

**MOTOR NEURONE DISEASE ASSOCIATION**  
**MINUTES of the 40<sup>TH</sup> ANNUAL GENERAL MEETING**  
**Held on 9 July 2025, 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**

Directors and Support Staff  
Milly Mbabazi (Minutes)

**APOLOGIES**

Tanya Curry, Chief Executive  
Jim Marshall, Honorary Treasurer

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

**1 Welcome and Apologies**

- 1.1 The Chair welcomed members and Trustees to the 40<sup>th</sup> AGM
- 1.2 The Chair acknowledged with sadness the passing of trustees Ed Cooke and Michael Hope.
- 1.3 Apologies were received from the Chief Executive Officer. Tanya Curry and Honorary Treasurer Jim Marshall.

**2 Minutes and Matters Arising of the 39<sup>th</sup> Annual General Meeting held on 26 June 2024**

- 2.1 The minutes and matters arising were accepted as a true record of the meeting.

Proposed: Shaun McGee  
Seconded: Ian Lev

**3 The Chair's Report**

- 3.1 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 2024.
- 3.2 The Chair thanked members and staff for their work over the last year.

**4 Honorary Treasurer's Report**

4.1 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 over £40 million in 2024, with expenditure at £33.9 million.

4.2 The Honorary Treasurer informed the members of the predicted financial outlook for 2025. 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 continue spending designated reserves on the Association's core mission areas, Care and Research. Campaign/Awareness, Volunteer Development.

## **5 Presentation from Lead Research Nurse**

5.1 The Lead Research Nurses shared a presentation on the MND Associations Funded Research Nurse Network.

5.2 The Members were informed that there have been applications to fund MND research nurses in 17 care centres, with approval being provided for 12 Care Centres to date, with 3 Research Nurses now appointed and in post.

## **6 Research Update by the Director of Research and Innovation**

6.1 The Director of Research and Innovation presented his update on the association's strategy goals, current external landscape on research, research leadership and the association's involvement in research funding.

6.2 Members noted that the MND Association funded scientists and medical professionals who are researching TDP-43 (TAR DNA-binding protein of 43kDa), which is a protein that plays a crucial role in motor neuron disease in a range of ways.

6.3 The Director of Research and Innovation highlighted that the UK MND Research Institute, launched in 2023, includes a flagship study called Expert ALS. This study emphasises drug selection based on indicators of potential human benefit, which can be identified in small patient groups within a relatively short timeframe. The methodology involves monitoring the neurofilament biomarker present in the blood of individuals living with MND. This initiative is being co-funded by the NHR, MRC, and various MND charities.

6.4 Members were informed that the Association is the principal funder of the Longitude Prize on MND, partnering with Challenge Works. It was understood that the Longitude Prize on MND will open data and utilise AI to identify and validate targets for transformative drug discovery.

## **7 Voting on resolutions**

7.1 **Ordinary Resolution 1: Voting to receive the Annual Report and Financial Statements to 31 December 2024.**

Proposed     Ian Lev  
Seconded     Simon Croxford  
Voting:

- Votes For                      373

- Votes Against 1
- Votes Withheld 9

The resolution was carried.

## **7.2 Ordinary Resolution 2: Voting to appoint as trustee of the MND Association the person elected as a trustee at this AGM.**

Proposed Catherine Knights

Seconded Ian Lev

Voting:

- Voting For 377
- Voting Against 1
- Voting Withheld 6

The resolution was carried.

### **7.2.1 Results of the trustee elections**

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

1. Marc Barlow
2. Eleanor Dalley
3. Sue Plummer

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

The Chair announced that Catherine Knights and Simon Croxford were standing down as trustees and thanked them for their contributions to the work of the Board.

## **7.3 Ordinary Resolution 3: To re-appoint Ian Lev as an elected trustee to the Board**

Proposed Hazel Carter

Seconded Shaun McGee

Voting:

- Voting For 356
- Voting Against 7
- Voting Withheld (19)

The resolution was carried.

## 8.0 Questions and Answer sessions with members

8.1 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.

8.1.1 The Director of Engagement read out the first question: Q1. *Will the MND Association consider directly funding the administration of tofersen for the 12 individuals whom the NHS is refusing to treat?*

8.1.2 The Director of Engagement conveyed the Association's concern that directly delivering drugs could set a troubling precedent, potentially leading the already overstretched NHS to transfer more responsibility for direct care delivery onto the charity. As a charity, it is not within their remit to assume this role. Instead, the Association believes it is crucial to focus on campaigning for equal access to treatment and to enhance the current national campaign by collaborating with individuals to lobby their local Trusts for funding. This approach will involve proactive support, including drafting letters, engaging local stakeholders, providing necessary materials, and establishing the MND Association as a campaigning organisation aligned with the national strategy. Additionally, members noted that the Association plans to go to Parliament to visually represent the issue, aiming to gain further media coverage.

8.2 The Director of Engagement read out the next question: Q2. *Can your association ensure that all future drug trials funded or supported by you include all individuals with MND, particularly those like myself who have had a slow progression for over two years, in order to provide access to these drugs?*

8.2.1 The Director of Research and Innovation highlighted that they would be unable to provide a unanimous agreement at this point in time. However, he noted that the Association is currently developing its research strategy and is looking into how best to support clinical trials. It has been acknowledged that individuals are not being offered the opportunity to participate in clinical trials as frequently as the Association hopes, and efforts are being made to extend this by providing funding through Care Centres and MND Research Nurses. It was understood that clinical trials have different inclusion and exclusion criteria depending on various factors. The Director of Research expressed that they would seek to include as many people as possible in trials as part of the research strategy development.

8.3 The Director of Engagement read out the next question: Q3. *Could you please provide a summary of the role of the International Alliance of ALS/MND Associations?*

8.3.1 The Director of Research and Innovation explained that the International Alliance of ALS/MND Associations is a global network comprising organisations like the MND Association, focusing on community support and advice. This network features a community advisory council, serving as a centralised resource that reviews and provides a global perspective on various opportunities. Recently, the Alliance has increased its activities, notably working on developing a unified database of research funding from all contributors to

ensure resources are allocated across different areas effectively. Additionally, they are making strides to enhance patient involvement in research initiatives.

- 8.4 The Director of Engagement read out the next question: Q4: *Are there any new trials or medicines for sporadic MND?*

- 8.4.1 The Director of Research and Innovation highlighted that there are always ongoing studies and trials, which can be accessed on the website as they are published. A notable current trial is the ASTRALS study, conducted by Novartis, featuring a new agent known as VHB-937. This agent specifically targets microglia cells. The ASTRALS trial is now advancing into its second phase, serving as an example of research focused on individuals with sporadic MND.

## **9 Chair Closing Remarks**

- 9.1 The Chair thanked those for presenting at the AGM. The Chair also thanked departing members for their time as trustees and welcomed the newly elected trustees to the Board.

## **10 Closing the meeting**

- 10.1 With no further business, the Chair of the Board closed the meeting at 18.33. The Chair thanked all members who had attended and participated in the meeting.