



# Muscular Dystrophy CANTERBURY NEWS

## Freedom round-up



Thank you to all of the wonderful volunteers who helped make this year's September Freedom campaign a success.

We raised \$1,566 dollars, through two major areas of focus in Christchurch – a sausage sizzle at Bunnings Warehouse Shirley and collection

at Riccarton mall. Special thanks to the Christ's College students who gave up time to support MDA Canterbury, as well as the volunteers & members, including Bonny Stephens and Andrew Munro for running the sausage sizzle.

## Information to manage your condition

Two member education and information sessions have been held, covering topic areas such as genetic health services and managing pain.

We appreciate the speakers who have been willing to come along to these events on a Saturday and hope that the members who attended have found the information helpful.

Following the session on pain management, one of the key messages we wish to share with members is to seek referral to a pain specialist if you have uncontrollable pain associated with your condition. Because everyone responds to pain differently, it is very important to try different combinations and doses of medications, to try and find what works best for you.



### INTHISISSUE

Fieldworkers update 02

Message from our  
Chairperson 03

Important branch  
changes including  
information on how  
you can have your say  
about the new branch  
name 04

## What's been happening in our area

As you all know, the past few months has been a time of change for me, MDA and the branch and Christmas seems to be approaching very quickly.

I am now working Monday to Thursday visiting as many members as possible. As I work through my list of members, please do feel free to contact me if you have a need for support, information or advocacy so that I can priorities you. You don't need to wait for me to make contact, as I am happy to respond to requests. It helps if you can keep me informed if you need support, advocacy, a hospital visit, or some assistance in applying for equipment or funding.

I'm using my three-day weekends to work on my property, which we are looking to sell. This is all part of my big picture retirement plan – I will keep you updated.

With all the recent changes at MDANZ, I will miss departing colleagues, including CEO Ronelle Baker, Chairperson Andrew Munro and Office Manager Gemma Foulds and wish them well for the future.

Best wishes, Paul

Dia Dhuit from Sunny Nelson, Hope this finds you all well and starting to enjoy some more warm weather.

We had our Coffee Group at the Wooden Spoon in Richmond on 18 October, and were joined by our new Chairperson, with her mum Claire, our new Treasurer, along with Rebecca's two sons.

We have one more coffee morning on November 29 at McCashins in Stoke, and Saturday 8 December is our Christmas BBQ, anyone in the regions of Nelson, Marlborough & West Coast are welcome. We hope you will come along and meet some great people and have a good time. Details are listed in the next column.

Miriam and I will be promoting MDANZ at the Paediatric Society of New Zealand Scientific Meeting in Nelson from 7-9th November.

I've recently spent time visiting the West Coast and will be heading over to Blenheim, and Auckland before Christmas. If you would like me to visit you, or provide some support or advocacy, please don't hesitate to contact me.

Slain, Marty

## Keep in touch!

The Canterbury Branch office moved into Christchurch Community House earlier this year.

We have a new integrated phone system. You can now ring Fieldworkers Paul or Marty, or the office on the same toll free phone number. Simply call, 0800 463 222, follow the options to be directed to the person you wish to speak to. Volunteers will provide cover for the office until a new Branch Office Manager is appointed.

The Timaru coffee group has reconvened and meeting about once every two months. Please ring local member Fran on (03) 686-6577 if you would like more information.

The Nelson Coffee group is going strong, their first meeting for 2019 will be on the 7th February venue to be confirmed.

Christchurch Coffee with a purpose will reconvene in February with dates to be advised in the next newsletter and on Facebook.

Do you follow us on Facebook? It's a great way to keep up or be reminded of events coming up in between our newsletters.

## From our Chairperson



My name is Rebecca Poad, and as the Chairperson, I have very much enjoyed meeting members at recent

events. The coffee with a Purpose in Christchurch, Nelson Coffee Group, the Freedom Appeal fundraisers, and the Education session in Christchurch. Going forward I will be attending Timaru Christmas Lunch on 24th Nov, the Christchurch Christmas Bring and Share BBQ on the 1st of December and Nelson Christmas BBQ 8th December. The branch committee are preparing next year's budgets & once that is finished, we will be looking to our calendar to plan events, coffee groups

& spread fundraising across 2019 to strengthen benefits for members. Next year the committee are looking to change the name of our branch, we feel that the name Canterbury does not represent the fact we are the biggest branch in New Zealand geographically. Look out for the members survey early next year, as we look for your suggestions.

A little about myself...I am from Canterbury, spending most of my childhood in Timaru, and some time on the Coast and Christchurch. I have twin sons who are 18 and they both have a rare form of MD. We joined MDANZ Canterbury in 2010 but became more involved when we moved to

Auckland in 2013 for medical and education support for my sons.

I was on the Northern Branch Committee for 2016 & 2017, then we returned settling in Kaiapoi. I feel the connections and knowledge from my time there will continue to enhance our local committee. I am pleased to welcome Mike and Kim Nolan from Franz Joseph who recently joined our merry band of worker bees.

I look forward to meeting you and am easily contacted through the 0800 number. From now until early 2019 I am in a voluntary bridging role for the Branch Office Manager position. You are welcome to catch up with me.

I wish everyone a safe and enjoyable summer season.

## Contact us



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## Branch news

Currently the Committee are researching changing the name of our branch to reflect the wider geographical region we represent, if you have an idea for your new branch name please let Rebecca Poad the Chairperson of the committee know.

The Canterbury branch committee would like to extend a warm welcome to new Committee members Michael & Kim Nolan.

Since our last newsletter, there have been several changes to the committee. We would like to thank past committee members for their service and thank them for their contribution. It has been a learning curve for the current committee members coming up to speed with the priorities and requirements for running the Canterbury regional branch of MDA. Chairperson Rebecca Poad and the current committee, are continuing to explore ways to create a more sustainable future for the benefit of our members.

As we approach Christmas, we offer our sympathy and condolences to families of members who have passed away this year.

## Acknowledgements and AGM

Thank you and farewell to Gemma Foulds, who has been with us for 16 months in the role of Office Manager. We wish her well for the future and thank her for contributing to the Branch.

We appreciate the hard work of dedicated fieldworkers Marty Price and Paul Graham who will take a well earned break during the two week Christmas closure period.

Next year's AGM is in March 2019. We invite members who have professional, admin, fundraising or other skills, to consider standing for the committee. This is an important governance role and will suit people able to make a time commitment of at least two hours per week. The committee is exploring video conference for meetings, to encourage members from the wider region to participate.

### Save the date:

#### **Christmas catch ups**

We hope you will make it along to one of our branch Xmas celebrations this year, to meet other members and enjoy food and festivities. Three locations and dates are planned in the region:

Timaru: 24 November from 12.30 at Zest please RSVP to Fran as soon as you can or contact Rebecca.

Nelson: 8th December at 295 Main Road Hope Richmond 7020 from 11am till 3 pm Please RSVP to [marty@mda.org.nz](mailto:marty@mda.org.nz) or 0274446681 as soon as possible.

Christchurch: 1st December at the Travis wetlands education centre 280 Beach Road Burwood from 11-3 this is a share lunch so please bring a plate, the committee will provide bbq sausages & a ham. RSVP to Rebecca

#### **Christmas closure**

The branch will close on Friday 21st Dec 2018 and re-open Monday 7th Jan 2019. If you have urgent needs during this time, please contact your GP, after hours services at your NASC or disability provider, emergency services or Lifeline.