

MOTOR NEURONE DISEASE ASSOCIATION
MINUTES of the 39TH ANNUAL GENERAL MEETING
Held on 26 JUNE 2024, commencing at 17.00
At Francis Crick House, Northampton, NN3 6BJ and Online

PRESENT (Online and In Person)

Dr Usman Khan (Chair)

Board of Trustees

68 Members of the MND Association

IN ATTENDANCE

Tanya Curry, Chief Executive

Directors and Support Staff

Professor Rebecca Gould,

Professor Martin Turner

Heather McLoughlin (Minutes)

The Chair, Dr Usman Khan welcomed everyone to the hybrid AGM and formally opened the meeting.

1 Apologies

1.1 None.

2 Minutes of the 37th Annual General Meeting held on 1 July 2024

2.1 The minutes were accepted as a true record of the meeting.

3 Matters Arising from the Meeting

3.1 There were none.

4 The Chair's Report

4.1 The Chair of the Board of Trustees provided the members with an update on the work of the Association over the last year. The Chair shared a video with the members for his report. The video highlighted to members the work of the Association in 2023.

4.2 The Chair thanked members and staff for their work over the last year.

5 Presentation from Professor Gould

5.1 External speaker Professor Gould shared a presentation with members on research on the COMMEND study.

6 Presentation from Professor Turner

6.1 External speaker Professor Turner shared a presentation with members on the EXPERTS-ALS work.

7 Honorary Treasurer's Report

7.1 The Honorary Treasurer presented his report on the finances of the Association to members. The Honorary Treasurer highlighted that the Association's income had grown to almost £38m in, with expenditure at £26.8 million.

- 7.2 The Honorary Treasurer informed the members of the predicted financial outlook for 2024. The members were notified that the beginning of 2024 had been a strong financial period for the Association. Members were informed of the plan to spend designated reserves on research, care services and campaigning in 2023.

8 Voting on resolutions

8.1 Ordinary Resolution Voting to receive the Annual Report and Financial Statements to 31 December 2023.

Proposed Jim Marshall
Seconded Simon Croxford
Voting:

- Votes For 286
- Votes Against 2
- Votes Withheld 2

The resolution was carried.

8.2 Voting to appoint as trustee of the MND Association the person elected as a trustee at this AGM.

Proposed Ian Lev
Seconded Kirrie Todd
Voting:

- Voting For 286
- Voting Against 1
- Voting Withheld 3

The resolution was carried.

8.3 Special Resolution 1. - By adding to the heading above Article 28.5 of "Automatic retirement" the words "and eligibility for reappointment", and deleting Article 28.5 in its entirety and replacing it with the following new Article 28.5:

"At the end of the third annual general meeting following the commencement of his or her term of office ("Retirement Date") each Elected Trustee shall retire from office, unless their term of office has already ceased under Article 30. Subject to Article 28.6, an Elected Trustee retiring under this Article 28.5, or who had resigned earlier during their term of office under Article 30.1.4, may stand for re-election at the annual general meeting on the Retirement Date, provided he or she is at that time eligible to serve and has been duly nominated subject to Article 28.2. For the purpose of Article 28.6, any Elected Trustee re-elected on the Retirement Date under this Article 28.5 shall be treated as commencing a consecutive term of office."

Proposed Kirrie Todd
Seconded Dr Shaun McGee

Voting:

- Votes For 281
- Votes Against 3
- Votes Withheld 5

- 8.4 **Special Resolution 2.** - By deleting Articles 28.6 and 28.7 in their entirety and replacing them with the following new Article 28.6:

"An Elected Trustee may serve for a maximum of three consecutive terms of office as an Elected Trustee (in accordance with Article 28.5)."

Proposed Dr Shaun McGee

Seconded Jim Marshall

- Votes For 282
- Votes Against 3
- Votes Withheld 5

The resolution was carried.

- 8.5 **Special Resolution 3.** – By deleting Articles 29.2, 29.3 and 29.4 in their entirety and replacing them with the following new Article 29.2:

"Subject to Articles 29 and 30, a Co-Opted Trustee shall remain in office for a term of up to three years. On expiration of the period of office for which he or she was appointed (whether or not the Co-Opted Trustee has already resigned from office during their term under Article 30.1.4), a Co-Opted Trustee shall be eligible for reappointment by the Board."

B) By deleting Articles 29.5 and 29.6 in their entirety and replacing them with the following new Article 29.3:

"A Co-Opted Trustee may serve for a maximum of three consecutive terms. A Co-Opted Trustee re-appointed in accordance with Article 29.2 shall be treated as commencing a consecutive term of office."

Proposed Simon Croxford

Seconded Ian Lev

- Votes For 281
- Votes Against 4
- Votes Withheld 5

The resolution was carried.

- 8.6 **Special Resolution 4.** - In Article 27.1.2 removing the words "*and chair-elect*", in Article 31.1 removing the word "*chair-elect*" and replacing it with the words "*new chair*", in Article 31.2 removing the word "*chair-elect*" and replacing it with "*Chair*", and in Article 38.3.3 removing the words "*and/or chair-elect*".
In Article 31.1 replacing the word "*third*" with the word "*fourth*", and in Article 31.1 by deleting the words "*shall be elected to the Board and shall take office as Chair automatically at the next annual general meeting*" and replacing them with the words "*shall be elected to the Board (if not already a Trustee) and shall take office as Chair at the end of the annual general meeting*".

- Proposed Kirrie Todd
Seconded Simon Croxford
- Votes For 281
 - Votes Against 5
 - Votes Withheld 3

The resolution was carried.

- 8.7 **Special Resolution 5** - In Article 31.3 by deleting the first word “A” and replacing it with the words “*Subject to the rules at Articles 28 and 29 about maximum terms, a*”, and inserting after the words “*may serve a term of*” the words “*up to*” before the word “*four*”.
- By deleting Article 31.5 in its entirety and replacing it with the following new Article 31.5:
- “Subject to the rules at Articles 28 and 29 about maximum Trustee terms, a Chair may serve no more than two terms of office as Chair after which he or she shall retire and shall not be eligible to serve as Chair. Any period of office as Chair served as a result of appointment in accordance with Article 31.4 shall not be counted as a term of office for the purposes of this Article 31.5.*”

- Proposed Ian Lev
Seconded Jim Marshall
- Votes For 280
 - Votes Against 4
 - Votes Withheld 6

The resolution was carried.

9 Results of the trustee elections

The Chair was pleased to announce that the candidate elected to the Board of Trustee by the membership were:

1. Liz Ellis
2. Ed Cooke
3. Alan Graham
4. Dr Michael Hope

The Chair thanked all candidates who had stood for election but were unsuccessful.

The Chair announced that Debbie Martin was standing down as a trustee and thanked her for her contributions to the work of the Board as a trustee.

10 Questions and Answer sessions with members

- 10.1 The Chair of the Board then opened the question-and-answer session to the Association’s members. The Director of Engagement hosted the Q&A session.

- 10.2 The Director of Engagement read out the first question: Q1. *Would the Board consider adding to its priorities the encouragement and funding of research of the causes the aspiration pneumonia?* (Peter Camburn)
- 10.2.1 The Director of Research Development replied that NICE has published a guideline in MND, and colleagues within the Association have been reviewing the guidelines. There are a lot of gaps, and knowledge of the disease has improved over the years. The Association was not specifically funding aspiration pneumonia currently, but is funding other studies that are related, for example, one in maintaining good oral health with MND. The hope is that this research will provide useful guidance.
- 10.2.2 A lot of research work is being conducted internationally who are looking into funding and researching other issues in relation to care of people living with MND.
- 10.3 The Director of Engagement read out a question: Q2. *We have heard a lot about research in counselling us to help change our mood and using NFL markers in trialling existing drugs in the hope that one will slow the pathway to death. What about research into a cure? How much money has been spent solely on this?* (Elaine Barnett)
- 10.3.1 The Director of Research Development responded that the lack of effective treatments for MND is not due to the lack of trying; hundreds of millions have been spent. We clearly have not been getting research right, so we need to ask how we can do this faster and take the drugs that have the highest chances of succeeding, and how do we know before we start investing millions in clinical trials? EXPERTS-ALS is trying to do that work. In the meantime, there are lots of trials going on, often in other parts of the world, such as North America. The UK MND Research Institute, a network of leading clinics and research centres, is to create the fertile ground to rapidly move drugs into clinical trials, but also would make the UK an attractive place for drug companies to come and run their trials.
- 10.4 The Director of Engagement read out a question: Q3. *Is there any research on PM2.5 re MND?* (Ray King)
- 10.4.1 The Director of Research Development explained the science behind PM2.5. They confirmed that there was no specific research on PM2.5 currently ongoing, though there was research on the cardiovascular system and air quality.
- 10.5 The Director of Engagement read out a follow-up question from Mr Peter Camburn, asking for clarification on whether the Board would prioritise funding research into aspiration pneumonia, as it sounded like the Board would not.
- 10.5.1 The Director of Research Development confirmed that the Association would not say no to funding research. However, any research into aspiration pneumonia had to meet the criteria set for funding research.

11 Chief Executive Speech

11.1 The Chief Executive started by thanking Professor Gould and Professor Turnery for joining the AGM and presenting to members. She also thanked Debbie Martin for her time as a trustee and welcomed the newly elected trustees to the Board.

11.2 The Chief Executive reflected on their experience of 2023 and how everyone in the Association community – members, volunteers, staff- is cause-driven, inspired by the urgency needed. Everyone was working towards a cure alongside supporting those living with MND in the now. Furthermore, the Association's profile is growing and the Association can present what the MND community needs. A new strategy and new leaders in the organisation would drive the Association forward to be proactive.

8 Closing the meeting

8.1 There being no further business, the Chair of the Board closed the meeting at 18.35. The Chair thanked all members who had attended and participated in the meeting.