



Muscular Dystrophy
New Zealand

**Minutes of the National Council of the
Muscular Dystrophy Association of New Zealand Inc. (MDANZ)
Held 9.00am – 3.00pm, Sunday 4th August 2019
at the National Office, 419 Church Street East, Penrose.**

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

Apologies:

Minutes: Natalie Foote (Board Secretary)

Mihi: Tristram Ingham

1. Welcome

Trevor Jenkin welcomed everyone to the meeting at 9.10am.

2. Apologies

Lateness apologies were noted from Brent Walker and Scott Laurenson.

3. Declarations of Interest

No new declarations of interest were raised.

4. Matters Arising

4.1 Minutes from June Meeting

Moved that the minutes of the meeting held 26th June are approved as a true and accurate record.

Moved: Tristram Ingham

Seconded: Jan Daly

All agreed - motion carried.

Moved that the In-Committee minutes of the meeting held 26th June are approved as a true and accurate record.

Moved: Tristram Ingham

Seconded: Bernadette Ingham

All agreed - motion carried.

4.2 Action items

No action items were discussed.



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5. Circular Resolutions

The following resolutions were circulated to the National Council:

19th July 2019 – Moved that the expenditure of \$4,048 to install GPS units into the branch vehicles be approved.

Moved: Joy Jenkin

Seconded: Andrew Willetts

All agreed - motion carried.

6. Financial Reporting

6.1 2019 – 6 Months to Date

On behalf of the Finance Committee, Trevor Jenkin provided an update on the finances. Trevor noted that 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

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

Moved: Trevor Jenkin

Seconded: Tristram Ingham

All agreed - motion carried

6.2 Budget Review

The budget review was discussed in section 6.1 of the meeting.

6.3 Update on the Draft 2020 Budget

Trevor Jenkin advised that the draft 2020 budget process will commence in October. Trevor noted that this will align with the annual operating plan.

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.

Trevor Jenkin - Chair & Operations

Tristram Ingham - Policies & Procedures

Joy Jenkin - Member engagement

Bernadette Ingham – Education

Scott Laurensen - Information Technology

Jan Daly - Parents & Carers Liaison



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Andrew Willetts - Marketing & Awareness

Scott Boyle - Young Rangitahi

Matthew Willetts – Design

Michael Schneider – Data & Sector Insights

Action: Each National Councillor is required to document their strengths, abilities and what the portfolio will cover.

All

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

The National Finance Sub-Committee raised concerns to the National Council regarding the Canterbury branches financial position which would be discussed later in the meeting.

Moved that the minutes of the meeting and recommendations of the meeting held 30th May are approved as a true and accurate record, subject to the above amendment.

Moved: Tristram Ingham

Seconded: Jan Daly

All agreed - motion carried.

9. Programme & Service Advisor Report

Trevor Jenkin tabled the Programme and Service Advisor report for discussion. The National Council discussed the report in detail and noted the need for more detail around the NRFT registry, governance structures and data. The National Council agreed that a job description is required for the role, so the National Council can better understand the role and responsibilities.

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

10. Membership Services Manager Report

No report available as the Membership Services Manager report. Dymrna Mulroy is returning to work on the 10th September 2019.

11. Marketing & Communications Manager Report

Natalie Foote provided the National Council with a verbal update on Marketing & Communications and advised the following;

- The 2019 Conference was a success with great feedback from all attendees. A debrief session will be held with the working group late August with the intent to start planning the 2020 event.



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- The next In Touch magazine is due out late August which has a focus on celebration. The magazine would have extensive coverage of the Conference and 60th Jubilee with a special pull out insert.
- The 2019 Freedom Campaign was underway with all collateral ordered (lollipops, pens & tote bags). The creative will be the same as 2018 to save costs but with a refreshed look. Due to cost, media coverage will be focused in newspaper and in regional papers plus the NZ Herald digital and NZ Herald newspaper. The National Council requested that the regional ads are specific to the closest branch which Natalie agreed to. The National Council also suggested local community radio ads which Natalie would follow up on.

Action: Investigate options for the campaign to be promoted via Community radio stations.

Natalie Foote

- Other focuses for the upcoming months for the Marketing department are the September EDM, sponsor partners and a review of the entire fundraising/donor programme.

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

Moved: Jan Daly

Seconded: Tristram Ingham

All agreed - motion carried

12. National Executive Chairperson Report

Tristram Ingham tabled the National Executive Chairperson report. The National Council queried;

Volunteer Policy

The National Council recommended removing this from consultation and formalise the policy with the branch feedback provided.

Action: Formalise and distribute the Volunteer Policy

Trevor Jenkin

Central Region Fieldworker Vacancies

The National Council queried when these roles will be filled. Trevor advised that he is currently working with the branch to advertise these roles and aims to have the roles filled by the end of September.

Staff working locations

A query was raised around staff working from home and what liability this had on MDANZ. Trevor advised he would speak with our employment lawyer, Justine Foden, on this issue.

Action: Discuss working from home requirements/liability with Justine Foden.

Trevor Jenkin

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

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

Seconded: Andrew Willetts

Motion carried.



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13. Branch Reports

Southern Branch – Andrew Willetts

Matthew Willetts noted successful grants from COG's.

Central Branch – Bernadette Ingham

Bernadette Ingham noted that the branch has had good responses to grant funding and a 3-year multi grant with COG's has been successful. One of the multi grants was to the value of \$18k. Bernadette noted that COG's are engaging more with the branch. Bernadette advised that Michelle Smith and Talitha van den Burg had been appointed as Community Co-ordinator's in the region on contract roles, both are members with conditions. These two roles will focus on member engagement and events. Bernadette advised that the current contract with the Ministry of Health for the Enabling Good Life scheme had been renewed for another year to the end of the prototype.

Northern Branch – Michael Schneider

Mike Schneider noted that the branch is going well. This is due to a strong Committee and strong branch network. Mike noted that at the last Branch meeting, a discussion was held regarding identifying risks. A main risk is identifying concerns around data which Mike raised with the National Council.

14. New Business

14.1 Appoint DCC Spokesperson

Trevor Jenkin noted that there is a requirement for a spokesperson to be appointed to the DCC. The requirement is a two-day meeting updating on the sector and is a four-year commitment. Tristram Ingham noted that the Terms of Reference for the appointment will be requested before a spokesperson is selected.

Action: Request the Terms of Reference for the DCC Spokesperson role.

Action: Request a post meeting report from Ken Green following the November meeting.

Trevor Jenkin

14.2 Cough Assist Machine

Trevor Jenkin noted that MDANZ own two machines available for renting. However, these machines are old, and parts are obsolete. Trevor tabled a rental system with a third provider which removes MDANZ's liability. The National Council approved for Trevor to investigate the options for leasing the machines.

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

Trevor Jenkin

14.3 NRFT October Research Recipient Call

Tristram Ingham provided an updated on the NRFT and noted that the NRFT is a grants award committee with funds coming in from the Richdale Trust. The NRFT currently has no strategic overview with MDANZ which the National Council agreed was a concern. Trevor Jenkin noted that there will be approximately \$110k this year for grants being made up of \$90k from the Richdale Trust and a \$13k grant from the Menzies Family Trust. Research applicants are called in October 2019 for these funds.



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The National Council discussed the NRFT in depth and agreed that the first step going forward is to meet with the NRFT and the trustees to discuss the structure and functions of the NRFT and ascertain whether they are meeting the written requirements of the trust. Tristram Ingham will draft an agenda with Natalie Foote and a meeting will be scheduled for the week commencing 12th August.

Action: Draft an agenda for the meeting with the NRFT and schedule a meeting for the week commencing 12th August.

Natalie Foote/Tristram Ingham

14.4 Nationwide Member Survey

Trevor Jenkin suggested it was timely to complete a member survey and suggested the timeline is for this to be completed by the end of 2019. The National Council requested that the branch reps take this initiative to their committees for feedback on possible questions for the survey. The National Council agreed that the survey needs to be developed with the intent to use the data for long term use e.g. by gathering data for a database on member feedback sectors.

Trevor advised that the cost of producing the survey will be an unbudgeted expense so approval will be needed.

14.5 Grant Funding Accountability

A discussion was held by the National Council regarding accountability on grant applications. The Northern Branch has highlighted the need for reporting on membership statistics which is required for many grants.

15. General Business

15.1 Update on Annual Operating Plan

Trevor Jenkin moved that circulated Annual Operating plan be approved.

Moved: Trevor Jenkin

Seconded: Andrew Willetts

Motion carried.

15.2 Risk Management Matrix

Due to time constraints, this agenda item was not discussed.

15.3 Meeting Frequency

The National Council agreed to increase the meeting frequency to monthly either by Zoom or teleconference. The National Council would still meet face to face bi-monthly.

15.4 Conference

Moved: Tristram Ingham moved that Brian Hadley be thanked and acknowledged for his contributions towards MDANZ & the Conference.

Seconded: Bernadette Ingham

Motion carried.



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Moved: Trevor Jenkin moved that Dion Ponga be thanked and acknowledged for his contributions towards the Conference.

Seconded: Bernadette Ingham

Motion carried.

15.5 Member Database

The National Council discussed the need for Trevor Jenkin to send a notification out to all staff mandating that if they are speaking to a Member, their contact details are updated at the same time.

The National Council agreed that a working group be set up to explore options of a new database. The working group will consist of Tristram Ingham, Natalie Foote, Michael Schneider and Darian Smith.

15.6 CMT Conference

Due to time constraints, this agenda item was not discussed.

16. Next Meeting

The next meeting will be held on Wednesday 18th December via teleconference.

Signed:

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Chairperson

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Date