



Muscular Dystrophy
New Zealand

**Minutes of the National Council of the
Muscular Dystrophy Association of New Zealand Inc. (MDANZ)
Held 7.00pm – 9.00pm, Wednesday 13th February via Teleconference**

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

Apologies:

Minutes: Natalie Foote (Board Secretary)

1. Welcome

Trevor welcomed everyone to the meeting at 7.03pm.

2. Apologies

No Apologies

3. Declarations of Interest

No major declarations of interest were raised.

Bernadette Ingham requested a copy of the current declarations of interest for review.

Action: Send National Council a copy of the current declarations of interest.

Natalie Foote

4. Financial Reporting

4.1 2018 Year End Report

Trevor Jenkins tabled the 2018 Year End financials for discussion. Trevor noted that the Branch financials of the Northern and Southern branches were completed and noted the branches had good results. Trevor advised the National Council that he work towards finalising the Canterbury branch financials on Monday 18th February when he is visiting the Branch.

The National Council raised no questions on the 2018 Year End report.

Trevor Jenkin moved that the 2018 Year End Report be accepted.

Moved: Trevor Jenkin

Seconded: Jan Daly

All agreed - motion carried.



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4.2 Branch Distribution

It was noted that there is a net surplus from the 2018 Financial Year End of \$19,242. (before depreciation). Schedule A of the branch agreement item 3 states that the association will disburse a proportion of its net operating surplus to the branch, the amount of such disbursement if any will be determined by the National Council.

Rebecca Poad moved that 50% of the net operating surplus be disbursed to the branches

Moved: Rebecca Pead

Seconded: Bernadette Ingham

Against – Andrew Willetts, remaining agreed - motion carried.

4.3 2019 Provisional Budget to align with AOP

Trevor Jenkins advised the National Council that there was a need for the 2019 provisional budget to be aligned with the Annual Operating Plan. Trevor noted the need for a working group to discuss and plan this. After discussion, it was agreed that the working group would consist of Tristram Ingham, Andrew Willetts, Trevor Jenkin and Scott Laurenson.

Trevor noted that the 2019 Provisional Budget will be approved via circular motion prior to the next National Council meeting in April 2019.

5. Programme & Service Advisor Report

Trevor Jenkins tabled Miriam Rodrigues' report. Trevor provided an update on Biogen's application to Pharmac for funding of Spinraza for SMA. Trevor noted that the rare disorders subcommittee met and have deferred a decision. Trevor noted the organisations support for the SMA group and advised the National Council he would write a letter to the group acknowledging this. Trevor noted that Miriam would be preparing a press release on Pharmac's decision for MDANZ.

Trevor Jenkin

Trevor Jenkin moved that the MDANZ Programme and Service Advisor Report be tabled as read.

Moved: Trevor Jenkin

Seconded: Tristram Ingham

All agreed - motion carried

6. Membership Services Manager Report

The Membership Services Manager report was not received and therefore not tabled. Trevor Jenkins noted he will send the report when it's available.

7. National Executive Chairperson Report

Trevor Jenkin tabled the National Executive Chairperson report. Trevor noted the following key updates;

- The next 'In Touch' magazine would be sent out in May. Because the first issue of 2019 was delayed there will now be three issues sent this year. Trevor noted he had a successful meeting with the team and BPSL to co-ordinate the May issue.
- Trevor noted the employment of Denise Ganley from the Northern Branch who will be assisting the National Office with grants writing. Bernadette Ingham queried if Denise was able to assist with grant writing for the 2019 Conference which Trevor agreed to speak with Denise about.



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Action: Discuss Conference grant writing with Denise Ganley.

Trevor Jenkin

- Trevor advised that a replacement Chief Executive or equivalent role would be looked at within 6 months, but the overall organisational structure and Chief Executive role review needs to be completed first, this is in the AOP for 2019 but has a timeframe of 12 months, the upcoming 2019 National Council election outcome could change this process.

The National Council raised no further questions on the National Executive Chairperson report.

Bernadette Ingham moved that the CEO report be tabled as read.

Moved: Bernadette Ingham

Seconded: Jan Daly

All agreed - motion carried.

8. Matters Arising

8.1 Minutes from December Meeting

Trevor Jenkin moved that the minutes of the meeting held 19th December 2018 are approved as a true and accurate record.

Moved: Trevor Jenkin

Seconded: Jan Daly

All agreed - motion carried.

8.2 Action items

No action items were discussed.

9. Branch Reports - For Distribution

Trevor Jenkin moved that branch reports from now on can be either verbal or a written report (previously written reports were required) for National Council meetings.

Moved: Trevor Jenkin

Seconded: Jan Daly

All agreed - motion carried.

Canterbury Branch - Rebecca Poad

Rebecca Poad advised the National Council that after resigning from the Canterbury Branch Committee, she had been seconded back onto the Branch to assist them until the AGM. Because of timing of this change, she noted that the branch report was not submitted. Rebecca noted that after the increased budget, the Branch would end the year with a \$900 deficit. Rebecca informed the National Council that she would be interviewing for the Branch Community Co-ordinator/Office Manager role with Trevor Jenkin and Andrew Willetts this week.

Southern Branch – Andrew Willetts

Andrew Willetts noted that the Branch is going well but will end up with an end of year deficit. The main reason for this deficit is the costs associated with the new Branch Co-ordinator role however Andrew was



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seeking a funding grant to cover these costs. Andrew noted that he has been putting in a lot of extra effort for the branch of late.

Central Branch – Bernadette Ingham

Bernadette Ingham advised that the Branch is going through a change management process to restructure the region and provide improved coverage of the field service work. This process was necessary to undertake due to the Manawatu/Whanganui region being under resourced. As a result of looking at the redistribution of field worker hours, an increase of 10 hours per week was required to cover the area entirely. Bernadette noted that grant funding will cover this extra cost. The committee has been working closely with the Executive Chairperson and the Associations employment lawyer to undertake the change management process.

Bernadette advised that the Branch had received a grant from the Ministry of Health for a 6-month prototype project, as part of the 'Enabling Good Life' project. The project would be rolled out in the Manawatu region and aligns with the model of supporting disabled people to set their own priorities and develop their own disability support budgets. As part of the project, 'Connectors' would be employed to work with the disabled. Bernadette noted that the Branch was responsible for employing the Connector role and had worked in conjunction with Trevor Jenkin and a Legal Advisor to ensure the role was set up correctly. Bernadette noted that the role would be funded with the MOH funds, but the person would be employed by the Central Branch. The National Council discussed the project and the employment of the Connector role in detail.

Trevor Jenkin received advise from the associations employment lawyer which was that as MDANZ is not party to any agreements or contracts that the Central Region branch may have entered into with MOH for this work we should not be employing such staff, the decision was that the Central region branch would employ and manage the staff member (connector) totally independent of MDANZ.

Bernadette Ingham moved that the National Council endorse the Central Branch directly and independently appointing a 0.5FTE Branch Connector role for a 6-month contract.

Moved: Bernadette Ingham

Seconded: Jan Daly

Andrew/Rebecca voted against the motion and seven others voted for - motion carried.

Northern Branch – Michael Schneider

Michael Schneider noted that the Northern branch is ticking along well and praised Denise Ganley for running the office so efficiently. Michael thanked and praised Trevor Jenkins for his contributions which have remained ongoing since he took on the Executive Chairperson role. Michael noted the Financials are healthy and the branch is in a good financial position. Michael advised that the Branch are continuing to think about the Appeal Week and noted the importance of ensuring National Office and the branches are well prepared for the appeal.

10. New Business – For Distribution

10.1 2019 Annual Operating Plan to be shortened adding in long term goals.

As per minutes documented in 3.4 above.



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10.2 Constitutional Change - Pecuniary Benefit

Trevor Jenkin tabled the changes to the Constitution regarding Pecuniary Benefit. After discussion, the National Council agreed to the changes. Trevor requested the correct wording from Tristram Ingham to include with the AGM agenda.

Action: Send Pecuniary Benefit wordings to Trevor Jenkin.

Tristram Ingham

Trevor Jenkin moved that the Constitution changes on the Pecuniary Benefit be accepted and proposed at the AGM for approval by the membership.

Moved: Trevor Jenkin

Seconded: Bernadette Ingham

All Agreed

10.3 DPO Volunteer Payments - AGM approval

Trevor Jenkin tabled DPO Volunteer Payments which needs approval at the AGM. Trevor noted that the DPO pay meeting fees to volunteers via payment to the association or group however MDANZ can then not pay the volunteer. After discussion by the National Council, it was agreed changes to the wording were required to allow payments to volunteers. Trevor requested assistance from Tristram Ingham on the wording which would then be included with the AGM agenda.

Action: Finalise wording for DPO Volunteer Payments prior to the AGM.

Trevor Jenkin/Tristram Ingham

10.4 Other Business

- Trevor Jenkin tabled the ongoing issues with Vega and the concerns he has with the system and the company staff. After discussion, the National Council agreed that a working group was required to look at the CRM of the organisation and its requirements. Trevor asked if anyone was interested in being a part of the working group to let him know.
- Tristram Ingham noted he would be requesting National Council approval via circular motion for branch Life Members, prior to the AGM. Trevor Jenkin noted that if applicable, other branches should follow the same process.
- Michael Schneider queried what the process was if a Branch was unable to fill all Committee positions. Trevor Jenkin noted that as per clause 16 of the branch agreement if a branch does not form a governing committee in accordance with its constitution, the branch operations will be managed directly by the Association.

11. Next Meeting

The next meeting will be held on Saturday 27th April following the AGM on Friday 26th April.

Signed:

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Chairperson

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Date