

**Annual General Meeting of the Motor Neurone Disease Association of New Zealand  
Incorporated held on 31<sup>st</sup> October 2021 via Zoom video conference**

**Draft Minutes**

The meeting was preceded by two presentations:

- Beth Watson – Life Member and former President – Celebrating our history of supporting people with MND since 1985.
- Alan Stanley – Council Member – MND best clinical practice recommendations for New Zealand, on behalf of the MND Clinical working group (of which Alan is co-chair)

The AGM commenced at 2.00pm

**Present**

Natalie Thain (Chairperson), Caron Palmer (Deputy Chairperson), Lucy Haberfield (Secretary/Treasurer), Greg Horton, Beth Watson, Edith McCarthy, Claire Reilly, Alan Stanley, Clive Ross, Jocelyn Tjeerd, Toni Foster, Melanie Glenn, Estelle Arts, and Chris Sawers.

**In attendance**

Greg Goldfinch.

**Welcome & Apologies**

Chairperson Natalie Thain welcomed people to the meeting.

**Apologies**

Carl Sunderland, Hayley Watkinson, Michael Fuyala, Philip Blewett, Alison Seaman, Wendy Smith, and Clive Ross.

**1. Minutes of the 2020 Annual General Meeting**

Agreed that they are a true and correct record of the meeting.

Moved: Caron Palmer

Seconded: Beth Watson

**2. Matters arising from the minutes**

No matters arising.

### **3. Presentation of the Annual Report 2020-21 from National Council**

Natalie Thain made the following comments:

*As you can see from our Annual Report, there has been a massive amount of work which has been undertaken and we have participated in in the past year, and the contributions that have been made from such a wide range of people have been enormous - especially in these unprecedented times that continue to challenge us and require us to really pivot and flex and work and live in new ways that we have not really tested before particularly to the MND community those with lived experience, their family, whanau, carers and supporters.*

*We are all living in an extremely difficulty time with Covid over and above everything else and you have been entirely inspirational. Together let us continue to focus on the challenges that lay ahead. A wonderful team at MND your compassion, empathy, commitment to our community is remarkable.*

*We want to acknowledge the efforts of the whole team to work together to commit to the way in which we operate in order to provide the vital services that we do. We should be extremely proud of the achievements of this year. A special thanks to Carl Sunderland who has left the role of chief executive but made a huge contribution over the four years that he was with us and also to Kate Dalders who over the last four years been instrumental in enabling MND to grow our fund raising. Kate leaves us to take on her next career opportunity and we wish her all the best.*

*To our National Council thank you all for your energy and for leading and navigating the Association through some pretty challenging times. To Dr Chris Drennan, Samara Wright-Scott, Wayne Phillip, Nick Molscan and Greg Horton who have all stepped down from Council this year. We want to thank you for your expertise, the time, the commitment and contribution whilst you were in your seats. A very special thank you to Greg for your ongoing contribution and commitment to the Association wearing your different hat this time as acting CEO. Your contribution to the Association is tireless so thank you so much. Also, thanks to Caron Palmer for stepping into the operations to share in the CEO responsibilities with Greg whilst we look to recruit our next leader of MND.*

*Now to the key highlights for the 2020/21 financial year. These include the ongoing success of course of the MND New Zealand Fulton Hogan Support Fund which was launched back in August 2019. We are really pleased to report that we have over 53 applicants have actually received support through that fund this year. We had our busiest, most successful MND awareness month in June raising over \$245,000 and we are hugely grateful to the support that we received through the MND Ice Bucket Challenge led by Greg Goldfinch from Colliers and the Cuppa Tea campaign for MND. The "David's Unusables" Trade Me campaign was a great success in developing further awareness for MND we are in public relations reach of 7.9 million New Zealanders. Big thanks to Special Group who are our campaign advisers and to David Seymour who was the face of the campaign and we look forward to continuing our partnership into the future. We have*

*had a solid year from a financial perspective and I would like to extend our thanks to our key partners Fulton Hogan, The Heart of Racing, Colliers, David Seymour, Special Group and Emirates Team New Zealand for their valuable support of MND New Zealand. Looking ahead, our key priority is to recruit our next chief executive and to commence work on our strategic planning processes for the years ahead.*

*We remain entirely committed to our support services, our role in advocacy and communications, our commitment to research, and to grow our partners and supporters to enable us to fund the great work that we do for our MND community.*

*Our goal and vision remain the same and that is to provide the very best quality support to those that are living with MND. We are one family and we are all in this together.*

The report was **accepted**.

Moved: Edith McCarthy

Seconded: Alan Stanley

#### **4. Presentation of Annual Accounts and Audit Report 2020-21**

Treasurer Lucy Haberfield presented the Annual Accounts, reporting a pleasing result for 2020-21.

MND New Zealand remains heavily reliant on donations, fundraising and grants for its revenues.

Revenue topped \$2.085 million for the year, with major donations via the Association with Emirates Team New Zealand and Fulton Hogan. We received \$70k in funding from Government, and the ice bucket challenge of approx. \$200k.

On the cost side, core people costs were \$630k, fundraising \$93k and research \$102k for the year. Overall surplus was \$762k.

The balance sheet remains strong at \$2.031m and funds invested have increased over the year.

Overall, the year was exceptional.

The Annual Accounts were **approved**.

Moved: Claire Reilly

Seconded: Caron Palmer

The **Subscription Levy** for the 2021-22 year will remain at \$0.

## **5. Officers & Members of National Council**

The Chair confirmed to the meeting that the number of nominations for vacant Council roles did not exceed in the number of vacancies on Council and so no elections needed to be held

Caron advised the meeting of the following Council Officer positions for the 2020-21 year:

- Lucy Haberfield - Chairperson
- Caron Palmer – Deputy Chairperson
- Treasurer/Secretary – to be appointed by Council

Caron welcomed the following new members to the Council:

- Estelle Arts
- Chris Sawyers

Estelle and Chris gave a short presentation on their background, connections with MND and reasons for joining Council.

## **6. Endorse the Council's appointment of Auditor**

The meeting endorsed Audit Integrity Ltd as the audit firm for the coming year.

Moved: Lucy Haberfield  
Seconded: Caron Palmer

## **7. Confirmation of Honorary positions**

The following Honorary positions were **carried by acclamation**.

**Patron** - Ruth Dyson

**Honorary Medical Patron** – Sir Richard Faull

**Honorary Medical Adviser** - Dr James Cleland

**Honorary Solicitor** - Scott Moran

## **8. Change to the structure of the Association**

Natalie Thain, as Chair, provided introductory comments on the rationale for the change, as follows:

*MND New Zealand has been examining its legal structure as an incorporated society, and considering what might be the best structure for the organisation as we look to the future. Most newly established charitable or community organisations select as their legal and operational structure a charitable trust as opposed to an incorporated society. There are many similarities between the two structures.*

*Both, for example, have a governing body, but in an incorporated society it is called a council, while in a trust it is a board of trustees. Both can be registered as tax-exempt bodies by virtue of their charitable status, and both can carry on an undertaking, business, or other activity in the pursuit of their objects or purposes. Both have legal standing – meaning they can own assets, lease property, enter into contracts, employ people, and do anything else that any other corporate body or person can do.*

*The key difference between a charitable trust and an incorporated society is the concept of membership. While a charitable trust can exist for the benefit of a defined class of persons, such as persons affected by motor neurone disease and their families, carers and related medical professionals, it does not naturally have a concept of membership. Similar structures can be replicated; for instance, “members” can become “friends” or “patrons” of the trust, and on payment of agreed “fees” or “dues” can access services not otherwise available to members of the public, and information can be made available to such persons – or to the public at large – in the same way as to members of a society (by email, mailing list, website information, public meetings and the like). On the other hand, a society must have a membership to exist. For some societies, this becomes a burden and an unnecessary administrative hassle, consuming management time and resources that could otherwise be put to use for the objects of the society. For these societies, the trust structure offers the same benefits but without this administrative burden.*

*Examples of significant societies that have in recent years transitioned their operations from a society structure to a charitable trusts structure include Plunket and Arthritis New Zealand.*

*Therefore, MND New Zealand proposes to members that we move our structure to a modern charitable trust. We will keep you updated on developments.*

*Can I ask please if there are any questions on this proposal.*

Edith McCarthy and Beth Watson both spoke to the proposal, and made the following points:

- Why change the structure given that things are going well?
- A membership concept is important, to keep the Association grounded and assists in fundraising.
- If there are no members, the trustees have power and without actual involvement of members there may be a lack of accountability, transparency, heart, empathy and substance. There would be a blockage on who gets to be a trustee, and no member participation, and the organization might be run by business minded people with no experience of MND.
- Disappointment that there seems to be no place for life members.
- Concern over a minimum of three trustees, and the option only for audited accounts.
- Concern that there is no role for people with MND to have any input.
- Could there be more consultation and discussion.

Jocelyn Tjeerd spoke in favour the proposal to change, particularly as to the benefit of accessing fundraising.

Claire Reilly raised the issue of specifying a minimum number of trustees of five, and rules for the makeup of trustees – e.g., someone with MND.

The meeting discussed the proposal, and resolved to pass the resolution on the following basis:

- Further comments can be provided on the Trust Deed.
- Further consultation to be undertaken with interested members.
- Following that Council would finalise a deed and implement a change, unless in the consultation it was decided not to proceed.

The form of resolutions, as set out below, were passed subject to those matters.

#### Introduction

- A Unless the context provides otherwise, capitalised terms in these resolutions (which are not otherwise defined in these resolutions) have the same meaning as those in the constitution of the Association dated 27 October 2018 and as amended from time to time (the *Constitution*).
- B The Association is an incorporated society and registered charitable entity under the Charities Act 2005. Since its establishment in 1985, the Association has provided support to people with Motor Neurone Disease and their carers in New Zealand, as well as other people affected by Motor Neurone Disease. To date, the Association has been the principal organisation representing the interests of people with or affected by Motor Neurone Disease.
- C After due consideration by the Council and discussion with Members, the Association has determined that an incorporated society structure is no longer the most suitable vehicle for it to carry on its undertaking, and it has been determined instead to transition the assets, liabilities and undertaking of the Association to a charitable trust, to be established by the Association for this purpose (the *Charitable Trust*). The aims and objectives of the Charitable Trust will be materially the same as those of the Association, and the needs of people with Motor Neurone Disease and their carers and others affected by Motor Neurone Disease in New Zealand will continue to be served by the Charitable Trust in the same way as currently served by the Association.
- D It is intended that the initial trustees of the Charitable Trust will apply for incorporation as a charitable trust board under the Charitable Trusts Act 1957, and for registration as a charity under the Charities Act 2005.
- E To that end, it is proposed that the Association establish the new Charitable Trust, to be called the Motor Neurone Disease New Zealand Charitable Trust. The proposed form of the deed of trust has been progressed by the Council on advice from Chapman Tripp, Solicitors, and has been circulated to members for review together with a short explanatory note.

- F After completion of the transfer of the assets, liabilities and undertakings of the Association to the new Charitable Trust, it is intended that the Association will be voluntarily wound up and dissolved, in accordance with clause 16.2 of the Constitution of the Association and section 28 of the Incorporated Societies Act 1908, on the basis that the Association at that point is no longer carrying on its operations, has no remaining assets and has discharged all known liabilities.

#### Noted

- G Clause 16.2 of the Constitution requires initial resolutions of Members to authorise the winding up and a subsequent confirmatory resolution at a subsequent General Meeting of called for that purpose and held not earlier than 30 days after the date on which the first resolution is passed. These resolutions are the initial resolutions so required.
- H The requirements of clause 15.1 (charitable purposes only), clause 16.3 (majority of votes by General Meeting) and clause 16.4 (prohibition of distribution amongst Members) of the Constitution will be complied with in the passing of this resolution.
- I The mover and seconder of these resolutions are Caron Palmer and Greg Horton, respectively, who are each Financial Members of the Association, in accordance with clause 8.2 of the Constitution.

#### Resolutions

The Members resolve to authorise that:

- 1 The Association cause the new Charitable Trust to be:
  - 1.1 settled (with an initial nominal capital), with a deed in materially the same form as that circulated to Members prior to this General Meeting (but with such edits as the Council may deem necessary or appropriate) and to have as its initial trustees the then current members of the Council (or such of them as are willing to accept the role); and
  - 1.2 registered as a charity under the Charities Act 2005; and
- 2 All reasonable assistance be given to the initial trustees of the new Charitable Trust to:
  - 2.1 open a bank account in the name of the Charitable Trust;
  - 2.2 apply for an IRD number for the Charitable Trust; and
  - 2.3 complete all necessary registrations including the aforementioned registration as a charity under the Charities Act 2005 and incorporation of the trustees as a board under the Charitable Trusts Act 1957.
- 3 Subject to these resolutions being confirmed at a subsequent General Meeting in accordance with clause 16.2 of the Constitution, following the establishment of the Charitable Trust and due completion of the registrations referred to above:

- 3.1 the Association proceed to transfers the assets, liabilities and undertaking of the Association to the new Charitable Trust and to take all steps necessary and advisable to achieve the same including consultation and engagement with employees who are to be offered employment with the new Charitable Trust; and
- 3.2 thereafter, on the basis that at that point it is no longer carrying on operations, has no remaining assets and has discharged all known liabilities:
  - (a) the Association be voluntarily wound up in accordance with clause 16.2 of the Constitution and section 28 of the Incorporated Societies Act 1908 and to that end the Council shall procure that the necessary application for voluntary dissolution is provided to the Registrar of Incorporated Societies at the applicable time; and
  - (b) the Council take such other steps and execute such other notices or other documents as may be necessary or desirable to give effect to the above resolutions.

Moved: Jocelyn Tjeerd  
Seconded: Chris Sawers

## 9. David Oliver Beacon Award 2021

Caron Palmer introduced the award with a brief explanation about Professor David Oliver, and the history of the award.

Caron was delighted to announce the winner for 2021 as **Greg Goldfinch and the Colliers team at Highbrook** for incredible fundraising efforts through the ice bucket challenge – raising over \$200,000.

Greg acknowledged the award.

Caron thanked Greg and the Colliers team at Highbrook for making such a massive difference to many of our community with this invaluable support.

## 10. General Business

There was no general business raised.

She declared the meeting **closed at 2.52pm.**

These minutes are a true and correct representation of the meeting.

Signed:

Date:



DRAFT