



Muscular Dystrophy New Zealand

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

Wednesday 13 December 2017, 7.00pm by teleconference

Attendees: Ken Green (National Council Chairperson), Robbie Verhoef (Southern Branch Chairperson), Andrew Munro (Canterbury Branch Chairperson), Trevor Jenkin (Northern Branch Chairperson), Annelize Steyn (Wellington Branch Chairperson, with apologies for lateness), Kerry Stephenson, Warren Hall, Michael Schneider, Tristram Ingham, Jan Daly (with apologies for lateness), Andrea McMillan (with apologies for lateness)

Apologies: Brent Walker

Present: Ronelle Baker (Chief Executive), Adam Bouman (incoming Executive Assistant)

Minutes: Ruth Church

1. Welcome & Declarations of Interest

Ken welcomed all, including Adam, and invited a quick round to share recent positive news. No new declarations of interest were recorded.

Annelize – attended Nikau Foundation presentation of grants certificate, really makes it real and great to be representing MDA.

Michael – good camp last weekend, well attended and enjoyed, great weather. Proactive and positive committee, looking forward to 2018 and increasing member participation.

Olivia – busy few weeks, working with Natalie and Tonya on Facebook project.

Robbie – \$4,000 donation from Bronze received, very grateful for their support.

Trevor – great camp, all our organising was well worth the outcome, already receiving very positive responses.

Tristram – met staff of FSHD Global while presenting in Sydney, looking forward to building relationship. Research trust has funded all research applications this year, very positive.

Warren – Nelson has very successful monthly coffee group of 30 plus members, expecting similar numbers to Christmas dinner. Pop-up wardrobe not as successful as hoped but lessons learned, and great cooperation between committee, families and volunteers. Branch seems very cohesive, 2018 calendar done.

Ronelle – three things: meeting new Disability Rights Commissioner Paula Tesoriero, very positive discussions about our community's needs; establishment of SMA member reference group, first meeting held yesterday; and attending northern branch camp with family, great event.

Ruth – great in-service held recently, staff working cohesively and lots of good sessions and relationship building.

Kerry – meeting Napier District Council and being part of decisions around new public toilets which will feature hoist and bed, great result. Lending out beach chair, and seeing disability group growing in Hawke's Bay.

Andrew – per Warren's summary, agree that pop-up wardrobe demonstrated great organisation and cooperation, and raised a reasonable sum, happy to share event plan with other branches. Lots of energy in committee, barbecues all well attended, planning for March 2018 adult camp well underway.

Ken – attended "Getting out there" expo with Miriam Hanna, met lots of people, great event. Thrilled by Hyundai's support and generosity.

6. Minutes of Previous Meeting

Ken assured council members that the "in committee" portions of the minutes will be removed and a version of the minutes without these details will be saved for publication as usual. The version containing "in committee" discussions will be held confidentially in national office records.

Moved that the minutes of the previous meeting (14 October 2017) be accepted.

Moved: Andrew

Seconded: Tristram

All agreed.

Matters Arising

[Confidential *In Committee* matters removed]

2. Financial Reporting

October 2017 Finance Committee minutes circulated. National office doing sterling job, income down slightly but very good cost constraint which offsets this, so about \$2,000 positive year-to-date.

Balance sheet – net equity \$1,934,000, this time last year \$1,830,000, so value for members is up. Cash balances \$968,000, last year was \$855,000, so looking good. Non-cash accounts (receivables) up slightly due to branch debt. Performing well in general.

End-of-year – collective group looks like cash deficit of \$27,000 projected forecast. National office surplus, less debt – write off \$31,000 as Wellington branch can't pay invoices owed for wages. When all washed up, worst case scenario will be \$10,000 group deficit, best case will be break even. Critical factor will be introducing two new Hyundai cars before year-end, and they recommend a fair market value as \$24,990 (incl GST) for insurance purposes. Very strong month from One4All, \$87,000 donations confirmed for November, though November accounts are not yet available. Ken commended this position, hoping to see best case scenario, reflecting hard work to get us to a better position now.

3. Chief Executive's Report

Taken as read and accepted, with following additions.

Ronelle notified council that decision made in consultation with Ken to offer token of thanks to all staff with Christmas card and \$50 New World voucher, acknowledging their efforts through a challenging year. Card was signed from Ronelle & National Council and was received positively.

Ronelle has been working to get meeting with new Minister for Disability Issues, Carmel Sepuloni - meeting now confirmed with visit to national office booked 2nd February 2018.

Member's discretionary fund – final round completed for 2017. Ronelle acknowledged and thanked all panellists for the huge amount of time and energy given to this process. Looking forward to fund continuing in 2018. Tonya currently finalising report for the year and will be circulated at Feb meeting.

Warren queried progress on tenancy of back office space – Ronelle stated that Northern Branch were offered first option but declined at this time. Now in discussions with Motor Neuron Disease Association (MNDA), but they are locked in current tenancy until June. Budget assumptions made on having tenants from March 2018, at a rate of \$1000 + GST per mth.

Ronelle acknowledged Trevor's contact at Seagar's for building valuation, thank you Trevor. Seagar's sent valuer who did original valuation in 2012, and was impressed with our improvements. Valuation tabled and accepted, \$600,000 purchase in 2012, valuation now \$1,050,000. Ken raised three points: 1) governance has fulfilled its obligation to maintain assets, 2) Brian and auditors should not be depreciating building as its going up not down, 3) should we be doing valuation reserve to reflect this in balance sheet? Michael queried impact of new valuation on insurance – Ronelle advised insurance to be examined in first quarter 2018, will report back after then. Warren queried earthquake percentage – Ronelle to follow up as that information not provided (noting 30% is acceptable). Tristram queried whether moving from historic cost to new valuation commits us to regular valuations – Ronelle to check with auditors.

Action: Ronelle/Brian to follow up on queries raised above following new valuation.

4. Branch Reports

Ken hadn't received any branch reports, but thanked and congratulated Wellington and Southern on their excellent recent branch newsletters.

Southern – Robbie advised no issues to raise, estimating better surplus year-end result following \$4,000 BRONZ donation.

Canterbury – Andrew advised should be close to break even, nice to be in that position for funding applications in 2018, Ken congratulated Canterbury on strong result. \$4,000 loan to national office has been repaid, plus arrears of outstanding invoices for wages. Warren queried reimbursement to Canterbury for branch manager's work on Southern grant applications, Ronelle said still working on process, her time has been minimal to date, but will be arranged as more time is expected from Jan 18. Robbie thanked Ronelle and Canterbury branch for their efforts and support with Southern admin & grants.

Wellington – Annelize made contact with their auditor, meeting early next year. Christmas party coming up, expecting 10% of members will attend, increasing awareness. Ronelle working with branch manager around grants applications becoming main source of income, to try and turn around deficit position.

Northern – Michael thanked Trevor for his efforts in figuring out projected deficit, which had increased over year and needed investigation. Ronelle and Trevor met with accountant to work through, now nowhere near as bad as originally thought, largely due to branch reporting template focussing on cashflow. Finance Committee to discuss how to get best information going forward.

Branch reports all accepted as verbal reports.

Ronelle discussed planning cycle – running behind, don't have annual report/ provisional budget for discussion at this meeting. Branch provisional budgets received. Starting from negative position, includes Wellington almost \$50,000 deficit, small Northern deficit, and research trust deficit – so potentially another tricky year ahead. Canterbury projecting \$11,000 surplus, Southern \$3,000 surplus, National \$5,000 surplus. Highlights importance of regional presence for grants applications going forward, and of demonstrating member engagement.

Discussion held regarding role of volunteers and coffee groups in regions to increase visibility and connection. Ronelle noted that the support network already in place, and that any change to service model would need frameworks around them. Ken suggested separate brainstorm session around engaging members, ideally at face-to-face council meeting.

Ronelle expects draft budget/ operating plan on Friday with provisional budget for new year, to then be endorsed by Finance Committee at special January meeting.

Action: Finance Committee special teleconference to be diarised for week ending 12 January 2018, to review provisional budget, then present to National Council meeting in February 2018.

Tristram expressed discomfort with no approved provisional budget so the CE can continue operational functions. Ronelle pointed out provisional budget was submitted to Finance Committee in November though limited discussion took place. Tristram sought assurance that in absence of provisional budget, the organisation will still be functional. Ronelle has discretionary authority to \$10,000 unbudgeted Opex, payroll can be up to \$20,000.

Move that December 2017 budget rolls over as provisional budget for January and February 2018, to allow continued operation.

Moved: Tristram

Seconded: Jan

All agreed.

5. AGM

Ronelle noted 20 April 2018 as national AGM, and asked that any if any Councillor terms are coming to an end, can council member please indicate if standing another term. Andrea advised she won't be standing again. Olivia clarified that she turns 26 within the next two-year term, after which time she won't be able to continue as Rangitahi Rep due to age. Brent will have been on council for the allotted 12 months at next AGM.

Branch AGM dates – Southern 10 March, Wellington 07 April, Canterbury and Northern to be advised (both will be in March).

5. New Business

Warren thanked Ruth for her contributions and wished her all the best as she finishes this week.

Tristram highlighted research trust report which was circulated. Taken as read and accepted. Main source of income has been Richdale Trust, majority of funding goes to registry, which is a critical resource. Great to have been able to fund all research applications this year, mix of clinical and translation, balancing investigative research and needs of members, mindful of research priorities. Will review assessment schedule and application process to add robustness. Will discuss ways to be more self-sustaining in terms of operating overheads in new year. Ken acknowledged generous support of Stern Foundation grant of \$16,500 for work done by registry, and highlighted that we

should be encouraging members to join registry. Tristram raised possibility of Trust producing its own report as a marketing tool – also to be discussed by trust in new year.

Ken noted that current MDA brochures don't list conditions we cover, suggests we consider this for future.

9.20pm – Ken closed the meeting, thanked all for hard work and dedication, have come a long way this year. Happy and safe Christmas to all.