

MOTOR NEURONE DISEASE ASSOCIATION

36TH ANNUAL GENERAL MEETING

1 JULY 2021

BY TEAMS

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

IN ATTENDANCE Sally Light, Chief Executive
Directors and Supporting Staff
Jo Darby (Minutes)

The Annual General Meeting was preceded by presentations from Dr Brian Dickie, Director of Research Development and Professor Chris McDermott, Consultant Neurologist and the Sheffield MND Care Centre Co-Director.

Following this, the Chair, Richard Coleman, welcomed everyone to the AGM, thanked the research presenters and formally opened the meeting.

Results of elections

The Chair was pleased to announce the re-election to the Board of Siobhan Rooney and Katy Styles and welcomed, as newly elected trustees, Liz Ellis and Debbie Martin. He thanked all who had stood for election and, given the very strong field of candidates, hoped that they would remain engaged with the Association and stand again for election in 2022.

The Chair announced that Alan Graham and Tim Kidd were standing down as trustees and thanked them both for their significant contributions to the work of the Board.

The trustees then introduced themselves individually, speaking of their personal backgrounds and their connections with MND and the Association.

1 Apologies

Apologies had been received from trustees Devia Gurjar and Dr Nik Sharma.

2 Minutes of the 35th Annual General Meeting held on 13 October 2020

These were accepted as a true record of the meeting.

Minutes of the Extra General Meeting held on 2 March 2021

These were also accepted as a true record of the meeting.

3 Matters Arising from the AGM and EGM Meeting

There were none.

4 Board of Trustees' Annual Report

4.1 Chair's Report

The Chair commended the Association for its work and achievements through 2020 and described how the Covid pandemic had affected activities. There had been online support groups set up for people living and affected by MND, numerous acts of kindness by volunteers and increased contact and support for the MND community.

Staff had been working from home and campaigners had continued to have influence, with a record number of mentions in parliament. The reality of MND had been brought home to many through the sharing of personal stories, including Rob Burrows', whose journey was featured on television.

It had been an extraordinary year for fundraising with increasingly creative ways being found to boost support for the Association. Strong partnerships had been forged, including those enabling advances in counselling and voice-activated technology. Work had continued through lockdown in research, with an online international symposium attracting 1,800 people from 48 countries.

The Chair thanked members, staff and volunteers for their support which, over the past year had shown the Association to be at its very best and demonstrating energy, resilience and strength.

4.2 Chief Executive's Report

The Chief Executive, Sally Light, expressed heartfelt thanks to all who, throughout this difficult and uncertain time, had demonstrated strong commitment and support for the whole community.

The pandemic had given the Association the challenge of looking at new ways of working. Technology had enabled continued engagement for people with MND, with online support groups, a podcast and new, innovative opportunities for campaigning, awareness raising and fundraising. As restrictions were eased, it was hoped that participation could be both in-person and online. An increase in donations had created a significant surplus in funds, accelerating plans to support people living with MND and Sally described the Association's work with children, young people and families. There was a growing interest in MND research and this was being capitalised upon to drive forward translational research, with care centres involved in trials and further partnership work with the My Name's Doddie Foundation and MND Scotland. The Association was a leading authority on MND research and Sally emphasised that achievement was possible through working together with partners to tackle the relentlessness of MND.

4.3 Honorary Treasurer's Report

The Honorary Treasurer, Tim Kidd, presented the financial highlights of 2020, which had been a difficult year for many charities. Thanks to the Association's generous and hardworking supporters, he was able to report a 7% increase in revenue at the end of the year. He presented a chart to show how income had been raised and pointed out that for every £1 spent on fundraising, £4.60 had been raised. Legacies showed a particularly strong revenue. The dedication of volunteers, branches and groups, and the outstanding support from Kevin Sinfield and others had contributed to this exceptional performance.

Turning to the Association's expenditure, another chart set out where money had been spent during 2020.

Tim reported on a strong level of reserves and explained that restricted funds were where a donor had specified exactly how a gift should be spent and designated funds were where the Association had committed money for specific projects. A slowdown in revenue had been expected because of the ongoing effects of Covid restrictions, but in fact, 2021 was continuing the 2020 trend, with a strong start to fundraising in spite of uncertainty about future fundraising events.

Tim spoke of caution in future budgeting, warning about uncertainty for 2022, although the strong levels of reserves and the continued dedication of supporters meant that existing commitments could still be delivered.

5 Resolutions

5.1 *Special Resolution*

To consider that the draft Articles of Association which could be accessed using the credentials circulated in the Annual General Meeting notice dated Thursday, 3 June 2021 be and are hereby adopted as the Articles of Association of the Charity in substitution for and to the exclusion of all existing Articles of Association of the Charity.

Proposed Heather Smith
Seconded Jan Warren

- Those present in favour 6
- Those present against 0
- Those present abstentions 1
- Proxy votes for 642
- Proxy abstentions 49
- Proxy votes against 4

The resolution was carried.

5.2 *Annual Report and Financial Statements*

To consider the consolidated financial statements as represented in the Formal Notice and Voting Guide for the year ended 31 December 2020.

Proposed Alan Graham
Seconded Cynthia Hopkins

- Those present in favour 7
- Those present against 0
- Proxy votes for 653
- Proxy Abstentions 40
- Proxy votes against 2

The resolution was carried.

5.3 *Re-appointment of Auditors*

To authorise the Board of Trustees to appoint haysmacintyre LLP as auditors from the conclusion of this meeting to the end of the next period for appointing auditors.

Proposed Jim Marshall
Seconded Shaun McGee

- Those present in favour 7
- Those present against 0
- Proxy votes for 649
- Proxy Abstentions 41
- Proxy votes against 5

The resolution was carried.

5.4 *Auditors' Remuneration*

To authorise the Board of Trustees to agree the remuneration of the auditors, haysmacintyre, for every year in which the auditors are deemed to be reappointed.

Proposed Catherine Knights
Seconded Heather Smith

- Those present in favour 7
- Those present against 0
- Proxy votes for 650
- Proxy Abstentions 39
- Proxy votes against 6

The resolution was carried.

5.5 *Appointment of Usman Khan as Chair Elect*

To approve the trustees' proposal for the appointment of Dr Usman Khan as Chair Elect of the MND Association.

Proposed Jan Warren
Seconded Steve Bell

- Those present in favour 7
- Those present against 0
- Proxy votes for 628
- Proxy Abstentions 60
- Proxy votes against 7

The resolution was carried.

6 **Membership Strategy**

Director of Engagement, Chris Wade, shared the new membership objectives of developing an active community of members combining their skills, insights and energies to further our shared cause. Membership is more than just voting at the AGM; it is about getting involved in co-production, gathering and telling stories, sharing information and getting involved in activities. He was proud of the enthusiasm of supporters and wanted to be able to use their skills to experience and shape activities.

Chris introduced a range of ideas and suggestions on how members may wish to get involved, and explained some of the ways the Association will facilitate and encourage this.

With a discretionary membership subscription, it was hoped that cost would not be a barrier to membership and that people would be able to join together to become involved in the work of the Association for the benefit of all living with and affected by MND.

7 **Introduction of Chair Elect, Usman Khan**

Usman Khan thanked members for their approval of his appointment to the role of Chair Elect. In applying for the position, he felt that he was at the start of a journey of understanding MND. He had seen hope in spite of the great challenges in healthcare and the fact that MND had not benefitted in the same way as other diseases had. As a person living with MS himself, he had the hope and belief that things would change, and he recognised the huge strength of volunteers, staff, members and trustees. This

had been particularly evident in the way that the Association had stepped up during the Covid 19 pandemic. Usman described his background in healthcare and senior leadership roles, and he had a strong network to call on to support the work of the Association through this time of change.

Usman acknowledged a competitiveness in terms of time and resources. He saw the need for the Association to continue to be a place of innovation for research, with a robust policy agenda to make sure that people with MND had full access to benefits and appropriate technology. He wanted to make every valuable moment of their lives to be as good as they could possibly be.

There was a lot of work to be done and Usman was looking forward optimistically to the challenge, and working with everyone to see what could be achieved.

8 Open Questions

The Chair opened the floor to pre-submitted and live questions, which are noted separately.

9 Closing remarks

The Chief Executive thanked members for their questions and, in relation to research, hoped that people would come away from the meeting with a real sense of optimism and the hope that research would soon bring us closer to treatments for some living with MND. Sally thanked the team that organised the event as well as directors and trustees and paid tribute to Alan and Tim, who were leaving the Board. She felt fortunate to be a part of such a close community, including members, supporters and volunteers. She promised to do all she could to drive the work and support people with MND, their carers and families and make the most of research opportunities and taking steps closer to a world free from MND.

The meeting was closed at 20:05