



## Muscular Dystrophy New Zealand

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

**Held 7.00-9.30pm Wednesday 22<sup>nd</sup> March 2017 by Teleconference**

#### **1. WELCOME, APOLOGIES & DECLARATIONS OF INTEREST**

**Present:** Heather Browning (Chairperson), Ronelle Baker (Chief Executive – apologies for lateness), Olivia Shivas (Rangatahi Rep), Robbie Verhoef (Southern Branch Representative), Trevor Jenkin (Northern Branch Representative), Warren Hall (Canterbury Branch Representative), Peter Tegg (Wellington Branch Representative), Andrew Munro (Canterbury Branch Chairperson, for branch agreement discussions only), Brian Hadley, Ken Green, Kerry Stephenson, Jan Daly (joined the meeting at 7.30pm – apologies for lateness)

**Apologies:** Sophie Tauwehe, Andrea McMillan, Derek Woodward

**Minutes:** Ruth Church

Heather opened the meeting and welcomed all with a round of introductions, for the benefit of new attendees.

#### **2. PRIORITY ITEMS**

##### **2.1 Branch Agreement Discussion**

Heather allocated one hour for discussion on the proposed branch agreement template which had been circulated for the past month as part of a governance consultation process involving National Council and Branch Committees. Written feedback had been collated and distributed with the meeting agenda (refer to separate document).

Peter had minor formatting changes to suggest. However notes a new Chairperson has been appointed and the new committee has not had the opportunity to engage fully in the process.

Ken highlighted the importance of being specific – e.g.: when referring to “the operational plan”, we need to detail which operating plan. Where “national office responsibilities” is referred to, should we also be summarising branch responsibilities - discussed option of including as bullet point list under “roles and responsibilities” heading.

Trevor noted that Northern committee have been busy with the employment of a new fieldworker, and now need more time to thoroughly consider the structure of the proposed agreement and associated risks.

Andrew advised that the former Canterbury committee were in agreement with the proposed template, however given the recent appointment of new committee members it was felt the incoming committee would need time to review. Andrew will circulate draft agreement to new committee seeking their feedback, then report back to Council.

Warren had some suggestions around wording changes, but Heather reminded the meeting of their obligations to abide by and respect the principles of The Treaty of Waitangi. The suggested wording changes were not supported and will not be adopted in the template.

All agreed to add a line to point 3.6 in service delivery to the effect of "MDA is an equal opportunity employer and embraces diversity in its workforce".

Southern Branch incoming Chairperson Robbie noted that his new committee had not yet had a face to face meeting and that teleconferences were not conducive to good debate.

The group discussed a need to establish reasonable timeframes, allowing time for incoming Chairpersons and new committee members to consider and review agreement. It is anticipated this work will be a priority for the new National Council appointed in April – note a new Chairperson and Vice Chairperson will be elected, so the change in leadership is relevant and imminent.

*Move that the proposed new branch agreement template be re-distributed to and considered by all branch committees, with first round of feedback to be sent in advance to Ruth (copy in Ronelle) in preparation for the next face to face National Council meeting, Saturday 29th April in Hamilton.*

Moved: Heather

Seconded: Peter

All agreed.

Branch representatives and National Council members agreed to recommend at the April meeting that the incoming National Council receive feedback on the proposed template, make refinements and seek to finalise the agreement at the following National Council meeting (which will be face-to-face, date to be confirmed in June).

8.10pm – Andrew left the meeting at the conclusion of the branch agreement discussion.

## **2.2 Grants Resolutions**

Move to proceed with grants applications to Infinity Foundation, Pub Charity and Four Winds for amounts proposed in supporting document.

Specifically these are:

For the Duke of Edinburgh's Hillary Award programme roll out this year.

- Infinity Foundation: apply for the amount of \$13,532 to cover the salary costs of the Award Unit Leader for twelve months.

- Pub Charity: apply for the amount of \$5808 to support five participants in the Duke of Edinburgh's Hillary Award programme (as outlined in the annual budget) for completion of Bronze Level of Award.
- Four Winds Foundation: apply for the amount of \$5000, towards travel, accommodation and associated expenses to hold a face to face Certification Ceremony event at completion of the first year (based on 5 participants, a parent/caregiver, Award Leader, Patron & MDANZ representatives).

Moved: Jan

Seconded: Peter

All agreed.

Move that a grant application be made to the Lion Foundation for \$30,000 (GST excluded) for the purposes of a partial funding contribution to the base salary costs of the Chief Executive.

Moved: Jan

Seconded: Warren

All agreed.

### 2.3 DMD Member Reference Group

Ronelle has circulated for the third time, a proposal to establish a member reference group for DMD as a resource to assist MDANZ with prioritisation and strengthen the consumer input around work being undertaken for the DMD community. Ronelle has sought National Council agreement for establishment of this reference group, due to the potential organisational risks of establishing a specific group for one condition. Discussion was scheduled for two meetings ago and a terms of reference drafted, however ran out of time at last meeting. At this point Ronelle is keen to address final questions from council and progress the initiative.

Ronelle suggests trailing the group for two years (per Jan's suggested tenure). Council highlighted the need for the group to be well facilitated, and for roles and responsibilities of the reference group members to be well managed. Ronelle indicated she would facilitate initially then hand over once the group was established. Purpose of group is to inform decisions and prioritise workloads, but there is some risk of the group acting outside its scope does exist so needs effective management. Would be a national group, probably meeting via Skype, so costs are minimal (namely Ronelle's time). Effectively a pilot group, could be a model for other future groups.

Terms of reference: Heather would like the word "address" changed to "explore", and supported the suggested change of tenure from three years to two.

*Move that National Council accepts the terms of reference for the establishment of the DMD reference group, with the above mentioned amendments.*

Moved: Ken

Seconded: Trevor

All agreed.

### 2.4 Financial Report

Ken noted January 2017 telemarketing and donations were down for the month of January, with no specific reason as to why. Direct mail similarly down - all went out as planned but

lower income received. Costs/expenses are still being maintained well, so while January is deficit, overall looking to meet break-even point. Balance sheet – assets/ investments looking healthy, slightly up on previous years.

The 2016 audit process has raised a question re; the Stern Foundation grant, which was received and banked in December prior to 2016 year end. Because we hadn't met grant requirements in the 2016 timeframe and there is a legally enforceable return clause, the auditors and Finance Committee have advised the grant will be recognised in the 2017 year. As this was initially budgeted for January 2017 this means following adjustment, the year end result for 2016 will be less favourable, but 2017 will be back on track.

Brian noted a few other changes suggested by auditors around donations in 2016 under the new accounting rules. This is the first time we have had to consolidate all branches and NRFT with group, and result is group loss of around \$98,000. Ken and Heather highlighted the need for an extraordinary finance committee to discuss this position, as this result had previously not been known.

Ken also noted that the organisation needs to continue working with One 4 All as our telemarketing provider, as we can't live without this revenue stream. Ronelle working with them to ensure maximum returns for MDA.

*Move that the provisional minutes of the Finance Committee meeting held 02 March 2017 be accepted.*

**Moved by: Ken**

**Seconded by: Heather**

**All Agreed.**

## **2.5 AGM Planning**

Progressing well, travel plans underway, with provision for incoming chairpersons.

Line up of confirmed guests include Larry and Jackie Stern, Dr Richard Roxburgh, Dr Alice Theadom and Nic Brockelbank.

Ken noted that it would be good to host a group meal for invited guests following the meeting. Ronelle to follow up on this idea.

Heather has given her apologies for the AGM as she will be overseas, but will pre-record a message to be shared at the meeting.

## **2.6 Seasons for Growth Pilot**

Presented by Ronelle for information purposes, has already been discussed and endorsed by finance committee. Pilot program addressing change and grief. Jo Smith is a facilitator and has used program previously with success. Now planning to undertake pilot in Southern region (in addition to her fieldworker hours). Anticipated pilot cost is \$2,500, and we intend to use some of the Stern Foundation grant which is a good fit. Will plan three separate programs, then evaluate and potentially scale to a national service if outcomes can be demonstrated.

### **3. OTHER BUSINESS**

Ronelle discussed Nic Brockelbank's cycle challenge fundraiser – cycling as many laps as possible of the Cambridge Avantidrome in 1 hour on Thursday 23<sup>rd</sup> March. Hannah and Miriam Rodrigues attending on MDA's behalf. Breakfast TV interested and some mainstream media already covering story, which has exposed some risk around Nic not presenting as typical DMD boy, and inaccuracies around his not having met anyone else with MD. Need to stay focused on his generosity and spirit, but just wanted council to be aware that there may be some negative feedback following media representations.

#### **Meeting closed at 9.05pm.**

Heather thanked all for their time and contributions.