

NEUROMUSCULAR WA INC.

Minutes of the fifty sixth Annual General Meeting of Members

held at The Niche, 11 Aberdare Road, Nedlands

Thursday 8 June 2023 at 5:00pm

1. MEETING OPENING

Chairperson Tanvi Haria declared the meeting open at 5:01 pm and welcomed Members and Guests and delivered the welcome to country.

Tanvi Haria acknowledged Honorary Life Members present at the meeting Josh Davenport, Rachel Davenport, Des Mclean, Sue Fletcher, Ruth Steven and Rick Steven.

Tanvi Haria acknowledged the passing of Honorary Life Member and founder Emeritus Byron Kakulas.

2. ATTENDANCE RECORD

Members Present: Deema Audeh; Matt Curnow; Rachael Davenport; Josh Davenport; Cathy Donovan; Anwen Handmer; Toby Gummer; Nirbhay Gupta; Anwen Handmer; Tanvi Haria; Mark Hullett; Emma Kenton; Lisa King; Piper Marsh; Brooke McGregor; Des McLean MBE; Abby Niven; Cara Philpott; Peter Rowe; Aaron Schier; Rick Steven; Ruth Steven; Shane Powell; Ellen Storey-Potter; Susan Trahar; Josh Wells; Bryony Whitwell; Sarah Williams; Adelaide Withers (Woodward)

In attendance: Hayley Lethlean

Apologies: John Gummer; Rob Storey (Hon Life Member); Jane Edwards; Lynette Mann; Holly Redman; Alan Stirling; Louise Storey; Peter Erceg; Steve Wilton (Hon Life Member); Anwen Handmer; Theodore Kailis (Hon Life Member); Amy Murphy; Brendan Murphy; Lesley Murphy (Hon Life Member); Nathan Patrick; Pat Emery (Hon Life Member)

Proxies Received: John Gummer; Brendan Murphy; Rob Storey

3. CONFIRMATION OF THE DRAFT MINUTES OF THE PREVIOUS ANNUAL GENERAL MEETING FOR MUSCULAR DYSTROPHY WA HELD ON THURSDAY 2 JUNE 2022

Copies of the Minutes were circulated prior to the meeting.

Tanvi Haria put forward a motion of confirmation that the Minutes be accepted as a true and accurate record of that Meeting.

MOTION: To confirm the minutes of the Annual General Meeting for Muscular Dystrophy WA held on Thursday 2 June 2022

Proposed: Ellen Storey-Potter

Seconded: Abby Macnish Niven

All in favour: All present

CARRIED

4. MATTERS ARISING FROM THE PREVIOUS MEETING ON 2 JUNE 2022

There are no action items arising from the minutes.

5. CONFIRMATION OF THE DRAFT MINUTES OF THE SPECIAL GENERAL MEETING FOR MUSCULAR DYSTROPHY WA ON 1 FEBRUARY 2023

Copies of the Minutes were circulated prior to the meeting. Tanvi Haria noted this special meeting was convened to change the constitution and change the name to Neuromuscular WA. Tanvi Haria noted one amendment to the minutes that were circulated. On page 2 in Housekeeping, it was incorrectly recorded the age for voting as 118. This has been amended in the minutes for signing today to 18 years.

Tanvi Haria put forward a motion of confirmation that the Minutes be accepted as a true and accurate record of that Meeting.

MOTION: To confirm the minutes of the Special General Meeting for Muscular Dystrophy WA/ Neuromuscular WA held on Thursday 1 February 2023

Proposed: Emma Kenton

Seconded: Shane Powell

All in favour: All present

CARRIED

6. MATTERS ARISING FROM THE PREVIOUS MINUTES ON 1 FEBRUARY

There are no noted action items arising from the Special General Meeting minutes.

7. ADOPTING THE CHAIRPERSON AND CEO REPORT

Tanvi Haria confirmed the Annual Report had been circulated in advance of the meeting to all members on and was also loaded on the website. Mrs Haria presented the Annual Report and highlighted sections of the CEO and Chair report. These included the receipt of NDC funding, the system navigation project, the name-change and a number of the ongoing research projects.

Tanvi Haria thanked the team for their efforts in putting together the annual report and for supporting the community.

MOTION: To adopt the Chair & CEO Report in the 2022 Annual Report

Moved: Josh Davenport

Seconded: Ellen-Storey-Potter

All in favour: All present

CARRIED

8. PRESENTATION OF THE AUDITED FINANCIAL STATEMENTS OF FOR 2022 – BY TREASURER ABBY MACNISH-NIVEN

Tanvi Haria handed the meeting to Abby Macnish Niven to present the financial statements. The audited accounts were circulated prior to this meeting with the annual report.

Abby Macnish Niven noted that overall, the Association reported a surplus of \$514,966 after payment of research grants and scholarships, which is approx. \$509,000 higher than the previous year. Whilst there was a general increase across most income streams, a significant donation of \$923,587 from the Neurodegenerative Disorder Centre (NDC) which will be attributed to research initiatives for Professor Anthony Akkari and his team over the next four years was recorded.

The total expenditure of \$1,572,264 in 2022 increased by \$450,176 compared to 2021, largely in line with costs associated with the Department of Health Grant for the System Navigation Project and a decrease of \$323,233 in the unrealised valuation of the investment portfolio. Abby Macnish Niven noted that the portfolio to date had fully recovered from this decrease in December.

Net assets and liabilities show some variation to 2021 balances with change in cash position from \$722,712 to \$1,675,057 predominantly as a result of the NDC funds received.

As December 2022, the Association's financial position increased by \$514,966, resulting in a closing net assets balance of \$3,244,574.

Abby Macnish Niven thanked the Board & staff for their contribution and continued support. She concluded that the Association's financial position remains sound. Abby Macnish Niven opened the floor to questions.

Abby Macnish Niven called for a motion for the acceptance of the Financial Statements and the Auditor's reports, therein.

MOTION: The 2022 Audited Financial Statements for Muscular Dystrophy WA be accepted by the membership.

Moved: Abby Macnish Niven

Seconded: Josh Davenport

All in favour: All present

CARRIED

9. APPOINTMENT OF THE AUDITOR FOR 2023 ACCOUNTS

Abby Macnish Niven noted new auditors were appointed at the AGM in June last year and in line with Board recommendation sought members approval to appoint HLB Mann Judd to audit the accounts for 2023 and called for the motion accordingly.

MOTION: To appoint HLB Mann Judd as the Auditors for 2023 financial year.

Proposed: Shane Powell

Seconded: Matt Curnow

All in favour: All present

CARRIED

10. HONORARY LIFE MEMBERSHIP NOMINATION

On behalf of the Board, Tanvi Haria proposed Susan Trahar as an Honorary Life Member of the Association.

During her 12-year tenure on the Board of Muscular Dystrophy WA (MDWA)/Neuromuscular WA, Susan has been an invaluable asset to the organisation. Her strong interest and close connection to research and community outcomes led to her representation on the Research Advisory Committee, where she served as Chair for seven years.

Susan's legal expertise and guidance have been crucial in supporting management, particularly during crisis management meetings, where she provided strategic input and ensured thoughtful decision-making and in her final two years as Vice-Chair of the Board, Susan continued to demonstrate her reliability, professionalism, and legal acumen. With over 20 years of experience in Allied Health practice, management, and legal practice, Susan brought valuable knowledge to the Board.

Susan's philanthropic efforts have been remarkable, as she has been actively involved in fundraising events and has attended numerous community gatherings alongside her son Michael, who has Becker MD. One of Susan's notable contributions was her pivotal role in launching and promoting the Truffles for Muscles Fundraising Auction in 2014, which has since evolved into the successful Kailis Club. Her business acumen and advice were instrumental in establishing a strong corporate support network for our events.

Susan's presence has always been characterised by warmth and friendliness. She has been a generous contributor to our events and has continued that support to Neuromuscular WA since stepping off the Board. Her calm demeanour, ethical approach and generous interactions with fellow Board Members, MDWA staff, stakeholders, and the community have always been commendable.

Motion: The membership approve the Honorary Life Membership of Susan Trahar

Proposed: Cara Philpott

Seconded: Josh Davenport

All in favour: All present

CARRIED

11. ELECTION OF BOARD MEMBERS

In line with Rule 11.2.(a) and (b) of the Constitution, Tanvi Haria confirmed the Board may comprise up to 8 Elected members and 2 Appointed members. Six current board members stepped down from their position at the AGM, leaving six position vacant for election by the membership. Constitutionally, the Board members are elected at the AGM for a three-year term and may serve for a maximum of three terms. Following this they must take a 12-month break.

The members concluding their term are Tanvi Haria, Josh Davenport, Abby Macnish Niven, Shane Powell and Matthew Curnow.

Tanvi Haria acknowledged that Dr Peter Rowe, whose term expires in 2025 stepped down from his position on the Board. Tanvi thanked Dr Rowe for his 12 years of service on the Board. Tanvi Harai confirmed Shane Powell and herself will not be standing for election given both concluded the three terms with eligibility for election after a 12-month break.

Hayley Lethlean confirmed the names of the nominees for 2023 Board being Abby Macnish Niven; Cara Philpott; Matthew Curnow; Nirbhay Gupta; Deema Audeh and Josh Davenport.

In line with Rule 11.10 of the Constitution and given number of nominations received is equal to the number of vacancies to be filled, Board members were duly elected.

MOTION: The six nominated members Abby Macnish Niven; Cara Philpott; Matthew Curnow; Nirbhay Gupta; Deema Audeh and Josh Davenport are duly elected to the Board.

Proposed: Ellen Storey-Potter

Seconded: Emma Kenton

All in favour: All present

CARRIED

12. ANY OTHER BUSINESS

Tanvi Haria called for any other business to be discussed from those present. Tanvi Haria thanked the Board and Staff for their efforts during 2022 and acknowledged the volunteers and donors who supported us this past year.

Abby Macnish Niven thanked Tania Haria for her service to the community during her 7 years on the Board and final year as Chair of the Board.

13. CLOSE OF MEETING

Tanvi Haria thanked everyone for attending requesting they join the Board and Staff for some drinks and food and declared the meeting closed at 5.31 pm

Signed as a true and correct record of the meeting:

NAME: _____

POSITION: _____

SIGNATURE: _____

DATE: _____