



## Muscular Dystrophy New Zealand

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

Held 9.00am – 2.30pm, Saturday 29 April 2017  
At The Distinction Hotel, 100 Garnett Ave, Te Rapa, Hamilton

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

**Present:** Ken Green (Chairperson), Trevor Jenkin (Vice Chairperson), Ronelle Baker (Chief Executive), Warren Hall (Canterbury Branch Representative), Jan Daly, Robbie Verhoef (Southern Branch Representative), Andrea McMillan, Kerry Stephenson, Annelize Steyn, Brent Walker (joined late), Brian Hadley (for financial reporting), Tristram Ingham (by teleconference), Olivia Shivas (by teleconference)

**Minutes:** Ruth Church

Ken asked Sophie Tamati to open the meeting with karakia and waiata. Sophie welcomed all on behalf of Tainui and offered best wishes. Ken thanked Sophie for her work on council. All present gave introductions. Ken acknowledged council members who have moved on, including Derek and Raewyn who were both committed long-serving members. Ken highlighted the wonderful job Heather did as Chairperson, and thanked Sophie for developing our waiata, which Ken would like to see performed at each meeting and gathering.

*Moved that National Council support nominating Raewyn Hodgson for a QSM or civic award to recognise her 24+ years of service.*

**Moved by: Robbie**                      **Seconded by: Kerry**                      **All Agreed**

*Moved that Raewyn Hodgson be confirmed as a life member of MDA.*

**Moved by: Trevor**                      **Seconded by: Robbie**                      **All Agreed**

With Ken moving from councillor at large to Chairperson, a casual vacancy has been created on council. Brent Walker proposed as candidate. Because this casual vacancy will be filled by resolution (as per Clause 11.1 of the Constitution) the role will be for one year (not two years per an elected councillor). New Northern branch representative to be advised following their pending committee meeting, as Trevor has moved into role of Vice Chairperson and recommends another Northern committee member take up the branch representative role.

*Moved that National Council appoint Brent Walker as Councillor at large, to fill casual vacancy created by Ken Green, under Clause 11.1 of the Constitution.*

**Moved by: Ken**                      **Seconded by: Kerry**                      **All Agreed**

Reminder to all that minutes of National Council meetings are public record (accessible via website). Any confidential matters should be flagged as "in committee", where non-council members (including the CE) will be asked to leave and no minutes taken.

## 2. **(National Councillors' Handbook – to be discussed when Brent Walker joins meeting)**

### 3. **FINANCIAL REPORT**

Consolidated group position - 2016 was first year to record financial results as consolidated group, including branches and NRFT. National office reached break-even position for 2016, but when combined with branches (some of which have done well, others not so well) result was overall deficit of \$98,000. Result is double-edged sword – great that we're giving contributing strongly to the community, but there are sustainability issues. Throughout the year there has been strong governance and diligent management, which is positive.

Going forward, the Finance Committee must broaden its scope to review each entity monthly, so more proactive and close monitoring occurs, as National Council is now responsible for operational and financial results for whole group.

Trevor tabled government bill and letter, and queried national body responsibility when branches are "autonomous" and not "controlled". Ronelle highlighted expert advice was sought prior to financial audit taking place and described the national body as having "influence" over branches, due to shared membership, strategic framework, and national governing structure involving all branches. Team work as a group of entities is the way forward, to ensure we are all able to continue to serve our membership.

As Chief Executive, Ronelle has managerial oversight of the whole group, but there are some gaps in reporting and visibility of information. It makes sense to include all Branch Chairpersons in the Finance Committee, as they key forum for financial discussions. This would add value and also provide professional development for the Branch Chairpersons. Ken noted the national body also underwrites all branches and can continue funding for one year if branch falls over. Jan questioned whether national office applying for funding then distributing to branches would be better – Ken noted the focus is moving to community-based funding, so national body applications are being turned down by many grants funders.

Brian advised that the 2016 NRFT deficit (which contributed to the group position) was one-off and unlikely to recur, as NRFT now in prospective funding. Partly caused by transition of Chief Executive role (including no revenue applied for in 2016), and poor record keeping. NRFT maintains separate accounts and has a very small reserve from seed funding. The Trustees of NRFT were aware and informed of the financial position, however NRFT financials will also need to be more visible to National Council going forward.

Kerry asked if we can help branches get out of deficit – Ronelle and Ken noted the need to be supportive, including stronger support and up-skilling to help branches get ahead. Ken stressed the importance of branches being open and transparent – please speak up early to avoid surprises!

***Action: Trevor suggested restarting the branch chairpersons' forum, to meet before National Council meetings and share ideas (to include Ronelle where appropriate). All agreed.***

Annual Report - Ken highlighted pie charts which show 50% going to member services. On income chart, telemarketing has been isolated as long-term goal is to live without it – have reduced contract to yearly (from two-yearly). Future aim of CE & National Council is to explore new long term options (including social enterprise).

Finance Committee - minutes circulated in e-mail packs and tabled, discussion focused on March 2017 results as this gives a three month position (first quarter) which is a better indicator. National office net profit year-to-date \$40,311 against budget \$42,474 so very close. Role of finance committee and executive team is to question variances - ask "why" – to identify what needs to be improved/managed, or if all on track.

Telemarketing improved, donations under budget by \$20,000 – over-forecasted, plus Stern Foundation funds came in as grant not donation (banked 31 December 2016, but recorded as 2017 due to compliance with how funds will be spent, so effected results). Some anticipated grants not yet received (Lions grant \$30,000 declined, ILS have granted \$9,000).

***Action: Finance Committee to look at grants/ donations alignment to ensure appropriate recording.***

Ken thanked Ronelle and Brian for keeping costs down. March had three pay cycles which pushed up salary costs, plus cost of branch agreement meeting in January pushed up governance costs.

Balance sheet – Brian does great job maximising interest. Net equity \$1.9million, was \$1.88 same time last year so maintaining position which is good. Budget end-of-year position looking good after three months of actual data, should break even at year-end.

***Moved that the financial report for March 2017 be accepted.***

**Moved by: Ken**

**Seconded by: Warren**

**All Agreed**

11.05am Brent Walker welcomed to meeting.

#### **4. APPOINTMENT TO SUB-COMMITTEES**

##### Finance Committee

Previous members were Heather, Ken (Chairperson), Brian and Ronelle. Proposing to now include branch chairpersons, meeting via monthly teleconference. New structure will upskill branches and allow focus on sustainability, ultimately benefiting our members. Note that Andrew Munro Branch Chairperson for Canterbury is not the Canterbury Branch Rep and not a sitting member of Council. Need to ensure we are not in breach of our Constitution inviting Andrew Munro onto a sub-committee of the National Council.

***Moved that the Finance Committee (as a sub-committee of National Council) be comprised of Ken Green (Chairperson), four branch chairpersons, and Ronelle Baker and Brian Hadley as guests.***

**Moved by: Ken**

**Seconded by: Jan**

**All Agreed**

## Remuneration Committee

Policy defines membership of remuneration sub-committee as Chairperson, Vice Chairperson and a representative of the Finance Committee, in consultation with branch representative if/when appropriate. Focus of committee is Chief Executive's salary, and general remuneration matters as arising in conjunction with Ronelle. Usually holds two meetings per year.

Andrew Munro has extensive HR experience and could offer expertise to Remuneration Committee. Ken proposed to include Andrew – as long as he is eligible as the Finance Committee representative. All agreed to approach Andrew pending above action.

***Action: Ronelle to check Andrew's inclusion in Finance/Remuneration Committee wouldn't breach constitution, then discuss with Andrew.***

## NRFT Representative

Ronelle advised NRFT trustees meet quarterly by teleconference, the Trust is well managed by Arthur Young and all other trustees are all involved in clinical research. Tristram Ingham was invited and agreed to be National Council representative on NRFT.

***Moved that Tristram Ingham become the NRFT representative.***

**Moved by: Ken**

**Seconded by: Jan**

**All Agreed**

*11.25am Tristram Ingham left meeting. Ken thanked Tristram for his time and commitment.*

## Members Discretionary Fund Representative

To date this has been a representative from each branch committee, plus National Council delegate. Ronelle asked how members felt about the workload, as conscious of not overburdening. Process is well set up, with four funding rounds per year, but still requires time and resourcing, so big commitment. Ken feels the position should rotate to ensure transparency, two-year term suggested. Kerry keen to stay on and do another year as National Council rep, which also gives consistency when new branch representatives join. Local committees to decide and advise chosen representatives by email confirmation to Ronelle.

Trevor extended thanks to Tonya for her great work in getting this set up. Ronelle advised that responsibility will move to Miriam Hanna as a permanent role.

## **2. NATIONAL COUNCILLORS' HANDBOOK**

Ken asked that all councillors (existing and incoming) ensure they're familiar with the handbook, which was revised in 2016.

Ken reiterated public nature of council minutes, and process for confidential matters. General points to note include: two-year term for elected councillors, avoiding conflict of interest where possible (should be covered at start of every meeting), councillors covered by public liability insurance, councillors entitled to reasonable personal expenses, councillors cannot be employees or contractors working for MDA, and that if a councillor misses three consecutive meetings without reason they may be asked to step down.

It was acknowledged that this role was quite a commitment – be aware of the hours, and please endeavour to read paperwork in advance, and share information early so no surprises. When replying to email please use “reply all” so email can be discussion forum.

Code of conduct expectations as per employees: specifically around honesty, commitment to Te Tiriti o Waitangi, confidentiality, and promoting MDA.

Channels of communication – only Ronelle is authorised to talk to media (small, local media excepted), please contact her in the first instance for any media matters or identified risks.

Annelise asked if handbook can be used for branch committees, Ronelle said definitely, just change “National Council” to “branch committee” as appropriate.

***Action: Ronelle to email Word version of handbook for use by branches. Contact details on the last page to be updated to include new councillors.***

Ken noted “reasonable expenses” is still a work in progress, working to finalise guiding document including parameters for expenses. Robbie asked if councillors can offer accommodation to others in their homes, Ronelle agreed with staff and council, but not appropriate with members.

## **5. PNEUMONIA VACCINE**

Ronelle introduced Miriam Hanna, Information and Resources Coordinator at National Office, who brings great skillset and pharmacy background to the team. Miriam acknowledged three nursing students who have been working on this project as part of a student placement with MDA.

Miriam outlined risks of pneumonia for people with NMCs. MDA recommending flu and pneumonia vaccination, with reimbursement available for unfunded vaccine Pneumovax 23 to the value of approx. \$70. Vaccination recommendations are included on the MDA website and being sent out in new member packs.

Two different pneumonia vaccinations are available – Pneumovax 23 (which covers 23 strains, cost approximately \$70), and Prevenar 13 (which very thoroughly covers 13 strains, cost approximately \$200). Ideally both vaccinations should be used. Children under five are now routinely receiving Prevenar 13 as part of national vaccination schedule, so those children would only need Pneumovax 23.

MDA will currently reimburse members for Pneumovax 23 at roughly \$70, not affordable at this stage to cover both. Possibility to consider funding “high-risk” members but further analysis and cost modelling required. .

Member survey completed with high response rate, and now using survey results to inform a submission to Pharmac to fund these vaccines for people with NMCs under the high risk category. Also continuing education with members and GPs.

***Action: Ronelle to circulate email copy of Miriam’s presentation, and come back to National Council with proposal to more comprehensively fund high-risk members.***

12.35pm Olivia Shivas left meeting. Ken took the opportunity to remind all that today is an opportunity to get to know each other, and set ourselves up for the year ahead.

*Idea of name tags raised – all agreed to go ahead with pin name badge, detailing name and “MDANZ National Council”. Trevor has contacts and kindly offered to facilitate.*

*Action: Trevor to send information to Ronelle to progress name tags.*

## **6. CHIEF EXECUTIVE’S REPORT**

Taken as read, as previously sent.

*Moved that the Chief Executive’s be accepted.*

**Moved by: Jan**

**Seconded by: Warren**

**All Agreed**

## **7. BRANCH REPORTS**

No reports tabled today.

Warren gave brief report for Canterbury branch – February year-to-date deficit \$8,000, cash reserves \$16,000, no March results available yet. Canterbury have disposed of almost all surplus equipment. Recent Rata Foundation grant application has been successful, Warren thanked Ronelle and Eris for helping facilitate. Ronelle noted flowers given to Eris who is retiring, plus gift and card sent.

*Action: Ronelle to communicate monthly financial reporting and operations report expectations to branch chairpersons, in preparation for next National Council meeting.*

## **8. BRANCH AGREEMENT TEMPLATE**

Ronelle still waiting on legal advice regarding intellectual property, otherwise no additional feedback has been received since last National Council meeting.

Annelize queried process and timeline. Ken summarised the need for new agreement that focuses on National Office as service provider and supports future funding options. Current agreements developed from 2010 and no longer fit for purpose, so new document will formalise what’s effectively already in place in generic agreement, consistent across all branches. Ultimate goal is to provide best service to members, this agreement is designed to fill gaps and ensure consistent expectations and requirements across the group (including financial reporting). Workshop held in January to start work on initial draft, this version is result of feedback. New branch committees now need time and space to discuss.

*Action: Ronelle to email template to Annelise as working document.*

Trevor concerned about “shared risk” around funding (e.g.: if a branch goes down it can pull others under), and escalation process, with focus on maintaining service to members. Ronelle noted addition of “Roles and Responsibilities” section which needs to be reviewed by the parties.

Ronelle offered to prepare a template for feedback if necessary to facilitate branch committees and discussions.

All agreed branch chairpersons to focus on template with their respective committees, with view to coming back to progress to final version at next face-to-face council National Council meeting

(minimising other agenda items if necessary). Branch chairpersons to send feedback before council meeting to allow time for others to digest and consider, all can then come to meeting prepared. If feedback is negative please offer suggestion/ alternative, remembering focus on members. Consider working on the document "live" at next meeting, then passing resolution to agree final version by email, before signing (to all be complete by end August 2017).

Once this document is complete, Ronelle wants to move on to outcomes reporting framework, building on the RBA presentation that Heather did last year and looking at how we measure and report what we do and how we do it. Ronelle noted that the previous CE had reported KPIs to council using a balanced scorecard methodology. Ronelle keen to see a more RBA and quality based methodology, focussed on improvement strategies. Easier to achieve in a small team environment, where new things can be tested, changed and re-tested. Ken suggested Ronelle circulate more information outside of the meeting.

*2.30pm Ken requested the meeting be drawn to a close, with closing words from Brent Walker as a resident of Hamilton. Brent thanked Ken as chairperson, and thanked everyone for coming to Hamilton, and for the opportunity to be part of council discussions. He looks forward to the year ahead and working together.*

**Meeting closed at 2.35pm.**