



Muscular Dystrophy
New Zealand

Minutes of the National Council of the Muscular Dystrophy Association of New Zealand Inc. (MDANZ)

Held 9.00am – 3.00pm, Saturday 9th November 2019
at the National Office, 419 Church Street East, Penrose.

Attendees: *Councillors:* Trevor Jenkin (Executive Chairperson), Jan Daly, Scott Laurenson, Dr Tristram Ingham, Bernadette Ingham, Mike Schneider, Matthew Willetts, Andrew Willetts, Scott Boyle and Joy Jenkin.

Apologies:

Minutes: Natalie Foote (Board Secretary)

1. Welcome

Trevor Jenkin welcomed everyone to the meeting at 9.03am.

2. Apologies

No apologies were noted.

3. Declarations of Interest

No new declarations of interest were raised.

4. Matters Arising

4.1 Minutes from October Meeting

Moved that the minutes of the In Committee meeting held 2nd October are approved as a true and accurate record.

Moved: Trevor Jenkin

Seconded: Jan Daly

All agreed - motion carried.

4.2 Action items

The following actions are outstanding;

1. **Action: Tristram Ingham, Trevor Jenkin and Natalie Foote to develop a generic template description for each portfolio.**

Trevor Jenkin, Tristram Ingham & Natalie Foote

- This action item will be carried over to the next meeting.

2. **Action: Formalise and distribute the Volunteer Policy**

Trevor Jenkin

- The National Council discussed and agreed that this policy is outdated and is no



Muscular Dystrophy
New Zealand

longer fit for purpose. The policy needs to be re-written with a branch affiliation.

3. Action: Trevor Jenkin to investigate options for Cough Assist machine leasing.

Trevor Jenkin

- This action was complete and covered in the meeting content.

4. Action: Canterbury Branch

- Trevor and Brian Hadley to send a proposal and corrected budget for the two options to the National Council.*
- Trevor to discuss the increase in hours for the Canterbury/Southern Community Co-ordinator role with Justine Foden.*

Trevor Jenkin/Brian Hadley

- This action was complete and covered in the meeting content.

5. Action: Obtain a second quote for migrating the server to the Cloud. This is due to no insurance for the current server.

Trevor Jenkin

- The second quote will be covered in the meeting content.

5. Circular Resolutions

The following resolutions were circulated to the National Council:

17th November 2019 – Moved that the out of budget expenditure of \$2,500 for branch morning teas for volunteers be approved.

Moved: Trevor Jenkin

Seconded: Tristram Ingham

All agreed - motion carried.

6. Financial Reporting – Not for Distribution

6.1 2019 – 6 Months to Date

On behalf of the Finance Committee, Trevor Jenkin provided an update on the finances with the key points highlighted below;

- The One4All income is budgeted at \$90,000 on average per month but for the past few months this has been significantly down with an income for June of \$17k.
- Trevor noted the forecasted net cash surplus of \$115k vs. a deficit of \$68k for 2018.

The National Council discussed the finances and questioned the income from the Community Power scheme and asked Trevor to follow up on this.

Action: Follow up on Community Power scheme income in the budget.

Trevor Jenkin



Muscular Dystrophy New Zealand

The National Council requested that the reporting template of the Financial Report be amended to a more user friendly and easier to read format.

Action: Amend the reporting template of the Financial Report.

Trevor Jenkin

Trevor Jenkin moved that the finance summary for the 6 months to date be approved.

Moved: Trevor Jenkin

Seconded: Bernadette Ingham

All agreed - motion carried

Tristram Ingham moved, on behalf of National Council, that the Vice Chairperson applies to the Te Poe fund for a grant for funding National Council meetings, training etc.

Moved: Bernadette Ingham

Seconded: Jan Daly

All agreed - motion carried

6.2 Budget Review

The budget review was discussed in section 5.1 of the meeting. The draft Annual Operating plan will be discussed and approved at a separate meeting in November, and a budget will then be allocated against the initiatives.

7. Councillor Portfolio Update

The National Council discussed the portfolios and the need for each portfolio to have a role description and a term of reference. Brief verbal discussions were held on each of the portfolios.

Tristram Ingham discussed the Councillor Portfolios as being 'Board Champions' or someone in a leadership role who takes on a strategic portfolio interest in a certain area. Tristram noted that the caveats of these roles are blurred accountabilities and role confusion, but the positives of the role are making connections, mobilizing resources in the broader communities, providing support for organisational initiatives nationwide and ensuring that change is implemented and to defer resilience. The Councillor Portfolios will work alongside the MDANZ Operational staff.

Action: Tristram Ingham, Trevor Jenkin and Natalie Foote to develop a generic template description for each portfolio.

Trevor Jenkin, Tristram Ingham & Natalie Foote

8. Finance Sub-Committee

8.1 National Finance Sub-Committee Minutes

Moved that the minutes of the meeting and recommendations of the meeting held 30th May are taken as read.

Moved: Andrew Willetts

Seconded: Trevor Jenkin

All agreed - motion carried.



Muscular Dystrophy New Zealand

9. Programme & Service Advisor Report

The National Council discussed the Programme & Service Advisor's report in depth. There was agreement that the report does not cover what the Programme & Service Advisor's role is and what the role is doing against the KPI's, for example the Neurological Alliance partnership and how it relates to MDANZ. The National Council requested an amended report as per the template of the Marketing & Communications Manager's report.

Action: Trevor Jenkin to request an amended Programme & Service Advisor Report as per above.

Trevor Jenkin

The National Council discussed the SMA Reference Group and the request for \$1,200 for a face-to-face meeting in 2019. The National Council agreed that the group is doing a lot of work in a current and subjective period with the funding requests to Pharmac for Spinraza, and that the meeting would be of benefit to the membership. The National Council agreed on the out of budget expense but asked that the Terms of Reference are reviewed at the 2019 meeting with the look for a MDANZ member to Chair the Reference Group and for the 2020 work programme to be established and the costs of the next face-to-face meeting worked into an operational budget. It was also agreed that a MDANZ staff member can be in attendance to facilitate the meeting.

Moved: Tristram Ingham recommended an out of budget expense of \$1,200 for the SMA Reference Group strategic planning session and resolved that the Terms of Reference be reviewed at this meeting to include that the group is chaired by a member. MDANZ will contract one of the members of the group to facilitate the meeting and will consider a facilitation fee to cover expenses.

Seconded: Andrew Willetts

All agreed - motion carried

Moved: Trevor Jenkin moved for an out of budget expense for a facilitation fee for the SMA Reference Group facilitator.

Seconded: Andrew Willetts

All agreed - motion carried

10. Marketing & Communications Manager Report

Natalie Foote provided the National Council with an update on Marketing & Communications and noted the following key points;

- A full review of the 2019 Annual Appeal will be completed, and preparations will begin for the 2020 Annual Appeal. A key suggested change is to remove and phase out the word 'Freedom' which causes confusion and unawareness with the public.
- The 2020 'Conference' will be a series of regional workshops around the country focused on specific conditions. The aim is to host two to three workshops per North Island and South Island which would make attendance much more feasible for our members. Allowances will be made for those from the opposite area of the workshop to attend if they are a member with that specific condition.
- The September Direct Mail went out on the 23rd September to around 10k of our donors. This Direct Mail was focused on Mike Nolan, a member from the West Coast. Currently this DM has accumulated \$11,300 however this is expected to grow over the coming month. The next Direct Mail will be coming out in December.



Muscular Dystrophy New Zealand

Trevor Jenkin moved that the Marketing & Communications Manager Report be tabled as read.

Moved: Trevor Jenkin

Seconded: Jan Daly

All agreed - motion carried

11. National Executive Chairperson Report

The National Council raised no further questions on the National Executive Chairperson report but requested that the report is in the same format as the Marketing & Communications Manager report.

Moved: Tristram Ingham moved that the National Executive Chairperson Report be tabled as read.

Seconded: Andrew Willetts

All agreed - motion carried

12. Branch Reports

Southern Branch – Matthew Willetts

Matthew Willetts noted the Freedom Annual Appeal events were successful and raised some money for the branch. Jo Smith, Fieldworker, has resigned and the role is currently being advertised with increased hours to a flexible 30 hour a week role. Matthew noted that two Committee members have resigned due to personal circumstances and that Stacey Smith has agreed to take on the position as the new Treasurer.

Canterbury Branch – Andrew Willetts

Andrew noted that no Freedom events were held due to circumstances of the branch. The Branch have been busy focusing on grant applications etc.

Central Branch – Bernadette Ingham

Bernadette Ingham noted that the branch has had good responses to grant funding after contracting specific grant writers to the Committee. These funds have been spent on support services with the appointment of two Community Co-Ordinator's; one in Hawkes Bay and one in greater Wellington. The purpose of these roles is to organise fundraising, community events and collections. A third Community Co-Ordinator will be appointed in Palmerston North. Bernadette noted that the branch has a new Fieldworker in the Manawatu region, Talitha Vandenberg, who is a member and used to run the Mysenia Gravis group. Bernadette advised that the branch is still tying in with the 'Enabling Good Life' programme and that Governance training from a Te Poe grant is going well. The Central Region had a successful Freedom appeal month, but it was very time consuming on Committee members.

Northern Branch – Michael Schneider

Mike Schneider noted that the annual appeal presence was lacking in the wider community with public awareness still low. However, the branch had an Auckland Airport collection which went well. The Northern camp was held early November which went well but numbers lower than other years. The Committee is running well with a new member seconded to the Committee with a strong business background.

Moved: Trevor Jenkin moved that the Branch Reports be tabled as read.



Muscular Dystrophy New Zealand

*Seconded: Jan Daly
Motion carried.*

13. New Business

13.1 Cough Assist Machine Lease Proposal

The National Council discussed the proposal and it was agreed that the paper needs to include further background information on how many members are using the machines, the projected demand, the success of treatment using the machine and what other avenues could fund the machines if MDANZ did not. An assessment was also to be completed with the current members using a cough assist machine as to how much and how often they are using them.

Action: Paper to be revised with further background information as described.

Miriam Rodrigues

The National Council discussed if any research on the cough assist machine treatment had been done and it was established that there was no research known. The research was commissioned by the National Council direct to the researcher and is not associated with the NRFT as the National Council asked for a specific information project to be done regarding an operational requirement.

Trevor Jenkin moved to commission a research project on the usage of the cough assist machines, member feedback on value and quality of life impact on a long-term perspective. The research will also include research on the funding and machines leased by the District Health Board. The research will be completed by Professor Alistair Neil.

Moved: Trevor Jenkin

Seconded: Scott Laurenson

All agreed - motion carried.

13.2 Rangatahi Rep Paper

Scott Boyle tabled a paper regarding the role of the Rangatahi rep on the National Council. It was noted that the role will be replaced at the next AGM in April 2020. The key points from Scott's report were;

- Key focus on finding a replacement via Fieldworkers.
- If possible, the rep to stand on a regional Committee before being appointed to the National Council to get a better understanding.
- Be appointed to the Bradley Jenkin Memorial Fund panel.
- Further involvement with the Duke of Edinburgh participants.

13.3 Office 365 – Moving to the Cloud

Trevor Jenkin noted that Horizon Pacific had been provided with the project plan and quote from Joel Latimer (excluding price). Trevor noted that the quote from Horizon Pacific came in at \$10,500 for 86 hours work which equates to \$140.00 per hour but less hours quoted on. Joel Latimers quote was \$12,500 for 100 hours work which equates to \$125.00 per hour but allowed for more hours.

The National Council discussed the two quotes and agreed that the decision will be left to MDANZ management to proceed with provider of their choice.



Muscular Dystrophy New Zealand

Trevor Jenkin moved for the National Council to approve an out of budget expense of \$15,000 for the project.

Moved: Trevor Jenkin

Seconded: Michael Schneider

All agreed - motion carried.

13.4 NRFT

Tristram Ingham noted that he had reviewed the Terms of Reference of the NRFT and noted that the roles set out are bigger than what the current Trustees are doing which, for historical reasons, was set by MDANZ. Tristram noted that the current Trustees are there as a grant's approval committee but if MDANZ wanted the Trust to be fully funded (research, fundraising, publishing reports etc.), then a new Board would need to be sought. The National Council agreed that the current portfolio of Trustees was to be left as is.

A discussion was held regarding the Registry and whether this aligns to the Richdale Trust's framework for research, which the National Council felt it did not as the maintenance of the registry is not specifically research. The National Council agreed that they do not want the Registry funded out of the NRFT budget and will fund this separately as an operational expense of MDANZ. However, the operational budget of the Registry will not be to the full amount requested. The National Council requested that MDANZ Management speak with the Registry on how to cut efficiencies.

Motion: The National Council have reviewed the terms of the Richdale Grant and believe the registry in its current form does not meet the definition of research and therefore request that the Registry is funded separately as an operation expense of MDANZ. The National Council charge MDANZ Management with negotiating with the Registry and the DHB but give an indicative budget of \$24k for the operational running cost. The National Council also request that no international travel is budgeted for.

Moved: Tristram Ingham

Seconded: Michael Schneider

All agreed - motion carried.

The meeting went into In Committee at 1.58pm.

The meeting came out of In Committee at 2.20pm.

13.5 Draft 2020 Annual Operating Plan

Due to time constraints, this agenda item will be carried over to the next meeting.

14. General Business

14.1 2020 Meeting Schedule

The draft 2020 meeting dates were reviewed and agreed on. The Central Branch offered to host one face-to-face meeting in Wellington with an approximate date of June 2020.

15. Next Meeting

The next meeting will be held on Tuesday 19th November via teleconference.



Muscular Dystrophy
New Zealand

Signed:

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Chairperson

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Date