



Muscular Dystrophy Northern

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New Committee for 2013

Thanks to those who came to our AGM on the 28th April. Our new committee is as follows: Chairperson: Trevor Jenkin, Treasurer: Andrea Clive, Secretary: Joy Jenkin, Committee members: Lew Pulman, Jeanette Brock, Brooke Clive, Barbara Hart, Mike Pulman and Cherie Reinders.

Our new committee members are from Whangarei, Auckland, Thames, Rotorua and Te Kuiti so we have a great geographical spread throughout our region.

CHAIRPERSON—TREVOR JENKIN

My name is Trevor Jenkin I am the father of a 14 year old boy with Duchenne Muscular Dystrophy. I am married to Joy and we own our own successful business.

We as a family have been associated with the Muscular Dystrophy Association for the past 12 years and with Muscular Dystrophy Northern since its formation.

I was elected to the position of Vice Chairperson of MDN in 2011 and again in 2012, and at the recent MDN AGM on the 28th April 2013 was elected Chairperson and Northern Branch representative on the National Council.

I am also the President of the Auckland Powerchair Football Club which promotes and runs

powerchair football games in the Auckland area.

I have been very active within MDN helping organise and attend family camps, Christmas Parties and many other events. As well as the normal committee stuff this gives me the opportunity to get out there and meet other members, talking to them understanding their views and expectations of MDN.

I also like to be actively involved in supporting MDN's many sponsors and funders in their



Trevor Jenkin: Chairperson Muscular Dystrophy Northern

events to show we as a membership do appreciate all they do for us.

I also get around to as many expos and other disability sector events as I can to show a presence as I think awareness is another important part.

I wish to continue to do all of

the above now as Chairperson and encourage any members to contact me if they want to get a message to the committee or even to our National council.

I am only too happy to help and please if there is something we are not doing right, tell me. I need to know so we can at least try and put it right, in saying that I also like to hear things we are doing or have done right from our members.

Within the next year I will be trying to get around and meet as many members as possible so if you know of an event that a few members will be at please let me know or let our Office Manager Denise Ganley know so I can attempt to be there.

All the very best to you all lets make 2013/14 a great year for MDN.

Below are my contacts please use them.

Trevor.jenkin@gmail.com

PH/TEXT: 021 267 4380

Thank you to the Trillian Trust for funding this newsletter.





Darian Smith, Fieldworker for Auckland, Waikato and Bay of Plenty.

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 Club
 NZ Community Trust
 Pelorus Trust
 Southern Trust
 Trillian Trust
 Trust Waikato
 WEL Energy

The year is speeding past and, to quote the TV show, *Game of Thrones*: Winter is coming. Now's the time to prepare, if you haven't already.

Things to think about include:

Flu vaccine. This is free to people with neuromuscular conditions and well worth the investment. While there are lots of rumours and misinformation about vaccines, this is still one of the best things you can do to protect yourself against a range of flu viruses and reduce the need for hospital admissions due to further complications.

Insulation in your home. The EECA Energywise insulation grant offers up to \$1300 towards the cost of insulating eligible homes. The rest of the cost can be paid off over time from as little as \$7 a week. Many people with neuromuscular conditions tell me they

feel the cold more intensely than other people so this is a good opportunity to help stay warm. For more information on this, check out

www.energywise.govt.nz

Another option for keeping warm is making use of battery powered electric slippers, gloves and jackets. A kind of new generation electric blanket, these items make use of a small cellphone-type battery to keep you toasty warm for a few hours at a time. Check out www.3volt.net, www.coreheat.net or <http://www.revzilla.com/gerbings-core-heat> for more information or to order these items. I suggest buying extra batteries to last you through the day.

Once the physical needs are taken care of, it's also worth thinking about the emotional ones. Bad weather and dark days can make

for a miserable time. Planning activities and setting goals to work towards gives something to look forward to in the dreary months. Get creative. What can you achieve over the next few months? Over the rest of the year?

On that note, I'm keen to celebrate the achievements and successes of our members, so let me know what you're good at so we can be part of the cheering squad! I know we have excellent shooters, writers, gamers and more among our number. I'd like to start acknowledging those skills here. Flick me an email at darian@mdn.org.nz and tell me what you've done. Nothing like some good news stories to keep us warm and cheerful. After all, Winter might be coming, but Summer is too!

Darian Smith

News & Events

Bowtie Week

Thank you very much to all of our members, supporters and businesses who supported



our Annual Appeal. To date MDN have raised over \$4,500.

Van Wanted

Toyota, Nissan or similar. Hightop van, automatic with electric wheelchair ramp. Please phone Des Dawson 09 437 0707.

Counties Manukau Special Needs Support Group

Do you have a child with special needs? Are you inter-

ested in coming along to a relaxed morning tea to meet other parents who have a child with special needs? Counties Manukau Special Needs Support Group meet once a month from 9.30-12pm at PACT (Papatoetoe Adolescent Christian Trust), 311 Great South Rd, Papatoetoe. You and your children are most welcome to come along, there is a playground and child friendly, safe environment. Please contact Joy on 0226752239 for more information or join us on Facebook.

Coffee Group



The next coffee group is Wednesday 29th May at 10.30am at the Hollywood Bakery, Westfield Albany. All welcome!

Emergency Planning Day

We recently had Catherine Gilhooly from Auckland Council present information to the coffee group around planning for natural disasters. She has forwarded us a list of community response plans that are currently in place and the names of the zone managers for each area. Contact the office for the list.

Mid Winter Dinner

Sunday 23rd June, 6pm at the Browns Bay RSA. \$25 per adult for a buffet dinner including seafood, ham on the bone, vegetables, salads, desserts. Children \$1 per year of age up to 12 years. RSVP 13th June.

Kristine Newsome



**Kristine Newsome,
Fieldworker for Auckland, Northland and Central North Island.**

Well here we are getting through 2013 quite quickly. It seems hardly any time at all since we had the AGM in Christchurch. That went very well and it was nice to catch up with council members again and also to meet others that I had not met before. It was great to hear what visiting neurologist Larry Stern had to say and I found him to be very hopeful for positive developments with muscular dystrophies in the near future.

After the AGM finished my husband and I stayed the weekend in Christchurch. I have not been to Christchurch for some years so found the devastation all the more shocking when on the spot. Like others, I had seen television cov-

erage of the earthquakes and consequent damage but to be there actually looking at piles of rubble, empty lots, beautiful facades of buildings propped up to preserve them but with absolutely nothing behind them or cordoned-off streets in the CBD all this time after the earthquakes made it all seem so much more raw.

The fact is, it is a huge problem. So much has been affected that I really don't know how the powers that be will cope with fixing it. I expect it will all take quite a long time.

I left Christchurch feeling really sad for those that live there but with respect for their attitude of coping and getting on with their lives as best they can.

It was quite cold while we were in Christchurch and this reminds me that it is time to get the flu vaccine. Every year it seems there are new potent strains of influenza and protecting ourselves from them by being vaccinated seems a sensible idea.

Here in Auckland our bow-tie appeal went well and we were grateful for those businesses who agreed to take a box to place on

their counters and also to those members who gave a hand in manning the stall down at the local shopping centre.

Some of those people were our coffee group members and we are pleased to report that this group is going strong with their monthly meetings. Last month we had more than a dozen people present at our get-together and were pleased to welcome a few new people.

Also Catherine Gilhooly came along from the Auckland Council to talk to us about preparing for situations of sudden disaster if wheelchair-bound. For those who could not attend we would be pleased to pass on Catherine's contact details if required.

If you would like a visit from me, your fieldworker, either for a catch-up and chat or for something that needs some input from our organization such as referrals or follow-ups, information or support, please contact either myself on Kristine@mdn.org.nz, 021 704 227 or the office on 09 415 5682.

Kristine Newsome

'It was great to hear what visiting Neurologist Larry Stern had to say and I found him to be very hopeful for positive developments with Muscular Dystrophies in the near future'

Auckland Powerchair Football Club

The Auckland Powerchair Football Club is on the lookout for new players. If you're in a powerchair and want to try an exciting team sport then come along and have a go.

What is it?

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 teams of four players use power chairs to attack,

defend and spin-kick a 13 inch football in an attempt to score goals.

When:

Sunday May 26th 12.30-3pm

Saturday June 15th 12.30-3pm

Sunday June 23rd 12.30-3pm

Check out www.apfc.co/calendar for more dates.

Where:

Auckland Spinal Rehabilitation Unit, 30 Bairds Rd, Otara.

On the web: www.apfc.co.nz,

Facebook: www.facebook.com/AuckPFC or email info@apfc.co



Mobility Dogs: Unleashing Life!

The Mobility Assistance Dogs Trust (Mobility Dogs) is a New Zealand non-profit organisation established in 2003 that trains highly skilled service dogs to assist a variety of New Zealanders with a wide range of physical disabilities. All Mobility Dogs are trained to International Standards guided by the standards of Assistance Dogs International. The work of the Trust is all about Unleashing Life! A Mobility Dog empowers you to maintain, or improve, your independence at home and within your community.

A Mobility Dog helps open the door to the world, assisting to break

social barriers; allowing you to do ordinary tasks independently; and is a constant, and faithful, companion. This in turn has the positive effects of increasing confidence, self-esteem and participation in the wider community. Have you ever wondered if a canine partnership could be right for you? If so, or you are now interested enough to learn more, read on...

How can a Mobility Dog assist you?

Mobility Dogs are trained in a variety of tasks to provide functional assistance with everyday tasks, including retrieving dropped items; opening and closing doors, cupboards and drawers;

pressing lift and pedestrian buttons; assist with transfers to and from a wheelchair; taking shoes and socks off; switching lights on and off; loading and unloading washing machines and driers; paying for purchases across the counter; carrying items; fetching the phone in an emergency or barking to attract attention. Tasks are directed towards a recipient's needs and a Mobility Dog can work with over 50 linked commands.

For Further Information:

Please check out our website: www.mobilitydogs.co.nz or contact our Client Services Coordinator: Michelle.Smith@mobilitydogs.co.nz.

Muscle Miles

Background:

In 1988 Dame Susan Devoy walked the length of New Zealand to raise awareness and fundraise for the Muscular Dystrophy Association. In 1988 she raised \$500,000. To celebrate 25 years Dame Susan is lacing up her shoes and doing it all again and the aim is to raise \$1,000,000!

Leaving Auckland Domain on Sunday 27th October and returning to Auckland on 12th December, Dame Susan will be retracing her steps of 25 years ago, winding through rural and urban New Zealand, once again raising awareness and funds for the Muscular Dystrophy Association.

Over this time we plan on organising events at all cities/towns that we pass through invoking support from multiple national and local organisations and communities. Each day Susan will be joined by a number of local celebrities and members of the general public, all set on raising funds and awareness for Muscular Dystrophy.

We have confirmed support from Attitude Pictures who are partnering with the walk and will devote an entire episode to Muscular Dystrophy Association, also updating Susan's progress on the website daily. Coast Radio/Newstalk ZB and Radio Sport will also ensure that we have full coverage, along with regular social media updates. Our own web-

site, "Muscle Miles" is nearing completion, so we will keep you informed of when this will go live, as well as a Facebook page to follow us on the journey. We are still finalising a number of sponsors and look forward to being able to update you when these are all confirmed. We have numerous celebrities on board with Sarah Ulmer, The Mad Butcher and Irene Van Dyk to name a few.

We welcome the ideas and involvement of all members and encourage you to 'jump on board' and be part of this wonderful campaign!

Stacey Pearson is the Event Facilitator for the Northern and Lower North Island regions and welcomes all ideas/comments that members may have. Please don't hesitate to contact her should you have any questions, would like to assist in setting up an event in your area or volunteer at an event or event Walk a Muscle Mile. We have a number of fundraising initiatives in place and look forward to sharing these with you very soon!

Events Facilitator: Stacey Pearson

I come from a background that extends from recently running two successful businesses simultaneously, to event management and hospitality. My strengths lie in my communication and organizational skills and at the end of this project my aim would be to leave a

portfolio of events that can be continued on an annual basis by the Muscular Dystrophy Association, the branches and their members.

I remember the original walk that Dame Susan Devoy completed 25 years ago and feel very privileged to have the opportunity to be part of this wonderful fundraiser in 2013.

I am very excited to be working with and for the branches here in the North Island and getting to know the members, their stories and how together we can all make this 25th Anniversary and "Muscle Miles" a huge success.

My role is to facilitate with the branches and develop events alongside the walk, including involvement from MDA members and supporters wherever possible.

Whilst we have some great ideas in place, I'd love to have the opportunity to discuss these with you along with hearing any ideas for events/any interesting celebrity or corporate contacts that you have and how we can make the 25th anniversary of Dame Susan Devoy's walk an outstanding event.

Please feel free to contact me on stacey@musclmiles.co.nz or on mobile 021 973 503.

I look forward to meeting you soon!

Stacey