



Muscular Dystrophy New Zealand

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

Held 7.00-9.30pm Wednesday 8th February 2017 by Teleconference

1. WELCOME, APOLOGIES & DECLARATIONS OF INTEREST

Present: Heather Browning (Chairperson), Sophie Tauwehe Tamati (Vice Chairperson), Ronelle Baker (Chief Executive), Olivia Shivas (Rangatahi Rep), Ken Green, Trevor Jenkin (Northern Branch Representative), Warren Hall (Canterbury Branch Representative), Brian Hadley (for financial reporting only), Raewyn Hodgson (Southern Branch Representative)

Apologies: Jan Daly, Kerry Stephenson, Andrea McMillan, Derek Woodward, Peter Tegg (Wellington Branch Representative)

Minutes: Ruth Church

Heather opened the meeting and welcomed all. It was confirmed that a quorum was present.

2. FINANCIAL REPORT

Minutes from the January 2017 Finance Committee meeting and December 2016 (financial year-end) financial reports were circulated to National Council prior to the meeting. Reports taken as read.

Ken Green, Chairperson of Finance Committee, summarised the year-end result of \$45,274 surplus, which is a great result. This surplus was bolstered by a Stern Foundation grant received just prior to end of year, but nonetheless congratulations to the team. Telemarketing and direct mail have gone well and expenses have been contained. This is a very pleasing result – well done to Ronelle and team for keeping under budget. Ken highlighted the members' discretionary fund as a great new initiative, distributing over \$20,000 to our members in 2016. This initiative is really giving back to our members. A huge congratulations extended to all involved, for their time, effort and discerning, empathetic work. Heather congratulated all on a great, productive year, which is particularly gratifying considering where we've come from.

Annual accounts now being prepared for auditing. It was noted that Brian's workload has escalated, in part due to support needed by Wellington, Canterbury and Southern branches to prepare their accounts and address any issues identified by auditors. Brian is thanked and acknowledged for providing this support and picking up the extra work required in this first

year of consolidation. However branches are encouraged to improve their financial systems and processes for 2017 so that end of year processes run more smoothly.

Move that the financial report for December/ year-end be accepted.

Moved by: Ken

Seconded by: Heather

All Agreed

3. CHIEF EXECUTIVE'S REPORT

Report taken as read.

Ronelle highlighted the fantastic year-end position.

Duke of Edinburgh – establishment phase going well, Marty and Tonya have been engaging with Olivia and other young members, seeking feedback which will help inform the programme development. Internal communications has gone out, next wave of communication going in Autumn issue of In Touch, hoping to recruit first cohort in March. Nic Brocklebank doing cycle challenge fundraiser at Cambridge Velodrome on 23rd March. Funds raised will be targeted specifically for the Duke of Ed, and this event can be used as a platform to launch the program.

Building relationships with Paralympics around MDA member awareness and participation in sport and recreation, and St Johns around promoting paramedic education and specific learning modules for working with people with neuromuscular conditions.

Annual operating plan has been finalised and will guide activities for the coming year. Is noted as a separate agenda item in this meeting.

A few staffing changes are occurring and being managed appropriately.

Financial Audit planning on track.

Social media – recent internal discussion regarding professional standards of behaviour extending to personal time/social media use. Staff reminded to manage boundaries and privacy settings and also to ensure they uphold MDA's code of conduct in all settings. HR policy includes guidelines and expectations around internet and social media use, and this has been re-circulated to staff. The team will run a scenario based training session in next staff in-service. Trevor queried whether branch Facebook pages should be similarly managed and directed, Heather recalled an historical discussion however there would need to be agreement/ permission to manage or direct branch Facebook pages – could be pertinent to revisit, and potentially include in branch agreement.

Action: Investigate whether/ how to include internet/ social media guideline in branch agreements. Ronelle/Heather/Branch Chairpersons

Ken queried the note in CE report about Vega and member database, asking what the impact would be on National Council election process. Ronelle outlined that issues persist around corrupted and duplicated data following transfer. Ronelle and Miriam Rodrigues are actively working with the Vega team to resolve the issues, and the current set deadline for resolution is 13 Feb. Heather queried what a contingency might be if the issues remained unresolved.

Ronelle identified that if not resolved team would need to manually work through backed-up data and manually add members who have joined since June 2016. This would take considerable time and labour. Heather suggested Vega be advised that National Council are extremely unhappy that this has languished and we expect results next week, and suggested a contingency action plan be developed.

Branch AGMs set: Northern 08 April, Southern 04 March, Canterbury 18 March, Wellington 26 February.

SIP ventilator – escalating to Finance Committee, donation paperwork completed, accepted ownership at \$15,000 book value, with good documentation between us and user.

Move that the Chief Executive's report be accepted.

Moved by: Warren

Seconded by: Ken

All Agreed

4. BRANCH REPORTS

Reports taken as read unless otherwise noted.

Northern Branch

Events - great Christmas party with 92 people attending. Last weekend held Whangarei picnic, thanks to Ken for organising the town basin and great weather! Investigated Marsden Point campground – price was too high but they've dropped \$3,000, so will book and run May camp there. Looking at organising picnics in Greenlane and Hamilton Gardens to engage those regions, plus Wheels on Ice again at Ice Skating rink in Auckland.

Constitution – wanting to amend few points, bringing to National Council because of how meetings dates fall. Proposing the following:

1. Two year term on branch committee (to align with National Council and for continuity), so odd/ even years for half of committee.
2. Chairperson to automatically be Branch Representative on National Council;
3. Communications – Northern constitution has nothing documented, so would adapt from national constitution.

Raewyn noted that any changes to any constitutions have to go to special meeting/ AGM – Trevor will ensure this happens. Ken queried whether the key roles of Chair & Vice Chair will be maintained as odd/even to ensure continuity. Trevor confirmed that the branch does not have a Vice Chair, but a Chairperson, Treasurer and Secretary. Chairperson and Treasurer will be on alternate years.

Move that the proposed Northern Branch constitutional changes be endorsed by National Council as outlined in the paper circulated by the Branch Chairperson, subject to approval by branch members at their AGM.

Moved by: Trevor

Seconded by: Ken

All Agreed

Canterbury Branch

Heather expressed concern re; financials. Ken noted the year-to-date deficit is \$40,000, but have reserves which could be cash or investment. Warren advised communication has been weak, working to address this. The branch is very reliant on Eris as grants fundraiser, who retires in April. Ronelle will ensure handover with new office manager. The branch had a long-standing fundraiser who sadly passed away before Christmas. Potentially a time for renewal and revitalisation, but definitely challenges ahead.

Southern Branch

Raewyn noted that since starting the fieldworker service, Jo's been very busy and doing a tremendous job. Some grants received. Have spent more than income, but had reserves to start fieldworker service. Financial position is somewhat concerning, but the branch is feeling positive - expecting to hear soon, the outcome of a Lotteries grant application and have scheduled to apply for other grants.

Raewyn wants to resign as Chairperson and AGM notice and nomination forms have been sent to all members. It is hoped that Jo's arrival will increase member engagement and the branch committee needs some commitment from local members. If this is not forthcoming, the future of the branch will have to be explored - Raewyn happy to spend time visiting members seeking input on what the branch's future might be.

Warren enquired how Jo manages to cover region in 20 hours per week, Raewyn advised she does very well managing these hours. In future, 25-30 hours might be better resourcing, but this it is early days and dependent needs of the area and funding availability.

Wellington Branch

Report not available, Ronelle passed on Peter's apologies. Peter has signalled that he'll stand down at their AGM. The branch has struggled with preparing accounts, due to staff turnover in Office Manager role and Treasurer not very available. Ronelle states the branch are in a stronger position than last year and are likely to achieve a small deficit position. Elizabeth McCallum started as new office manager last week.

Lost visibility of AGM notification/ nomination process during staffing change – have just picked up that the appropriate time for nominations has not been allowed, so the branch is in breach of their constitution and could be challenged. Heather and Sophie highlighted importance of seeking legal advice and ensuring council are covered in this unprecedented circumstance, technically the meeting cannot be an AGM without appropriate notice.

Move that in light of information regarding notification of AGM and seeking nominations being outside of constitutional requirements, legal advice would urgently be sought as to how to remedy, and Peter Tegg (Branch Chairperson) consulted and included in discussions and actions.

Moved by: Heather

Seconded by: Sophie

All Agreed

5. MINUTES OF PREVIOUS MEETING

Clinical Advisory Group

All read, please send feedback, still in working draft stage. Ken queried why children, young adults and adults are specified separately (instead of just "members") – Heather advised that funding silos exist and we need to denote these groups to effectively advocate for seamless, holistic care from paediatrics to adulthood. Ken also noted the importance of being specific (eg: references to "code of conduct" need to specify which code). Heather supported Ken's comments, noting that conditions and context need strengthening.

Ronelle would like to engage clinical partners (eg: Richard Roxburgh) in reviewing the draft, Heather approved forwarding the document to them now (watermarked as "draft terms of reference for review"), seeking their feedback at the same time as National Council.

Branch Agreement Update

Ronelle reported on a productive workshop with Branch Chairpersons - very strong engagement – good, robust discussions, including focus on RBA and reporting accountability. The draft agreement circulated was worked on at the workshop, with agreed amendments highlighted. The new document is quite different to the existing branch agreements and hasn't yet been distributed to branch committees. Now seeking feedback and comments from National Council. Heather agreed that the workshop was very positive and made good headway. Legal advice still to be sought regarding intellectual property.

Ken noted the commitment made earlier, for National Council to get a minuted record of the workshop, however, only the draft agreement and a 1-page action list was received. Ken noted he was dissatisfied with this and has many questions. Ronelle advised the workshop was a conversation more than a structured meeting and would have been difficult to minute. Heather added that there were extensive discussions around the history of the agreement, so the summary of the workshop is effectively the draft document and action list.

Heather highlighted the purpose of the agreement as providing a more formal construct between branches (as the funder) and national office (as the provider) of services. Heather and Ronelle drew up this draft using an existing health and disability sector agreement as a template, then refined for our purposes. Ronelle added that the agreement recognises branches as funding services that national office delivers (ie: employees), and gives power to branches to hold national office accountable for these services. The funder/ provider construct seemed most appropriate, but consultation is needed to ensure it fits our needs, defines the shared relationship and provides an appropriate contractual foundation.

With branch chairs keen to send the draft to their respective committees, it was agreed that the draft template be re-circulated to all governance members for a month of consultation, with feedback to be gathered and collated by Ronelle and Ruth. Heather would like to see more of preamble to seeking feedback, potentially with specific questions. Ideally feedback to be integrated into new draft for discussion by special teleconference late March.

9.10pm – Olivia and Sophie left meeting. Quorum no longer present.

Annual Operating Plan - resolution to be endorsed by email.

DMD Reference Group – hold over to next meeting.

National Council Handbook – resolution to be endorsed by email.

6. NEW BUSINESS

AGM/ Council Elections

National Council members who are reaching the end of their two year term, must be re-elected if they want to serve another term. Members have been asked to confirm their availability to stand for another term or whether they intend to stand down completely.

Ronelle seeks confirmation again as she is planning the member mail out and will call for nominations next week, then moving to voting process if the nominations exceed the positions available..

Heather advised Council she is standing down from both Chair and National Council, having served on Council since 2009. Heather notes the last two years have been time consuming and required energy and commitment. While she is happy to advise the incoming council, it is time for her to step down.

Ronelle provided a summary report to the National Council identifying the current threats to leadership continuity, due to timing of Chairperson and Vice Chairperson being due for re-election at the same time. This dates back to 2013 and is an unfortunate circumstance for the organisation. This highlights the need for succession planning and perhaps taking steps to maintain organisational stability and leadership continuity. To mitigate risks, National Council would need to propose a constitutional change – consult with members, and adopt at the AGM on 28th April.

Action: Heather and Ronelle to investigate timing around making these changes.

Meeting closed at 9.30pm.