27th November, 10.30am at Mitre 10, 260 Oteha Valley Rd, Albany. Guest speaker Phil will be talking about gardening for people with disabilities. Please contact Kristine if you would like a lift to either coffee group.

Central Coffee Group:

The second Thursday of each month. Next meeting 12th December 10.30am, Hollywood Bakery, Manukau Rd, near the Lido Cinema.

Room to let:

Large, sunny room available in a Glenfield house for an independent person with a mild

disability (house not wheelchair accessible). Part of a bigger complex administered by the Lagacy Trust. Evening meals provided Mon-Fri. Further information from tessamullane@gmail.com or phone 027 618 2725.



Did You Know?

Power Buddy:

The “Power Buddy” lets you charge your phone and other electronic devices from your electric wheelchair. Check out <http://dme.co.nz/>



news.aspx?newsID=40 for more info.

Transition Funding:

Transition funding is available for those who have been ORRS funded at school with “very high needs”.

This is a substantial amount (around \$15,900 a year) aimed at assisting the transition from school into the community and can be used for purchasing laptops, phones, equipment, travel, social outings, etc.

Talk to Elevator or other transition services providers about

this.

<http://www.elevator.org.nz/For+Candidates/Leaving+School+Transition+Services.html>

Duchenne Muscular Dystrophy:

There's an interesting exploration of Duchenne Muscular Dystrophy on Youtube, here: <http://www.youtube.com/watch?v=wVvNmBW5kgs>



Muscular Dystrophy Northern (MDN) provides a Fieldworker service that aims to do the following:

Muscular Dystrophy Northern

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Phone: (09) 415-5682

Free phone: 0800 636 787

E-mail: support@mdn.org.nz

- Home based visits
- Support for new diagnoses
- Referrals to appropriate agencies
- Advocacy and support
- Liaising with other services to coordinate clients needs
- Information and knowledge on Neuro-muscular Conditions
- Facilitating social contact with others
- Attendance at multi-disciplinary clinics

Providing Information and Support to people with Neuromuscular Conditions and their families.



Celebration Corner

Michael Wilson is a purposeful man who achieves what he sets out to do. He recently completed a horticulture course over a 3 year period on a part time basis, simply for his own interest.

Michael lives with his family on five acres. He also has Limb Girdle muscular Dystrophy. Formerly he was a dairy farmer but realized when he was diagnosed in 2007 that he needed to make a different plan for his future.

Four years ago he and his family moved from the farm onto their current land and Michael put in a good sized vegetable garden.

It has a screened off area with six raised beds, each with a fruit tree at the end. These he has planted in discarded truck tyres and has painted them bright green. He also grows potatoes in old car tyres.

In between the raised beds, clucking happily are eighteen very healthy



looking brown hens. They keep the family well supplied with eggs.

In addition, Michael raises his own

seeds and plants them in newspaper seed pots he makes himself from the local paper, as it's exactly the right size, he says. This is a skill he picked up from the horticulture course. Michael's crop includes beetroot, broccoli, carrots, corn, garlic, lettuce, peaches, potatoes and tomatoes.

The local school benefits from Michael's knowledge and experience. He has been volunteering his time there once a week with the children for the last three years and is known as 'Gardening Mike'.

A couple of years ago a giant pumpkin of 180 kilos was produced. More recently Michael organized a grant to install raised beds at the school.

Kristine Newsome