



# Muscular Dystrophy Northern

VOLUME 1, ISSUE 31

JUNE 2014

### Contact Details:

PO Box 300-429

Albany, Auckland 0752

Lion Foundation House,  
3 William Laurie Place,  
Albany, Auckland

(09) 415-5682

0800 636 787

(0800 MDN Support)

support@mdn.org.nz

Charities Commission  
registration number:  
CC29049

Join us on Facebook!

[http://  
www.facebook.com/#!/  
profile.php?  
id=100000800815656](http://www.facebook.com/#!/profile.php?id=100000800815656)

### INSIDE THIS ISSUE:

Importance of Respite 2

Respite Providers 2

News & Events 3

Fieldworker Visits 3

Going for Gold 3

Powerchair Football 4

## Thank You to our Funders

Finding enough money to keep our service running is always a struggle. MDN doesn't receive any government funding so the money required to keep our service going is mostly sourced through Charitable Trusts and other funding bodies.

To supplement this we also have our annual Bowtie Appeal Week and it's great to report that the amount raised for this year has now exceeded \$5,000. Thank you very much to all of our dedicated members and supporters who helped raise this amount by taking boxes, doing stalls and other fundraising/awareness raising activities.

Thanks also to everyone who has already paid their annual donation to MDN. We have included the donation form with this newsletter for anyone else who wishes to make a donation. Remember that you can make a claim against this on your annual tax return.

We also still have a few Entertainment Books left, great value for anyone who likes to go out for dinner occasionally or visit various attractions around Auckland. The Books only cost

\$65 each and that money is recouped if you use it just a couple of times. For the first time there is also a downloadable option for Smart Phones. Contact the office for further information.



**Thank you very much to the following funders without whose support we would not be able to operate:**

ASB Community Trust  
Auckland Airport Community Trust  
B.A Lewis Trust  
Bay Trust  
Bluegrass Trust  
Bluesky Trust  
COGS  
Endeavour Community Founda-

tion  
Four Winds Foundation Ltd  
Geoffrey & Nell Esme Adams Trust  
Hamilton City Council  
HOG Auckland Chapter  
Infinity Foundation  
James Seale Say Foundation  
JM Thompson Trust  
Lion Foundation  
Lottery Grants Board (Auckland & Waikato)  
LW Nelson  
Newmarket Rotary Club  
NSPH Trust  
NZ Community Trust  
Outsource IT  
Pelorus Trust  
PUB Charity  
Sargood Bequest  
Southern Trust  
Trillian Trust  
The Trusts Community Foundation  
Trust Waikato  
Wel Energy

## Short Story Winners

First place: The Magic Boy by Nod Ghosh.

Second place: Fighting Dragons by Lesley Ayers.

Third place: Meat for Tea by Lynne Roberts.

Congratulations to our winners and everyone else who took

part.

Thanks also to Judy Bailey for judging the results.



## The Importance of Respite...

Respite is a strange word. It's sometimes fraught with emotion. Partners and parents can feel guilty about taking time out for themselves and worry that their loved one may feel abandoned. A person with a disability may worry that they will have an unpleasant experience or not be cared for properly. Often, though, the reverse is true. A good respite experience is an enjoyable break for both parties and allows for a valuable opportunity to recharge.

We need to consider how we view respite care. The medical viewpoint tends to focus on the things that are wrong so they can be fixed. From this perspective respite is seen as a solution to a problem... but that makes it sound like caring for a loved one with a disability is a problem

that needs solving. The danger is that it can feel like making use of respite is saying "you're a burden and I need a break." And nobody feels good about that message!

In reality, respite is about maintaining something that is already working well. It's the WOF and tune up of your relationship as carer/caree. We don't want to wait until things break down. A strengths-based approach – that is, focusing on what is working and helping to do more of that – looks at respite care as part of a supportive process that keeps the partnership running smoothly.

We all need rest to perform at our best. We have sleep, weekends, and holidays built into our working lives to help achieve this. Relationship

experts advise couples to take time out for themselves as individuals and as a couple away from their children (even when those children are not dealing with a disability). The same applies here. Taking care of oneself is a vital part of taking care of others. That's what respite is about. So how can we make the most of it?

**Take it before you need it.** You don't wait for your car to run out of gas before refuelling, do you? Why do the same to yourself?

**Investigate the options.** Not all respite care options will suit all people.

**Provide information.** Make sure the respite care provider you have chosen has all the information about what your needs are and how

best to provide the care required. They want to do a good job! Ask your field-worker to do an education session with them about your condition if need be.

**Plan ahead with people you know.** See if you can arrange respite days in common with friends so the person going into respite care has someone with them that they like to spend time with.

**Enjoy the space!** Both of you get a chance to do your own thing for a while. Enjoy that! Think about what you might like to do during that time.

**Enjoy the return.** Do something nice together when the respite time is over and appreciate what you have.

*Darian Smith*

All respite funding requests go through Taikura Trust or your local Needs Assessment Agency



## Respite Service Providers for Auckland

### Respite Service Providers:

All respite funding requests go through Taikura Trust or your local Needs Assessment Agency.

A Supported Life: adolescents / adults with intellectual challenges (09) 836 1740  
[www.asupportedlife.co.nz](http://www.asupportedlife.co.nz)

CCS Disability Action  
[www.ccsdisabilityaction.org.nz](http://www.ccsdisabilityaction.org.nz)

Creative Abilities & Assoc Ltd (09) 444 0608  
[www.creativeabilities.co.nz](http://www.creativeabilities.co.nz)

Idea Services  
[www.ihc.org.nz](http://www.ihc.org.nz) (Very High

Needs Provider)

Laura Ferguson Trust (09) 524 0537 Respite 16+  
[www.lauraferguson.co.nz](http://www.lauraferguson.co.nz)

Masada (09)5765229  
[www.masada.org.nz](http://www.masada.org.nz)

Northland holidays: Northlink Trust offers care and support services to people travelling in Northland who needs assistance with personal care.  
Dove's Tail Tourism 09 430 3406 [www.dovetail.co.nz](http://www.dovetail.co.nz)

NZ Care Group Ltd (16 – 30yr) (0800 227 348) [www.nzcare.co.nz](http://www.nzcare.co.nz)

Oasis: is a disability respite service through the Open Home foundation. We cater for children from 5 to 20 years who have a variety of disabilities. Helen (09) 624 2057 or email

[Helen.williams@ohf.org.nz](mailto:Helen.williams@ohf.org.nz)

Open Home Foundation: (09) 634 2057 [www.ohf.org.nz](http://www.ohf.org.nz)

Renaissance: (09) 250 4346 email [in-fo@ren2001.co.nz](mailto:in-fo@ren2001.co.nz)

[www.renaissancegroup.co.nz](http://www.renaissancegroup.co.nz)

Spectrum Care: (09) 634 3790

[www.spectrumcare.co.nz](http://www.spectrumcare.co.nz)

# News & Events



A few Hamilton members enjoyed a night out for dinner timed with Darian's visit. If anyone would like an opportunity to do something similar in their area please let us know.

### Mid Winter Functions Auckland & Hamilton

Saturday 19th July at the Swanson RSA, 12pm. Buffet lunch for \$16.50 and children \$1 per year of age up to 12 years. RSVP by 15th July.

Sunday 6th July at the Hamilton Workingmen's Club, 11.30am. Come along and meet the MDN Committee. Buffet lunch for \$10 (large plate) or \$8 (small plate). RSVP by 22nd July.

### Coffee Groups

North Shore: last Wednesday of

the month, 10.30am, Hollywood Bakery, Westfield Albany.

Central Auckland: second Thursday of the month, 10.30am, Hollywood Bakery, Manukau Rd, Epsom.

All welcome!

### Disability Electoral Forum... are you being heard?

For individuals with disabilities and their families. Monday 30th June from 10.30am-1pm or 6pm-8.30pm. University of Auckland, Faculty of Education. Music Auditorium B Block (Gate 3), 74 Epsom Ave, Epsom. Parking in car-park building (Gate 2). Register with Parent & Family Resource Centre, ph (09) 636-0351 or email [pfrcadmin@pfrc.org.nz](mailto:pfrcadmin@pfrc.org.nz). Topics include: Housing, NASC, Employment, Income, Health & Education.

### Buzz Surveys

Do you like doing quick online surveys? If so you can help raise money for MDN. We currently have 40 supporters who have raised \$457 for us. To register go to <http://www.buzzthepeople.co.nz/helpfundraise.aspx?s=3082E89E>

### Max Hales

Congratulations to Max Hales for doing so well with his shooting.

Max had been selected to travel to Thailand for the World Cup but unfortunately the event has had to be cancelled due to the coup.

We wish Max all the best for his future competitions.

### Community Lunch

Any Wednesday there is an open invitation to MDA members and friends to the Rawene Centre Community Lunch on **Auckland's North Shore**.

This is \$4 for a main and dessert. The location is accessible and the food is wholesome and freshly cooked by MDA member Alex Malcom.

Just mention you are member of the MDA. 33-35 Rawene Street, Birkenhead ([map](#)) menu available on [Facebook](#)



## Fieldworker Visits

### Kristine

Kristine will be visiting Rotorua and surrounding areas in June, and would like to invite you to share dinner at the Citizens Club, 1146 Rangiuru St, Rotorua 3010 (corner Rangiuru and Arawa Sts) on Thursday 19<sup>th</sup> June at 6.30pm.

The Citizens Club is accessible. Food prices are varied, depending on what you order.

It will be a night out and also a chance to meet other members of the Muscular Dystrophy Associa-

tion in the central North Island.

If you can get back to us so that we have an idea of numbers, Kristine can organize enough places at the table. Also if you need a ride, perhaps we can arrange lifts, etc.

Kristine

### Darian

Darian will be in the Bay of Plenty from the 17th-19th June and in Waikato from the 28th—30th July. Please call the office if you would like a visit.



Darian and Kristine with Melanie Hopley MDA's new National Service Leader.

**June dinner for members in the Rotorua area on Thursday 19th June at the Citizens Club.**

# Powerchair Football

I had my first turn at Powerchair Football at our Family Camp in March this year...and I am hooked!



Players at the MDN Family Camp held in March.

teams of four players use power chairs to attack, defend and spin kick a 13 inch football in an attempt to score goals'. APFC website.

rule which essentially means that there is space around the ball without everyone trying to get to it at once.

There are other rules but I'm still learning what those are!



I've always known about the various powerchair sports that members play but I guess I've been busy with small children and their pursuits to find time to play any kind of sport myself.

I am still very much learning but can see the definite skill level from the players who have been around for some time.

'Powerchair Football is a competitive

team sport for people with physical disabilities who use power wheelchairs. The game is played in a gymnasium on a regulation basketball court. Two

There are a few key rules to remember, number one being that this is supposed to be a



Fitting a plastic guard to the front of the wheelchair.

'non contact' sport (although there are occasional crashes). Apart from trying to avoid hitting other players I am trying to get to grips with the '2 on 1'

Each wheelchair is fitted with either a metal or plastic guard as this protects the footplates (and people's feet) if there is any contact.

The Auckland team practices at the Otara Spinal Unit every fortnight alternating on either a Saturday or Sunday and new players are always welcome.

See [www.apfc.co](http://www.apfc.co) or check out their Facebook page for more information including a promotional video and a practice calendar.

New teams are being organized for Whangarei and Hamilton.

Email Chairperson Trevor Jenkin for more information:

[Trevor.Jenkin@gmail.com](mailto:Trevor.Jenkin@gmail.com).

Denise Ganley