



## Muscular Dystrophy New Zealand

### MINUTES OF THE NATIONAL COUNCIL MEETING OF THE MUSCULAR DYSTROPHY ASSOCIATION OF NEW ZEALAND (INC)

Held 7.00pm Wednesday 16 August 2017, by teleconference

#### **Welcome, Apologies, Whakawhanaungatanga, Declarations of Interest, & Previous Minutes**

**Present:** Ken Green (Chairperson), Brent Walker, Tristram Ingham, Olivia Shivas (Rangatahi Rep), Annelize Steyn (Wellington Branch Representative), Robbie Verhoef (Southern Branch Representative), Warren Hall (Canterbury Branch Representative), Jan Daly (joined 7.53pm, apologies for lateness)

**In attendance:** Ronelle Baker (Chief Executive)

**Apologies:** Michael Schneider (Northern Branch Representative), Kerry Stephenson, Andrea McMillan, Trevor Jenkin (Vice Chairperson)

**Minutes:** Ruth Church

Ken opened the meeting, welcomed all and asked everyone to share a positive MDA experience since last meeting. Thanks to all for completing declarations of interest, no conflicts declared.

*Moved that minutes of the previous meeting (01 July) be accepted as a true and correct record.*

**Moved: Tristram**

**Seconded: Warren**

**All agreed.**

#### **Financial Reporting**

Provisional Minutes of Finance Committee meeting held 26 July 2017 – circulated prior to meeting. All received and read. June was good month for national office, year to date variance of \$5,000 against where expected to be, forecast \$5,000 surplus. NRFT deficit \$4,000, mostly related to baseline & additional audit costs – no revenue stream to cover these. Balance sheet – holding equity at \$1.8 million, comparable to 12 months ago.

Fringe benefit tax - research and advice from RSM confirms we are not subject to FBT on vehicles for work use, but could be for personal use of vehicles and credit cards. Andrew Munro drafting credit card use policy (to be reviewed by Finance Committee) and Ronelle sending reminder to all staff about restrictions on personal use of work vehicle, including a declaration form for signing. Warren advised Canterbury branch committee feels vehicle can be used personally within reason, Ronelle to address this with Andrew. Ken added FBT is to do with employment, not ownership of

vehicle, so feedback to Canterbury is that this position is to protect the organisation from FBT, including ensuring vehicles in good working order and appropriately insured.

Unreconciled accounts - still discussing with branches, has prompted improved reconciliation procedures at branch and national office.

Forecast deficit for group of \$86,546 - major issue, big challenges ahead to try and pull back. Northern and Canterbury branches both looking better, hoping to see further progress at next Finance Committee meeting. Ken advised that last year's consolidated group loss of \$98,000 and this year's forecast loss of \$86,000 mean we need to make some tough decisions and cease discretionary expenditure. Ronelle added that grants funders are questioning what we're doing about deficit positions, and in this environment, we need to be seen as viable organisation that lives within its means, or we'll be relegated to low priority with grants providers and seen as "at risk". Ken reminds the group that we need to be more proactive, not rely on reserves, and start thinking, planning, and applying well in advance. We are currently committed to Duke of Ed program, but at this time, need to carefully consider all other discretionary spending (including Members Discretionary Fund). All need to work as a group, examining all expenditure and challenging any discretionary spending. There was some discussion about the impact on the Member's Discretionary Fund and most agreed that it was desirable to maintain this if possible (it is budgeted for).

*Moved that MDA as a consolidated group needs to ensure all expenditure is essential and already committed to or budgeted for, with additional and separate income generated and targeted to any further expenditure.*

**Moved: Ken**

**Seconded: Tristram**

**All agreed.**

### **Chief Executive's Report**

Australasian Neuromuscular Network conference in Melbourne - Ronelle, Miriam Hanna and Miriam Rodrigues all presented after receiving grant to fund all three to attend. Ronelle very proud to represent our community as the only person attending with a neuromuscular condition. Great networking opportunity with clinicians and researchers.

Friedreich's ataxia family day - very successful, held in national office, 11 out of 51 people in New Zealand attended with their families. Australian experts flew in, interesting model with all parties contributing to event, worked well and hope to do more in future.

Policy work - lots going on, thanks to Tonya Baker and Miriam Hanna, and Branch Chairpersons for their involvement. Once policy framework in place we can apply for MSD accreditation, slow process but will get there.

Annual operating plan – doing quite well, achieving some great things, will review October/November.

Research priorities – link sent to all members for their feedback (last done 2013). Current priorities list includes prevalence, but may want to re-prioritise now that MD-Prev has concluded. NRFT annual research funding round open, will make decisions late September, informed by feedback.

Tenant at national office – CCS Disability Action has given notice on their tenancy, and will not be renewing from November 2017. Bad timing financially as this equates to \$17,000 annual rental (note that payment is in advance and \$2800 budgeted for November/ December will further impact negative forecast). Aim to advertise space, with opportunity for new partnership.

[Confidential component removed for publication]

Risk register – Ken asked that *income generation for national office* be changed from Med to High risk, and that *induction for branch committee members* be changed from Med to High. Trevor questioned why this only related to branch committees, and it was agreed that the wording be changed to encompass all governance groups, as induction and training needed to improve across the board.

Health & safety – Ken asked that the free “Life 360” app be explored urgently as a phone based GPS system for tracking fieldworkers, as matter has been outstanding for some time. Tristram queried whether the new policy is working effectively, Ronelle noted generally low rate of incidents so hasn’t been tested, but fieldworkers and staff are more vigilant and some strong health and safety champions in team.

## **Branch Reports**

Ken thanked those who have submitted their reports and reminded all that for good governance we need to meet deadlines, to enable consideration and informed decision-making. All need to take responsibility for timely reports in future.

Rangatahi report - Olivia currently planning closed Facebook page for young members, working on age group, terms and conditions, and standards of behaviour, to be progressed with Natalie. Hope to do something around appeal, also connecting with Bonnie re involvement in kids’ camp. Ken asked that the Facebook page guidelines comply with existing policies, and asked Olivia to present final proposal.

## **Next Meeting**

Ronelle and Ken discussed next planned face-to-face National Council meeting, balancing financial position around essential expenditure, and the need to work on building cohesive strength around our principles, mission and strategies as governing group. Proposal made to hold National Council meeting evening of Friday 13 October (3.30 - 7.00pm), then externally facilitated workshop Saturday 14 October (9.30am – 2.30pm), acknowledging that cost of not working together is far greater than cost of this meeting. General agreement for proposal, with advance apologies from Robbie and Olivia.

## **AGM**

Ken proposed focus in future be on branch AGMs, putting energy, resources and staff into regions. National AGM had minimal member turnout, so emphasis on branch meeting with national

support, researchers attending and contributing would be more cost effective. Tristram suggested video link, Ken agreed this could ensure accessibility and engagement for all AGMs.

All agreed with Ken's proposal, decision made to hold national AGM in Auckland with media screening to branches, then work with branches to coordinate regional AGMs with national support and contribution. Ronelle and Trevor to discuss video conferencing solutions.

### **Other Business**

Ronelle to circulate proposal for paperless boardrooms (including set up of specific email addresses for councillors and using Dropbox for document sharing) as this matter is outstanding.

Ken thanked all for their participation, hard work, and sharing good news, and looks forward to receiving papers earlier in future.

Meeting closed 9.12pm.