

MOTOR NEURONE DISEASE ASSOCIATION
MINUTES of the 38TH ANNUAL GENERAL MEETING
Held on 1 JULY 2023, commencing at 10 am
At Francis Crick House, Northampton, NN3 6BJ and Online

PRESENT

Dr Usman Khan (Chair)
Board of Trustees
57 Members of the MND Association

IN ATTENDANCE

Tanya Curry, Chief Executive
Directors and Support Staff
Heather McLoughlin (Minutes)

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

1 Apologies

Apologies were received from trustee Debbie Martin.

2 Minutes of the 37th Annual General Meeting held on 27 June 2022

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

3 Matters Arising from the Meeting

There were none.

4 Board of Trustees' Annual Report

The Chair of the Board of Trustees and the Honorary Treasurer provided the members with an update on the work of the Association over the last year.

4.1 The Chair's Report

The Chair opened his report by noting the passing of Richard Coleman, former Chair of the Board of Trustees and member of South Bucks Branch, in early 2023.

The Chair presented his report, which highlighted to members the work of the Association in 2022 and the progress against the 5 Promises.

The Association won't rest until:

- 1 MND is treatable and ultimately curable,
- 2 Everyone gets the care they need, when they need it,
- 3 Every day with MND counts,
- 4 You are heard,
- 5 No one faces MND alone.

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

4.2 Honorary Treasurer's Report

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 in 2022 to £30 million, with expenditure at £22.8 million, producing a surplus of £7.2 million.

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

5 Voting on resolutions

5.1 Voting to receive the Annual Report and Financial Statements to 31 December 2022.

Proposed Simon Croxford

Seconded Ian Lev

Voting:

- Votes For 462
- Votes Against 0
- Votes Withheld 10

The resolution was carried and passed unanimously.

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

Proposed Catherine Knights

Seconded Dr Shaun McGee

Voting:

- Voting For 462
- Voting Against 0
- Voting Withheld 12

The resolution was carried and passed unanimously.

6 Results of the trustee elections

The Chair was pleased to announce that the candidate elected to the Board of Trustee by the membership was Hazel Carter.

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

The Chair announced that Siobhán Rooney and Katy styles were standing down as trustees. The Chair thanked them both for their significant contributions to the work of the Board as trustees.

6 Questions and Answer sessions with members

The Chair of the Board then opened the question and answer session to the Association's members.

Q1. Have we given considerations to raising the cap on the grants the Association award? (Debbie)

The Director of Care Improvement replied that grants are an area of focus this year as the Association are aware of the financial pressures on our members due to the cost-of-living crisis. The Board agreed at the end of 2022 to launch the Cost of Living Support Fund to support the Association's MND community. In the first 6 months of 2023, the Association has spent £1.1 million, which is double the amount spent by the Association in 2022.

The Director of Care improvement also explained that a volunteer group made up of members and staff meet monthly to review the Association's grant work and put forward recommendations towards the Board. The Association is focused on looking at the level of support we are offering to members.

Q2. What help is available for someone who is disabled and who's wife has been diagnosed with MND. (Ray King)

The Director of Care Improvement informed the member that there is a lot of support the Association offers locally, via the branch and groups and the Association Visitors. The Director of Care Improvement confirmed that he would speak to the member after the meeting to detail the level of support the Care Directorate can offer. The member was also informed that the Association's website has considerable literature on how the Association can support carers.

Q3. How does the MND Association support patients in developing countries like Pakistan, and are there plans to expand their services by establishing sub-chapters of the MND Association in these regions? (Rahim Ahmad Khan)

The Director of Care Improvement informed the member of the International Alliance of MND/ASL Associations, which meets quarterly and has representation from about 50 global organisations. The International Alliance is always looking to expand with the goal of sharing best practices globally.

The Director of Research explained that the direct support that the Association can give can only be in England, Wales and Northern Ireland due to the Articles of Association. The members were informed that the Association looks to translate guidance into multiple languages. There are also research projects, like Project Mind, that are working internationally.

7 Chief Executive Speech

The Chief Executive started their speech by recognising and honouring the work of former Chief Executive Sally Light, who stepped down from the role at the end of 2022.

The Chief Executive reflected on their experience of the first six months of 2023 and future plans for 2023. The Chief Executive praised the Association's members, trustees and staff for their dedication to the Association and thanked them for all their work.

8 Closing the meeting

There being no further business, the Chair of the Board closed the meeting at 10.58 am. The Chair thanked all members who had attended and participated in the meeting.