



Muscular Dystrophy  
New Zealand

**Minutes of the National Council of the  
Muscular Dystrophy Association of New Zealand Inc. (MDANZ)  
Held 9.30am – 3.00pm, Saturday 27th April 2019  
at the National Office, 419 Church Street East, Penrose.**

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

**Apologies:** Brent Walker and Scott Boyle

**Minutes:** Natalie Foote (Board Secretary)

**Mihi:** Tristram Ingham

**1. Welcome**

Trevor welcomed everyone to the meeting at 9.00am.

**2. Apologies**

Apologies were noted from Brent Walker and Scott Boyle.

*Moved: Trevor Jenkin*

*Seconded: Jan Daly*

*All agreed - motion carried.*

**3. Declarations of Interest**

The following declarations of interest were raised;

- Mike Schneider declared he works for CCS Disability.
- Scott Laurenson declared he works for the charity, Unity Four.
- Joy Jenkin declared her role as the Secretary for the Auckland Whanau Special Needs Support group.

**4. Matters Arising**

**4.1 Minutes from February Meeting**

An amendment to 4.2, "It was noted that there is a net surplus from the 2018 Financial Year End of \$19,242". The correct surplus should read \$21,515.00.

Moved that the minutes of the meeting held 13<sup>th</sup> February are approved as a true and accurate record, subject to the above amendment.

*Moved: Scott Laurenson*

*Seconded: Jan Daly*

*All agreed - motion carried.*



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### 4.2 Action items

No action items were discussed.

### 5. Circular Resolutions

The following resolutions were circulated to the National Council:

*7<sup>th</sup> March 2019 – Due to not being able to get the working group to meet to sort out the Annual Operating Plan and budget, Trevor Jenkin moved that the 2019 budget be approved in its current form.*

*Moved: Trevor Jenkin*

*Seconded: Rebecca Poad*

*All agreed - motion carried.*

*11<sup>th</sup> March 2019 - Trevor Jenkin moved that the motion to apply to the Southern Trust for the amount of \$6191.00, which is half of the leader's salary for the Duke of Edinburgh award*

*Moved: Trevor Jenkin*

*Seconded: Bernadette Ingham*

*All agreed - motion carried.*

*28<sup>th</sup> March 2019 – Trevor Jenkin moved that MDANZ provide the funding for the travel and accommodation for the 11 families to attend the screening visit for the current Clinical screening been carried out in Sydney, Australia. As the organiser hadn't arranged travel and this would mean MDANZ members missing out this would be a bridge cost recoverable from the Organiser.*

*Moved: Trevor Jenkin*

*Seconded: Michael Schneider*

*All agreed - motion carried.*

*2<sup>nd</sup> April 2019 – Trevor Jenkin moved that the following members who have been nominated by their branches be approved to the next stage of the Life Member process which is to be approved by the membership at the National AGM on the 26th April 2019. Raema Ingles, Katie Noble, Denise Ganley, John Hawkins and Lyn Hawkins.*

*Moved: Trevor Jenkin*

*Seconded: Brent Walker*

*All agreed - motion carried.*

*5<sup>th</sup> April 2019 – Trevor Jenkin moved that MDANZ apply to Pub Charities for the cost of AV hire equipment for the Education And advocacy seminar in August 2019.*

*Moved: Trevor Jenkin*

*Seconded: Scott Laurenson*

*All agreed - motion carried.*

*5<sup>th</sup> April 2019 – Trevor Jenkin moved that MDANZ MDA apply to Infinity Foundation for the cost of Collateral for the 2019 Freedom appeal.*

*Moved: Trevor Jenkin*

*Seconded: Rebecca Poad*

*All agreed - motion carried.*

*11<sup>th</sup> April 2019 - Andrew Willetts moved that the Members Discretionary Fund be now known as the Bradley Jenkin Memorial Fund.*



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*Moved: Andrew Willetts*

*Seconded: Scott Laurenson*

*All agreed - motion carried.*

*15<sup>th</sup> April 2019 – Trevor Jenkin moved that he be appointed as the Canterbury Branch Committee administrator for the purpose of making governance decisions until further notice.*

*Moved: Trevor Jenkin*

*Seconded: Brent Walker*

*All agreed – motion carried.*

*29<sup>th</sup> April 2019 – Trevor Jenkin moved that Joy Jenkin be appointed to the Bradley Jenkin Memorial Fund panel.*

*Moved: Trevor Jenkin*

*Seconded: Bernadette Ingham*

*All agreed – motion carried.*

### **6. Financial Reporting**

#### **6.1 2019 – 3 Months to Date**

On behalf of the Finance Committee, Tristram Ingham provided an update on the finances. Tristram Ingham noted a decline in the fundraising income due to the Christchurch Terrorist attack. It was noted that the March Direct Mail is going well with a generated income of \$14,000 to date.

#### **6.2 Budget Review**

Trevor Jenkin that the budget is on track as per the circular motion carried 7<sup>th</sup> March 2019. No outstanding issues raised.

### **7. Councillor Portfolio Initiative / Introduction**

Trevor Jenkin tabled the initiative of individual portfolios for the National Councillors. The purpose for the portfolios was for each Councillor to take a lead and focus on the area within the association that best suits their expertise. Discussions were held regarding this initiative and the possible portfolio allocations. The National Council agreed that there is a need for an overarching strategy and annual operating plan to be established and formalised before allocating portfolios. Trevor requested that the Councillors put thought into the initiative for further discussion at the next meeting.

The possible portfolio allocations discussed were; Education – Bernadette Ingham, Marketing – Andrew Willetts, IT – Scott Laurenson/ Tristram Ingham, Policy & Procedures – Tristram Ingham, Membership Engagement– Joy Jenkin, Children & Parents – Jan Daly, Rangitahi – Scott Boyle, Research & Advocacy – Scott Laurenson.

Trevor would oversee all portfolios.

### **8. Finance Sub-Committee**

#### **8.1 National Finance Sub-Committee Minutes**



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The National Finance Sub-Committee raised concerns to the National Council regarding the Canterbury branches financial position.

Trevor Jenkin noted he has been working with the Community Auditor on the branch financials and highlighted to the Committee that once all outstanding bills are paid, the branch will be left with \$7,000 in the bank which will not be enough to cover the operational costs for April if a grant is not received. This will make the branch technically insolvent.

The National Council suggested writing a letter to the branch underwriting the branch in the current financial year to ensure they do not go insolvent and can continue to apply for grants.

*Trevor Jenkin moved to issue the Canterbury branch with a letter underwriting their financials.*

*Moved: Trevor Jenkin*

*Seconded: Jan Daly*

*All agreed - motion carried.*

*Action: Trevor Jenkin will issue the Canterbury Branch with a letter underwriting the branch.*

*Trevor Jenkin*

*Moved that Andrew Willetts, Southern Chairperson, be appointed as the interim Chairperson for the Canterbury branch and Jan Daly be appointed to the Canterbury branch as a branch representative.*

*Moved: Michael Schneider*

*Seconded: Joy Jenkin*

*All agreed - motion carried.*

*Tristram Ingham moved to prepare a business case on the branch income/expenses and include a sustainable budget model.*

*Moved: Tristram Ingham*

*Seconded: Joy Jenkin*

*All agreed - motion carried.*

*Action: Brian Hadley to prepare the business case/sustainable budget*

*Brian Hadley*

### **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 agreed further clarification and detail on how it advanced the association and the panel objectives were required on item 3, the Brain Week Panel discussions. It was also noted that under item 4, Paediatric Clinical Neurology Network, concerns had been raised from the Network Members about MDANZ. The National Council agreed that they should have been informed of these concerns earlier given the financial and reputational risk involved and requested further action on this from Trevor Jenkin.

*Action: Discuss the Paediatric Clinical Neurology Network concerns with Miriam Rodrigues.*

*Trevor Jenkin*

*Moved: Trevor Jenkin moved that the Programme and Service Advisor Report is not accepted due to the clarifications required above.*

*Seconded: Tristram Ingham*

*All agreed - motion carried*



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### 10. Membership Services Manager Report

Trevor Jenkin tabled the Membership Services Manager report for discussion. The National Council discussed the report and noted the positive points regarding the increased contact with new members. The National Council agreed further clarification was required under item 2, the GP Online Module as to who is on the advisory panel. Further discussions were held on implementing a medical advisory board and it was noted that the NRFT hold similar roles. It was agreed that Trevor Jenkin will confirm the names of the current clinical advisory group and work with Tristram Ingham to review the members and the ToR.

*Action: Confirm names of the clinical advisory group for review with Tristram Ingham.*

Trevor Jenkin

The National Council discussed item 2, CAM Services in detail. The National Council requested a paper on the CAM machines covering the role of the machine, future strategy/plan for the machines, how many to service and the costs plus options for the future.

*Action: Prepare a paper on the future strategy of the CAM.*

Dympna Mulroy

The National Council requested that under item 11, the 'Teachers Resource for Secondary Schools' draft be circulated to the National Council for review before being finalised.

*Action: Send the draft 'Teachers Resource for Secondary Schools' to the National Council for review.*

Dympna Mulroy

Trevor Jenkin moved that the MDANZ Membership Services Manager Report be tabled as read subject to the clarifications required by the National Council.

*Seconded: Tristram Ingham*

*All agreed - motion carried*

### 11. Marketing & Communications Manager Report

Natalie Foote tabled the Marketing & Communications Manager Report for discussion. The National Council discussed item 2, the Freedom Annual Appeal in depth and agreed it was imperative to raise awareness as well as funds. The National Council agreed to amend the campaign from a month-long event to a week long intensive campaign focusing on awareness of the brand and the conditions associated. The National Council advised that it is important to involve the Branches to ensure no crossover of work i.e. contact with local schools, and to ensure that a comprehensive resource kit be made available to the branches to ensure a successful appeal.

*Moved: Trevor Jenkin moved that the Freedom Annual Appeal campaign be amended to a week-long intensive campaign.*

*Seconded: Jan Daly*

*All agreed - motion carried*

*Action: Rework the Marketing Plan for the Freedom Annual Appeal & circulate to the National Council.*

Natalie Foote

The National Council discussed communications of MDANZ and in particular regarding Social Media. The National Council were advised that at present, all online communication was managed by Natalie Brunzell (independent contractor). The National Council questioned this given there is now a Marketing and Communications Manager in place and advised that this work should be managed internally.



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*Action: Reallocate online communication workload to be managed internally.*

Trevor Jenkin

The National Council discussed fundraising and in particular around the telemarketing with One4All. The possibility of bringing this work in house was discussed and employing Members to do the work. It was agreed that this type of social enterprise had merit and was worthy of investigating further.

*Moved: Andrew Willetts moved that the telemarketing social enterprise be researched and explored further.*

*Seconded: Bernadette Ingham*

*All agreed - motion carried*

### **12. National Executive Chairperson Report**

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

- HR Update + resignation of Dympna Mulroy as Fieldworker, Central Branch.
- Central Region Branches change management process.
- The 2019 Education and Advocacy Seminar will now be managed within the Marketing team.

The National Council queried the staff use of EAP and was advised by Trevor that two staff members have asked for extra EAP services. Trevor reassured the National Council that there are currently no further heightened stress levels.

The National Council queried the Risk register and it was noted that reputational risk is the main risk to the Association at present. Trevor acknowledged the Risk Register was not sent out to the National Council prior to the meeting and agreed he would circulate this within the next month.

*Action: Update the Risk Register and circulate to the National Council.*

Trevor Jenkin

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

*Moved: Andrew Willetts moved that the National Executive Chairperson Report be tabled as read.*

*Seconded: Bernadette Ingham*

*Tristram Ingham abstained from voting.*

*Motion carried.*

### **13. Branch Reports**

#### **Canterbury Branch**

Discussed earlier in the meeting.

#### **Southern Branch – Andrew Willetts**

Andrew Willetts noted that the audit went smoothly despite the Treasurer no longer being on the committee. It was noted that the AGM went well and a new Committee Member, Stacey Smith, has been appointed and will take on the Treasurer role. The new Branch rep will be Matt Willetts.



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### **Central Branch – Bernadette Ingham**

Bernadette Ingham noted that the finances and audit have kept the branch busy with the audit taking many weeks to complete due to the demands of the Auditor. Bernadette advised that the AGM was successful with a new Committee Member being appointed from the Myasthenia gravis group, Talitha Vandenberg. Bernadette noted that the Fieldwork service has been a big issue over the past year which saw them go through a change management process for fieldworker services. It was noted that funding has been very successful of late with the ANZ funding a digital connect grant to connect members better. Bernadette noted that the MOH Project in mid-central had been running well for the past two months with good engagement from the first three members who are all MDA members.

### **Northern Branch – Michael Schneider**

Mike Schneider noted that the branch is ticking over well despite a quiet month. The AGM was held with 22 in attendance which is a strong result. Trevor Jenkin noted a \$920 deficit for the end of year but noted this was gone by the end of March. Trevor noted the following appointments to the Branch Committee; Trevor Jenkin – Chairperson, Michael Schneider – Vice Chairperson, Andrea Clive - Treasurer, Joy Jenkin – Secretary, Chloe Hovell, Alex Heke, Melanie Hopley, Naomi Vailima, Yaz Dolbel-Neville and Lew Pulman.

## **14. New Business**

### **14.1 2019 Annual Operating Plan**

The Annual Operating Plan was discussed by the National Council with the view to realigning the objectives to a more achievable and realistic focus. It was agreed that Trevor Jenkin would discuss the plan with current staff to ascertain what work they are currently doing that aligns with the operating plan and the time each work function takes. Once this process is complete, the objectives can be split by time to see what is achievable and what will become 'reach goals' for when more resource is available.

*Action: Realign Annual Operating Plan after discussions with staff.*

*Trevor Jenkin*

### **14.2 Structure & Review**

The National Council had a brief discussion and it was decided after some advise that as we have policy and procedures, DPO requirements, The New Inc Soc Act this year and all these things need to be set at a governance level before we start looking at an organizational structure review. National Council has stated looking at these different things and will systematically work through them. It was noted this would not be an easy task so it will take time.

### **14.3 Staffing (In Committee)**

The meeting went into In Committee at 1.52pm and came out at 2.36pm.

### **14.4 Vega Issues**

Due to time constraints, this agenda item was not discussed and will be carried over to the next meeting.



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**14.5 CE Replacement**

A discussion was had on a replacement CE for the association it was decided that a CE would not be recruited in the foreseeable future and the National Executive chairperson would remain as leader of the association.

**14.6 Limb-Girdle Conference**

Due to time constraints, this agenda item was not discussed and will be carried over to the next meeting.

**14.7 IT**

The National Council held brief discussions on the current Server and discussed possible options going forward. No specific outcomes or actions came from this discussion.

Tristram Ingham noted that the Central Region branch has been trialing Office 365 with positive feedback so far.

**15. General Business**

The National Council held a brief discussion regarding the MDANZ Patrons and whether they need to be refreshed. No specific outcomes or actions came from this discussion.

**16. Next Meeting**

The next meeting will be held on Wednesday 26<sup>th</sup> June via teleconference.

Signed:

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**Chairperson**

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**Date**