



Issue 08 March 2015

Muscular Dystrophy Association News and Outcomes from National Council Meetings.

## MATTERS DISCUSSED AT THE FEBRUARY 2015 NATIONAL COUNCIL MEETING

At its December 2014 meeting the National Council gave its approval in principle to replacing the MDA's donor and member customer relations management (CRM) system with a less costly, more efficient and more user friendly alternative, subject to production of a satisfactory implementation plan. Since then a preferred provider has been identified, there has been extensive consultation with MDA staff, and a detailed proposal including an implementation plan has been developed. This proposal was considered by the National Council at its February meeting, where it was agreed that a due diligence exercise be undertaken to enable us to be fully confident that the system will deliver on what's been promised within the quoted price. The National Council will then be asked to make a final decision as to whether or not to purchase.

*Sophie Tamati outlined how National Council members could be involved in the powhiri for MDA's Life Without Limits Neuromuscular conference. We're delighted to advise that kaumatua Warahi Paki has kindly agreed to lead the powhiri on MDA's behalf, and both he and the MDA intend that this will signify the beginning of an ongoing relationship between us.*

2015 targets for the success measures identified in the MDA's Strategic Plan were approved, and progress will be reported regularly to the National Council via a "balanced scorecard".

*The final version of the MDA's employee remuneration policy was approved. This will ensure that, within the limits of affordability,*

*all MDA National Office and Branch based staff are paid fairly and appropriately in a way that also recognises exemplary performance.*

A policy on running MDA camps was also approved, particularly to ensure that we comply with changes to health and safety laws and do all we can to ensure the wellbeing and safety of camp attendees, staff and volunteers.

*It was agreed to invite Judith McMorland to the April National Council meeting to assist in discussing future structural options for the MDA. This was originally considered by the National Council in April 2015, but has not progressed since then. Judith is co-author of the well regarded book "Stepping Through Transitions: Management, leadership and governance in not-for-profit organisations."*

The next meeting of the National Council will be face to face from 9.00 am to 3.00 pm on Sunday 19th April in Auckland, the day after the MDA conference. If there's anything you wish to have discussed please let your branch committee representative know. MDA members are able to "sit in" and observe National Council meetings - let Chris Higgins know if this is something you'd like to do.

*As always minutes of National Council meetings are available in the members' only section of the MDA's website. As a member you are welcome to request copies of any associated agenda papers that you wish to see.*

## LIFE WITHOUT LIMITS NEUROMUSCULAR CONFERENCE



16-18 April 2015  
at SKYCITY Auckland  
Convention Centre  
[www.mda2015.org.nz](http://www.mda2015.org.nz)

Don't forget to register at  
[www.mda2015.org.nz](http://www.mda2015.org.nz)

If you're an MDA member who lives outside of Auckland needing assistance with travel and accommodation costs please contact your MDA Branch.

If you have conference queries, please feel free to contact Lynda Booth,  
+64 9 845 5550.

## PERSONAL DEVELOPMENT WORKSHOPS - Christchurch pilot programme

Life can provide us with tough challenges and some times the only person that you feel that can truly empathise with you is someone who has shared similar experiences. With this in mind the MDA would like to offer our members the opportunity to attend 3 workshops over the course of 3 months. The focus being on personal experience, sharing and gaining new strategies to manage the challenges in life.

The workshops will be facilitated Avrael Semple a registered counsellor who will be your guide. Your privacy and confidentiality is assured.

### The workshops will be on the following:

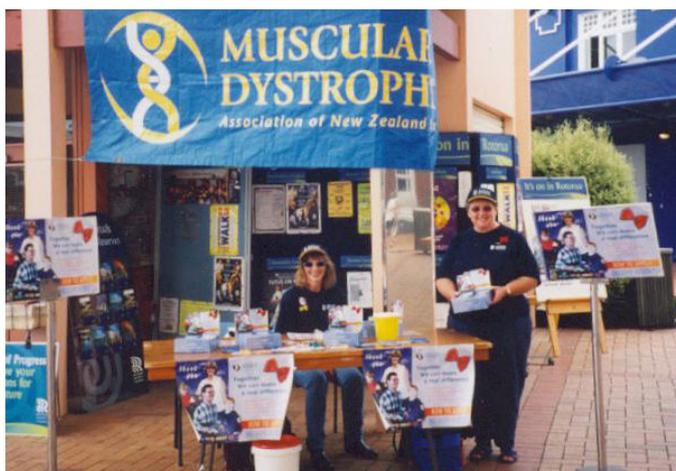
- Monday 13 April; 10.30am - 12.30pm
- Monday 11 May; 10.30am - 12.30pm
- Monday 8 June; 10.30am - 12.30pm

### The venue is:

The Boardroom  
Papanui Library  
35 Langdons Road (corner Langdons Road & Restell Street)  
Christchurch 8053

Use the Restell St entrance.

Register your interest with [jayne@mda.org.nz](mailto:jayne@mda.org.nz) please note there will be limited spaces.



## ANNUAL APPEAL WEEK

It's our 'Annual Appeal Week' on the 21 - 28 March 2015 and we need your help! Can you spare one hour to help us collect or could you host a collection box at your workplace? Let us know at [bowtie@mda.org.nz](mailto:bowtie@mda.org.nz)

## MDA BRANCHES

### Northern Branch

Phone: 0800 636 787

### Wellington Branch

Phone: 0800 886 626

### Canterbury Branch

Phone: 0800 463 222

### Southern Branch

Phone: 03 486 2066

Round the Bays  
2015



GOOD LUCK  
TO ALL  
OUR MDA  
RUNNERS  
THIS SUNDAY!

## CHRIS HIGGINS' CORNER



The NZ NMD Registry now has over 700 participants! If you're interested in signing up please email [registry@mda.org.nz](mailto:registry@mda.org.nz).

The AUT/MDA study of the prevalence and impact of genetic muscle disorders in New Zealand

is underway! All MDA members with one of the nineteen conditions covered by the study are invited to participate. More details will be available in the March issue of In Touch. This ground breaking research will help to put neuromuscular conditions "on the map" and will enable us to lobby more effectively for a fairer deal for people living with these conditions.

Progress is being made on establishing a New Zealand based multidisciplinary clinic for people with Friedreich's Ataxia. Thanks to MDA members living with Friedreich's Ataxia who have given of their time to participate in the working group for this project.

The development of the Allied Health and Nursing guidelines for the care of Duchenne muscular dystrophy is now underway. These will contribute significantly to a NZ version being produced for Starship's Clinical Guidelines, which are available on the Starship Foundation's website, and which are recognised throughout NZ as a source of information for managing paediatric patients.

The Chief Executives of the MDA, Foundation for the Deaf and Autism NZ are formally registering a Trust (to be known as Human Rights for All Trust) to attract funding to support the disability sector's CEOs to more effectively monitor and report on the government's response to the United Nations Convention on the Rights of People with Disabilities.

Nominations are being called to fill vacancies on the National Council when the two year terms of five current members expire as at the date of the MDA's AGM on 17th April. Full details of the nomination process accompany this newsletter.

Sadly, we farewell MDA's National Service Leader Melanie Hopley who finishes with us on 6th March. We wish her all the very best for the future. Recruitment of a replacement is underway and applications are welcome from suitable qualified and experienced MDA members. Please see <http://www.seek.co.nz/job/28208967?pos=1&type=standout>.

Finally, greetings from all of the staff here at the National Office:

- Jayne McLean (Information and Resource Manager),
- Penelope Crow (Marketing Manager),
- Miriam Rodrigues (Programme and Service Advisor),
- Kate Longmuir (Grants Fundraiser),
- Brian Hadley (Accountant and Business Manager),
- Olisia Sparey (Accounts and Admin Assistant),
- Chris Light (Membership and Marketing Assistant),
- Kimberley Cameron (In Touch editor)
- and myself, Chris Higgins (Chief Executive).

*Chris*



We can be contacted at [info@mda.org.nz](mailto:info@mda.org.nz) or by calling either our Freephone number 0800 800 337 or 815 0247 for Auckland callers.