

MOTOR NEURONE DISEASE ASSOCIATION

37TH ANNUAL GENERAL MEETING

27 JUNE 2022

BY TEAMS

PRESENT Richard Coleman (Chair)
Board of Trustees
Members of the MND Association

IN ATTENDANCE Sally Light, Chief Executive
Directors and Supporting Staff
Heather McLoughlin (Minutes)

The Chair, Richard Coleman welcomed everyone to the hybrid AGM and formally opened the meeting.

Formal recognition of Andy Cawdell

Richard opened the meeting by paying tribute to Andy Cawdell, a trustee living with MND but who passed away a week before the elections. Andy was standing for re-election in 2022 and had been successfully elected to the Board.

Results of the elections

The Chair was pleased to announce the re-election of Catherine Knights to the Board and welcomed, as newly elected trustees, Simon Croxford, Susan Fletcher Watts, Ian Lev and Dr Katherine Jackson.

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

The Chair announced that Andy Cawdell, Dr Heather Smith, Vicky Paeschel and Jan Warren were standing down as trustees. He thanked them both for their significant contributions to the work of the Board

1 Apologies

Apologies had been received from trustee Dr Shaun McGee and member Lesley Ogden.

2 Minutes of the 36th Annual General Meeting held on 1 July 2021

These were accepted as a true record of the meeting.

3 Matters Arising from the Meeting

There were none.

4 Board of Trustees' Annual Report

4.1 Chair's Report

Richard presented the report, which set out the work of the Association in 2021. Richard reflected on his time as Chair of the Association and how the Association has grown from an £8 million organisation to a £20 million organisation. He gave credit to Sally Light and her Directors Team. He wished Sally Light well for her future once she stands down as CEO at the end of 2022. Richard noted that he hands over the role of Chair to Dr Usman Khan.

4.2 Honorary Treasurer's Report

Jim Marshall introduced his presentation, which highlighted the finances of numbers for 2021, and the future finances of 2022. Jim informed the membership that 2021 was an incredible strong year financially with the highest ever recorded year for income. Fundraising income was £18.2 million and £3 million alone from Kevin Sinfield's 7in7 and Extra Mile Challenges.

Jim then outlined how the expenditure of the Association. Jim explained that the two highest areas of spending was care and support at £5.9 million and research at £4.6 million. The research portfolio is now 83 projects, worth £15.1 million. Jim then explained the balance sheet summary and the Association's reserves policy. The Association is planning on spending £28.3 million on research and care in the next financial year.

Jim looked forward to the 2022 outlook and explained that the Association does not expect to match or exceed their fundraising income from 2021. He explained that the Association is planning on running a deficit in 2022, with spending being covered by designated reserves.

4.3 Chair Elect Report

Richard introduced the new Chair of the Association, Dr Usman Khan. Usman reflected on his time as Chair elect over the last 12 months. He thanked Richard and the Board for their support as Chair elect. He praised Richard's skill and experience as Chair.

Usman also gave words of reflections on Andy Cawdell and expressed his condolences on Andy's recent passing. He commented that Andy always showed great resilience as someone living with MND. He thanked Andy for his support over the last year.

Usman then thanked Sally for her work as CEO and reflected on her passion and leadership in her time as CEO.

He then reflected on his priorities as Chair. The first is the work #UnitedtoEndMND partnership to ensure the £50 million promised by the Government is given out. The second is the partnership work with other leading organisations. Another priority is ensuring we represent all members of our communities across the three nations.

5 Voting on resolutions

5.1 Voting to receive the Annual Report and Financial Statements to 31 December 2021

Proposed Jim Marshall
Seconded Jan Warren

Voting:

- Those present in favour Unanimous
- Those present against 0
- Proxy votes for 395
- Proxy Abstentions 12
- Proxy votes against 1

The resolution was carried.

5.2 Voting to appoint as trustees all those elected at the AGM

Proposed Catherine Knights
Seconded Jan Warren

Voting:

- Those present in favour Unanimous
- Those present against 0
- Proxy votes for 395
- Proxy Abstentions 1
- Proxy votes against 12

The resolution was carried.

6 Questions and Answer session

Richard now opened the question and answer session to our members.

*Could we please elaborate on our huge contribution to the international alliance of ALS/MND (which the Association founded) and the International Symposium and the relevance of our international work and contributions.
(Steve Bell)*

Sally thanked Steve for his question. She said that we were one of the founding members of the alliance and it has now grown into a large international alliance. The Association is one of the largest organisations within the alliance, and this presents an opportunity and responsibility to support other emerging organisations around the world. We do this in a number of ways, offering support and mentoring, allowing them to translate our literature into local languages. We also learn from them, for example the Argentinian organisation and their use of video and social media. Brian also informed the membership that the Association organises the world's biggest medical, scientific meeting on MND/ALS with the International

Symposium. He reflected on some of the Association's shared global work, for example, Project Mind which is a large global gene hunting study.

Have there been any developments in regard to leaving Lloyds. (Maria Holmes)

Mark informed the membership that there have been a number of challenges with Lloyds bank. Northern Ireland have had a worse experience of using Lloyds than branch and groups based in Wales or England. Mark said that the Finance Team have tried to resolve these issues, but changing banking providers is not easy due to the size and scale of our banking requirements. However, conversations are starting with other banking providers and we intend to go out to full tender, end of 2022, and it to be a collaborative exercise with the branch and groups to understand what requirements they need from banking operators.

Does the Association feel that they should recommend Lee, Chris, Dave, Emma, Nicola for Queens Honours awards. (Mark Gately)

Chris James explained that these are all people who are living with MND and have played a key part in the campaigning work of the Association – for example the #UnitedtoEndMND campaign. Chris explained that the Association cannot make comments on the Queens Honours Award as that format is rather secretive process. Chris commended them on their phenomenal campaigning work over the last few years.

The technology work and the Think Tank work that has grown over the last few years (Anonymous)

Nick explained how the MND Association Next Generation Think Tank was created with Steward Moss, Head of IT Innovation at Rolls Royce. The idea was to create this ecosystem of ideas with tech partners and neurologist. Now have a number of projects that focus on speech and has resulted in the I Will Always Be Me book created with Dell, Intel and Rolls Royce. Also work with Google and their Google Assistant work and with Rolls Royce and Artificial Intelligence for those who have lost their voice. Also work with Toyota (one of our charity partners) and using robots to help care in the home. Nick reflected that the world is our oyster at the moment for tech and that it also presents nice fundraising opportunities as well.

Are we offering any public recognition for the work of former trustee, Peter Scott Morgan, in his robotic work. (Steve Bell)

Nick replied that Peter Scott Morgan had set up his own foundation to explore his robotic work. The Association looks forward to seeing the work that comes out of the foundation. We did recognise Peter Scott Morgan's passing and his contributions to the Association as a former trustee on our website and social media.

The Chair then thanked everyone who had participated in the meeting and closed it at 18.10.