



Issue 10 July 2015

Muscular Dystrophy Association News and Outcomes from National Council Meetings.

**MDA CATCH-UP** is our regular newsletter to keep you as members informed and up to date about what's happening in your Association and to give you the opportunity to have your say. If you have suggestions or thoughts about how we can improve its content and presentation, then simply let us know. We appreciate your opinions and feedback.

## CHRIS'S CORNER



Chris Higgins (Chief Executive)

A small group from the Disability CEOs network (comprising myself, the Foundation for the Deaf's Louise Carroll and Autism NZ's Dane Dougan) are inaugural trustees of the Human Rights for All Trust which has been established to attract funding to support the Disability CEO Network's initiatives to monitor and report on the New Zealand government's response to the United Nations Declaration on the Rights of people with Disabilities.

Joseph Boon, MDA's representative on the Ministry of Health's Disability Support Services Consumer Consortium, has resigned following his success in getting a job with the Ministry of Health's Disability Support Services. Congratulations to Joe on his appointment and thanks for his contribution on behalf of MDA members. There's now an opportunity for the MDA to be represented on this important forum by somebody else, and **expressions of interest are invited from MDA members with a condition, by emailing Ronelle Baker at [ronelle@mda.org.nz](mailto:ronelle@mda.org.nz) by Thursday 6<sup>th</sup> August.** It is hoped that the National Council will make a decision about our new representative at its August meeting.

A new set of online resources are now available to help carers look after their own needs, make time for themselves and stay connected. The new resources comprise three on-line programmes known as Time Out, Work and Care, and MeetUps, have been developed by the Ministry of Social Development and Carers New Zealand. Other resources include a Facebook page for young carers and a series of online seminars. The launch of the resources coincides with the 10th anniversary of the Carer's Alliance, a consortium of 45 not for profit organisations, including the MDA, that supports and advocates for carers. All the resources are available now on the new carers' website: [www.carers.net.nz](http://www.carers.net.nz).

We have said farewell to Kate Longmuir from the National Office as she has left the role of Grants Fundraiser to focus time on completing her PhD. The MDA team would like to take this opportunity to thank Kate for her valued contribution to our team and membership services. Kate will continue to work with us on campaigning for improved use of disability supports for members who are inpatients. See Page 4 for more information on this campaign.

*Chris*

A strategic planning session was held prior to the National Council Meeting on Saturday 27th June 2015 at the MDA's National Office premises, with National Council and National Office staff representatives in attendance. The session was facilitated by Denis Snelgar of Tipping Point Performance and many ideas were developed and shared by the participants. A revised draft strategic plan has been developed from this process for consideration. Once draft changes are agreed by National Council, the document will be shared with all staff and MDA members to seek feedback. It is expected that the National Council will endorse a final version of the plan at its October meeting.

At the National Council meeting itself, Heather Browning was appointed to the National Council's Finance Committee, joining existing member Roger Loveless. John Dobson from PriceWaterhouseCoopers had been invited to be on the Finance Committee, but declined in favour of being available in an advisory capacity.

## Statement about Muscular Dystrophy Association NZ's Financial Situation

To clarify:

The previous National Council of the MDA, via the Finance Committee, approved a deficit position for the 2014 budget. This was done after careful consideration and deliberation and in the knowledge that we have financial reserves that were specifically accrued as a buffer for difficult times.

The National Council are aware that concerns have been raised by some members about the deficit position of the National Office in 2014 and we thought it important to specifically address those concerns.

The deficit position has come about as the result of reduced revenue and not as result of overspending. All costs in the budget were examined closely and well managed throughout the year such that expenditure was below that budgeted.

However the anticipated revenue from fund raising efforts was not realised and the budget deficit was larger than anticipated. This wasn't for lack of effort and was largely attributable to increased competition for limited funding both from donors and grants and philanthropic trusts.

As Lindsay McGregor noted in the Annual Report, "Fortunately in prior years the organisation built up considerable financial reserves which allow us the time to focus on improving our income". Further, recent feedback from the MDA's financial advisor noted, "The organisation looks healthy given the strong cash position" and further noted that given our tight budget and reliance on fundraising, this (fundraising) is where we need to focus.

The National Council delegates responsibility for the day-to-day management of the budget to the Chief Executive via the Finance Committee, and keeps a watching brief on the financial situation. The National Council is well aware of the need to generate more revenue.

We will be calling on members to support us in these efforts.

In addition we have been stepping up our efforts to increase donations from the general public, to secure additional revenue from government contracts, and to generate new revenue streams through fundraising events and social enterprises.

It was also noted that there has been some misunderstandings about the cost of the MDA/ANN conference. When approving the budget in December 2014, in the interests of being financially prudent, provision had been made for the conference to make a loss of \$60,000 (which was a worst case scenario based on income and expenditure predictions at the time). However over 80 MDA members participated in the conference free of charge (an equivalent value of approximately \$31,000 for conference registration that the MDA was able to extend to members), and as a result of grants funding the estimated net financial cost to the MDA is less than \$9000. This is a very gratifying result when balanced against the value the conference has delivered.

It was further noted that the imminent change to a new donor CRM and a new initiative for targeted radio advertising were likely to result in a significant increase in donations.

As always minutes of National Council meetings are available to members on request or via the MDA's website, and you are also welcome to ask for copies of any associated agenda papers that you wish to see.

## STAFF WELCOME



We welcome Penny Piper to the fieldworker team. Penny will be working with the Wellington Branch team until June 2016, to provide cover for Dympna who is currently involved in the MD-Prevalence study. She will be offering fieldworker services to members in the Tairāwhiti, Hawkes Bay,

Palmerston North and Manawatu regions. Dympna continues her role in the Wairarapa, Wanganui Taranaki, Hutt and Wellington regions.

Warm greetings to MDA members, I am a keen relationship builder with strong ability to get alongside others and support through life's challenges. I hold a BASS degree and majored in psychotherapy, which supports my natural interest in others and what they are experiencing. Originally from Auckland, I relocated to the sunny Hawkes Bay in 1997 so that my family could enjoy an easier pace. I have five children, two of which have disabilities, so have a personal awareness of the impact of disability on a child, the family and life in general. My mobile hasn't arrived yet, but I can be reached by emailing penny@mda.org.nz. Looking forward to meeting some of you soon! From Penny

## MDA Counselling Programme

A free confidential nationwide service for MDA members



## FREE COUNSELLING

The MDA NZ provides up to three free confidential counselling sessions per year to MDA members living with a neuromuscular condition. If you want to take advantage of this please phone 0800 SELFHELP (735 343) and let EAPworks know what you need and give them your membership number\*. \*If you do not know your membership number please contact MDA National Office on 0800 800 337 or email info@mda.org.nz to find out.

## CONGRATULATIONS TO FOOTBALL PLAYERS

Congratulations to the Auckland Powerchair Football team who are heading to Australia in October to compete in the Australian nationals competition. Four of the six players competing are MD members and we wish them well in this sporting event.



## THANK YOU TO SURVEY AND RESEARCH PARTICIPANTS

Thank you to all members who participated in the MDA survey and to those who are getting involved in other research opportunities, such as the MD-Prev study. Having research based information and evidence to draw on helps MDA and the New Zealand health and disability sector to identify what is important to our members. For MDA, this means we can review the services we provide and target our lobbying toward the things that matter most. We appreciate members giving time and sharing their experiences to support relevant research endeavours. Please keep an eye out in the In Touch magazine or our website mda.org.nz for summary information from research and news on publications.



## CAMPAIGNING FOR CHANGE

We have many members who are allocated personal care hours and access this support via Individualised Funding or Disability Support Service providers. If they become unwell and are admitted to hospital as an inpatient, then these hours are no longer available to them and their support worker/carer is not allowed to continue their support in the inpatient setting due to funding barriers. If the support worker/carer chooses to provide informal support in an inpatient setting they will not be paid.

The impact of this funding barrier leads directly to poor experiences of acute and planned hospitalisation and can have serious consequences for the individual receiving health care within the hospital setting. Our members report that being unable to have their trained support workers in hospital compromises their health and they cannot meet their own needs in a manner that keeps them safe and maintains their dignity.

We are committed to lobbying for a policy change within the Ministry of Health to allow unrestricted use of disability related supports that ensures all individuals with an impairment have access to safe and effective services while they are an inpatient. If you want to become involved and help us to lobby/campaign for this change please contact us, by phoning (0800) 800 337 and speak to Jayne on extension 1 or Ronelle on extension 6; or email Jayne at [jayne@mda.org.nz](mailto:jayne@mda.org.nz) or Ronelle at [ronelle@mda.org.nz](mailto:ronelle@mda.org.nz).

## LIMB GIRDLE MUSCULAR DYSTROPHY AWARENESS DAY

The first Global Limb Girdle Muscular Dystrophy Awareness Day will be held on September 30th 2015. Social media will be utilised to enable the participation of interested people all over the world.

Visit <http://lgmd-info.org/lgmd-awareness-day/> for more information.



## WORLD DUCHENNE AWARENESS DAY

September 7th 2015 is the second World Duchenne Awareness Day held globally and this year the balloon campaign has a focus on supporting education and awareness programmes. Northern Branch Chairperson Trevor Jenkin and his wife Joy are organising something in Auckland to acknowledge the day. Contact Joy at [joyj1408@gmail.com](mailto:joyj1408@gmail.com) to get involved or visit <http://www.worldduchennday.org/> to find out more about the campaign.



## RADIO ADVERTISING

MDA is about to trial a six month radio campaign with Radio Rhema (Life & Star) to raise awareness and fundraising opportunities. The well known Christian radio network is available nation wide. Check your frequency at [www.rhema.co.nz](http://www.rhema.co.nz)



## WINTER WARMERS

Branches have been busy with mid-winter Christmas events and other MDA social groups are continuing through the colder months. We hope you have had opportunity to attend some of these events, though recognise that winter is not the easiest time of year for mobility. May you and your whanau stay warm and well. Spring is just five weeks away! In the meantime, here are some tasty recipes to try

<http://www.healthyfood.co.nz/recipes/collections/winter-warmers>