

DRAFT Minutes of the Annual General Meeting of the Motor Neurone Disease Association of New Zealand Incorporated held on 31st October 2020 via Zoom video conference

The meeting was preceded by a presentation from MND New Zealand Honorary Medical Advisor, James Cleland, FRACP entitled, “MND – My thoughts on moving forward in New Zealand”.

The AGM **commenced at 2.35pm**

Present

Greg Horton (Chairperson), Caron Palmer (Deputy Chairperson), Lucy Haberfield (Secretary/Treasurer), Fiona Hewerdine, Nick Molcsan, Michael Fuyala, Wayne Philip, Beth Watson, Dave Waugh, Edith McCarthy, Melanie Glenn, Samarra Wright-Scott, Sharon Mannion, Alan Stanley

In attendance

Carl Sunderland, James Cleland, Jules Fulton, Miriam Rodrigues

1. Welcome & Apologies

Chairperson Greg Horton welcomed people to the meeting.

Apologies

Jodie O’Doherty, Steve Green, Alice Robertson, Richard Ryan, Jak Slaven, Toni Foster, Kate Dalders, Lorraine Darcy, Reima Casey, Ron Gibbons, Alison Seaman, Lawry Bassett, Janet Shield, Mark Grimes, Geoffrey Sedon, Maria Minnaard, Philip Blewett, Denise Glynn, Steve Jukes, Robina Davies

Greg handed over to Deputy Chairperson Caron Palmer to run the rest of the meeting.

2. Minutes of the 2019 Annual General Meeting

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

Moved: Greg Horton Seconded: Caron Palmer

3. Matters arising from the minutes

No matters arising.

4. Presentation of the Annual Report 2019-20 from National Council

Caron spoke to Greg’s report outlining the previous year’s achievements and highlights split into two halves – ‘pre-COVID and post-COVID’. This included,

- The honor of being the charity of choice for Emirates Team New Zealand and the opportunities for fundraising and exposure this relationship brings,
- The success of the Fulton Hogan MND New Zealand Support Fund with large numbers of families receiving this additional support since its launch in August 2019,
- The Hui hosted at Parliament in September 2019 which was attended by clinicians and ministers and the subsequent formation of the clinical working group who are developing national guidelines to improve better MND care nationwide,
- The inaugural MND Research Conference in December where we hosted world leaders in MND research in Auckland which provided incredible insights, invaluable contacts and a lot of hope to all in the room.

Caron spoke about the disappointment of the small amount of Government funding we receive (which only covered 5% of costs in the previous year) remaining the same as it has for many years when the contract was rolled over this year despite a strong submission from the CEO.

She went on to describe the rapid changes we had to undertake in response to the COVID-19 pandemic. She acknowledged the remarkable effort of the whole team to work together swiftly to adapt our services and continue to provide our vital service through these difficult and uncertain times. Caron thanked the team on behalf of National Council.

A number of additional, individual thank yous were made to,

- Emirates Team New Zealand and Fulton Hogan for their ongoing support
- Our dedicated support team who do a very difficult job, travelling all over the country doing their utmost to help people with MND and their families and the amazing way they adapted through changes in alert levels,
- Claire Reilly (MND Community & Research Advisor) for her enormous contribution especially on the research strategy, hui, conference and clinical working group,
- The CEO and national office team for an outstanding year,
- Our volunteers and supporters including our National Council for their passion, time, energy and ideas

Caron thanked staff who had left during the year – Sarah Tora, Comms Manager and Carol Matthews – Waikato/Taranaki Support Team member – and welcome their replacements to the team, Emily King and Megan Te Boekhorst.

Caron said farewell and thank you to our retiring Council Members – Fiona Hewardine, Steve Green and Jodie O’Doherty for their devotion, commitment and expertise. They will be missed. She then welcomed our new Council members joining us at the AGM.

Caron closed by saying the Association is in good shape, but there is always more work to do and we are always trying to do it better. We welcome your feedback and ideas at any time on how to achieve that. Our goal every day is to help our MND community – and always will be.

*He aha te mea nui o te ao
He tangata, he tangata, he tangata*

The report was **accepted**.

Moved: Fiona Hewerdine Seconded: Dave Waugh

5. Presentation of Annual Accounts and Audit Report 2019-20

Treasurer Lucy Haberfield presented the annual accounts, reporting a pleasing result for 2019-20.

MND New Zealand are heavily reliant on grants, donations and fundraising which made up the bulk of our income for the year. \$1.3M out of a total \$1.4M. We received \$74K in funding from Government and accessed the wage subsidy scheme during the COVID-19 lockdown.

Providing support and advocacy to people with MND and their families is by far our largest financial commitment, but we aim to keep contributing to the growing body of MND research. We can only do this through raising awareness and increasing stakeholder engagement.

Costs are managed very carefully with core people costs at \$749K, fundraising \$69K and research \$61K for the year. Overall surplus was \$247K with underlying administrative costs at 21% of total revenue.

The balance sheet remains strong at \$1.2M and funds invested have increased over the year.

The accounts were **approved**.

Moved: Lucy Haberfield Seconded: Dave Waugh

The **Subscription Levy** for the 2020-21 year will remain at \$0.

6. CEO Report

CEO Carl Sunderland presented an update on the Association's strategy, highlighting current projects and activities including,

- The completion of the support service review,
- Development of our communications strategy and information plan,
- Creation of guidelines and frameworks for support groups and MND education programmes,
- Development of our brand personality and key messages,
- Creation of a new website,
- Establishing new corporate partnerships,
- Re-engaging with the Ministry of Health and Government on increasing funding and support,
- A huge focus on fundraising and growing our team of supporters, fundraisers, donors and volunteers.

Carl thanked the MND New Zealand team, national council, our volunteers and supporters and stated we should all be very proud of what we've achieved together.

The report was **accepted**.

Moved: Caron Palmer Seconded: Edith McCarthy

7. David Oliver Beacon Award 2020

Fiona Hewerdine introduced the award with a brief explanation about Professor David Oliver, the history of the award and this year's theme 'Excellence in Solution Finding'.

Fiona was delighted to announce the winner for 2020 as **Fulton Hogan** for finding a solution to the unmet practical needs (such as help around the home, mobility solutions, equipment and home modifications) our community identified through the 2018 survey. Fulton Hogan have provided generous support to establish the Fulton Hogan MND New Zealand Support Fund to provide additional support in meeting these needs.

Jules Fulton, General Manager – Culture, accepted the award on behalf of Fulton Hogan stating, "it was very humbling" and "it is our privilege to serve the MND community through this true partnership".

Caron thanked Fulton Hogan for making such a massive difference to many of our community with this invaluable support.

8. Officers & Members of National Council

Caron 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,
- that Fiona Hewerdine, Steve Green and Jodie O'Doherty are retiring from Council

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

- Greg Horton - Chairperson
- Caron Palmer – Deputy Chairperson
- Lucy Haberfield – Treasurer/Secretary

Caron welcomed the following new members to the Council:

- Alan Stanley
- Melanie Green
- Samarra Wright-Scott

Alan, Melanie and Samarra gave a short presentation on their background, connections with MND and reasons for joining Council.

9. 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: Fiona Hewerdine

10. 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

11. General Business

Caron, Greg, Beth Watson, Edith McCarthy and Robina Davies (via email) thanked retiring Council member Fiona Hewerdine (who was present at the meeting) for her many years of dedication and hard work on Council.

Edith McCarthy also commented that we should continue to provide the AGM via Zoom, she was thrilled to see so much being done out there and thank you to whoever does it.

Caron thanked everyone for their attendance and support and well wishes for the future.

She declared the meeting **closed at 3.24pm**.

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

Signed:

Date: