



# Muscular Dystrophy Northern

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Thanks to Four Winds Foundation for funding this newsletter.



## MDN Camp 14th-16th March

Thanks to funding from PUB Charity our 2014 Family Camp can go ahead. This year it is from the 14-16th March and will be at Narrows Park Christian Camp, Airport Rd, Hamilton.

It will be a fun filled weekend of games, sports and opportunities to meet with other members and their families. A great way to get to know others and share common experiences.

We are hoping to bring down the ATV featured on page 2 so that people can have a go on it.

We have also extended an invitation to members from the Wellington region so we

are hoping for a really good turn out.

further information and to put your name down.



Family Camp 2011 at Waitomo.

People are welcome to join us for the day on Saturday but do need to register for that.

The cost is \$10 per person for the weekend.

Please contact our office for

**AGM:**

The MDN Annual General Meeting will be on Saturday 15th March at 1pm at Narrows Park Christian Camp, Airport Rd, Hamilton. All welcome. Please contact our office for a nomination form. Nominations close on the 21st February.

## Bowtie Week 22nd-30th March

This is our big annual appeal and awareness week so we would very much appreciate any help you can give us.

Please consider taking a few boxes of the Bowtie brochures and seeing if you can leave them in local cafes or shops. Many owners don't mind having a box on their

counter for a week and we have found this to be a great way to fundraise. All money raised in our Branch area stays with the Branch to help fund our Fieldworker service.

We are also looking for volunteers to help with one of our fundraising BBQ's at

Mitre 10 New Lynn on Saturday 22nd March from 9am.



## 6x6 Explorer Available for Hire

### Adventure ... Freedom ... Fun with the 6x6 Explorer

Explore the great outdoors and access beaches like never before with the 6x6 Explorer scooter.

The Explorer is designed to enable you to go over rough ground where other scooters are not able to

travel. Imagine being able to accompany your family and friends to places that up to now have been inaccessible.

The Explorer may be hired from the ILS (Independent Living Service, Royal Oak) on a weekly basis.

A trailer is supplied to transport your Explorer to your next adventure.

Contact ILS for further

information and to make a booking, Ph. 09 625 0322.

*One of our members, Mitchell Fels hired this over Christmas. His Mother Jan wrote that 'he was able to climb the Matauri Bay hill where the Rainbow Warrior Memorial is. He was also able to go down onto the beach this year which he hasn't been able to do for at least the past 5 years. It was the best holiday ever!!'*



Mitchell enjoying his first outing onto the beach in 5 years.

### THANK YOU!

ASB Community Trust  
B.A Lewis Trust  
Bay Trust  
Bluegrass Trust  
COGS  
Four Winds Foundation Ltd  
Geoffrey & Nell Esme Adams Trust  
HOG Auckland Chapter  
Infinity Foundation  
James Searle Say Foundation  
JM Thompson Trust  
Lion Foundation  
Lottery Grants Board  
LW Nelson Trust  
Newmarket Rotary Club  
NSPH Trust  
NZ Community Trust  
Outsource IT  
Pelorus Trust  
Southern Trust  
Trillian Trust  
Trust Waikato  
WEL Energy

## Writing Competition Extended

### MDA Short Story Competition EXTENDED

So let's be honest.

Running a short story competition over the Summer holidays sounded like a good idea but in reality we all sat on the beach and ate pavlova 'til our brains melted. So we're changing things up!

You now have until Febru-

ary 28<sup>th</sup> to enter the Muscular Dystrophy Short Story Competition.

First prize now includes: Publication in the nationally distributed In Touch Magazine, a Nokia cellphone, a petrol voucher, and a commemorative pen.

Second prize: A bottle of wine and a commemorative pen.

Third prize: A commemo-

rative pen.

Best story from an entrant under 20 years of age: a video game and a commemorative pen.

Entries are welcome from all ages, topics, and genres. Maximum 1500 words. Winner will be selected by celebrity judge Judy Bailey.

For an entry form, go to [www.mda.org.nz](http://www.mda.org.nz) or phone (09) 415 5682.

## HOG/MDN Poker Run

Thank you once again to the Auckland Chapter of the Harley Owners Group for fundraising with the annual Poker Run.

The total amount raised was almost \$2,000!!

Thanks to all of those generous HOG members for



their continued support of MDN.

# News & Events



One of our young members, Jacob Lane was lucky to enough to meet with some of the All Blacks recently.

## Ice Skating

Sunday 16th February 1-4pm at Paradise Ice, 150 Lansford Crescent, Avondale. \$7 for a person with a disability and caregiver free. Contact Darian@mdn.org.nz for further information.

## Hendry House

Hendry House at Orewa is still being run as a holiday home by CCS. \$75 per night. Contact Auckland@ccsdisabilityaction.org.nz

## Ronald McDonald House

The Ronald McDonald Family Retreat in Rotorua provides one week's free accommodation for immediate families of chronically ill children and for bereaved families. Contact retreat@rmhc.org.nz.

## Coffee Groups

We have North Shore and Central Auckland coffee groups.

Next North Shore meeting: Wednesday 26th February, 10.30am at Hollywood Bakery, Westfield Albany.

Next Central Auckland meeting: Thursday 13th February, 10.30am at Hollywood Bakery, Manukau Rd, Epsom. Contact the office for further information.

## A Word from Kristine...

New Year's Greetings! So far this year is shaping up to be quite busy. Therefore, with limited time, I am going to just say how inspiring I find so many of you.

I am privileged to be able to visit some really remarkable people in my work as a Fieldworker of the Muscular Dystrophy Northern branch.

You, the members make my job so rewarding. There is a lot of "good stuff" happening out there in the community with members and their parents. I am so pleased to be involved with you and help where I can. Keep it up and know you are amazing!

*Kristine Newsome*

## Did You Know?

Switch Sticks has a range of stylish, collapsible walking sticks with interesting and fun designs. Want a walking stick to match your outfit or to show your personality? Check them out.

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

[www.Supercare4u.com](http://www.Supercare4u.com) provides airport transfers for people with disabilities and their staff are medically trained.

You can get a pillow that is contoured to fit your cpap machine mask and make sleeping with it more comfortable. Ask your OT or check out [www.sleeptech.co.nz/info/welcome-to-sleeptech/cpap-pillow](http://www.sleeptech.co.nz/info/welcome-to-sleeptech/cpap-pillow)

Boccia New Zealand are currently seeking Expressions of Interest for their free Professional Development Course. This has been designed to provide participants wishing to get involved in the sport with the skills and knowledge to be able to run your own Boccia group / club. For more info visit <http://boccia.org.nz/pages/courses.html>

Rod Milner Motors has a range of adapted vehicles for hire to people with disabilities.

Check out the range at [www.rodmilner.co.nz](http://www.rodmilner.co.nz)

Your MDA fieldworker is available to give a presentation to your child's school about their condition. This could be to the staff, to keep them better informed about your child's needs, or to the students, to help them understand and include classmates with difference. Contact us: 09 415 5682 or [darian@mdn.org.nz](mailto:darian@mdn.org.nz) to discuss the options.

# Celebration Corner

Congratulations to Oliver Groom, who has just released a CD of relaxing, chill-out music under the name State of Flux. The album is called "Lucid Frequency" and is an enjoyable collection of laid back tunes recorded and produced by

Oliver with the help of his computer.

"I hear tunes in my head and try to transcribe these into pieces of music," he says. "I am almost entirely self taught and have been working on this album for around 5 years."

Due to his muscular dystrophy, Oliver is unable to physically play any instruments, but makes use of technology to bring his songs to life. He also has the assistance of friends Dan Hew-

son and Georgia Grimme on guitar and vocals respectively.

You can purchase "Lucid Frequency" on CD via Muscular Dystrophy Northern for \$30 (some of the proceeds of these sales will be donated to MDN as a fundraiser) or buy the songs direct from Itunes.

Check out the work of this talented young man. We hope to see a lot of support for this album and many more to come.





# How I got Here and How it's Going So Far

Since I moved out of home, it is fair to say that my life has changed in ways that not even I could predict beforehand.

That isn't to say that the process of getting to this point in my life wasn't difficult, because it was a long road, and one which in its own little way changed my life in itself.

The idea of moving into residential living was first presented to me in 2009, and officially signed off on in late 2011.



Mike Pulman

It took me two years before I really thought about moving out in any real way with purpose, and it wasn't easy to first of all see myself making such a major life change.

But it felt almost unimaginable that I would be able to live the independent life that I have in the last month or so.

How could I possibly do this with the level of reliance I have on others for the most basic of day to day things?

There were many reasons why I decided to move and make this big change.

The idea of living independently was exciting, but unimaginable as I said. It was one of those things where I was never going to know whether I could or not until I tried, so in many ways the

mindset was that I had nothing to lose.

I tried to put my disability out of my mind as much as possible and just focus on what I wanted to do with my life, my life as a human being with dreams, goals, and aspirations, not a human being who lives in a wheelchair.

You really have to put the wheelchair aside, but at the same time remain very realistic in how things will have to be to keep you healthy and as able as possible.

For me, I tried thinking about what I wanted to achieve as a person first, plan that out, then incorporate the wheelchair and reliance on others into the thinking afterwards.

So on December 17<sup>th</sup> 2013, which happened to be my 22<sup>nd</sup> birthday, I finally moved out of home.

It's early days, but the ways that my life has changed are many. My newfound independence has brought with it so much opportunity to simply explore my life and all my interests on a much grander scale.

Going out, spending more time with friends, going to sport events, exploring my sexuality, so many different little milestones have already been achieved in the last month.

I love the ability to go into a shop on my own and buy little things, sometimes something as simple as a birthday card or a pie for lunch, being able to do that 100% on my own is a huge confidence booster.

I love that my parents are now just that, parents, not also caregivers and it has added such a refreshing and stronger bond between us. I enjoy giving back to them.

So, at this early stage, moving

out of home was a long time in coming, but the wait was worth it and everyday it seems like there is another opportunity knocking at my front door.

I feel like I have the support in place and the confidence to take advantage of all of those given opportunities that my new life is currently bringing.



Chris & Mike

Disability? What disability?

That is perhaps the greatest thing moving out has brought to my life. It has adjusted my mindset so much, I now actually believe that my disability isn't a barrier to achieving my dreams. In short, the confidence that this new life has given me through independence and experiment has taken the fact that I am disabled and confined to a wheelchair almost completely out of my mind.

A big thanks to everyone.

Mike Pulman