



ANNUAL GENERAL MEETING

Minutes

**December 2, 2023 - 8:00-9:00 AM (CET)
Virtual & In Person (Basel, Switzerland)**

1. Call to Order

The meeting was called to order at 8:06 am (CET).

2. Confirmation of Quorum

As per the bylaws, quorum was confirmed.

3. Welcome & 2022 Review

Calaneet Balas welcomed everyone to the meeting. She gave a brief outline of the history of the International Alliance of ALS/MND Associations, an outline of the many councils and the work they do.

David Ali and Evy Reviere were thanked for their years of service as they completed their terms and retired from the Board.

The 2022 Award winners were honoured – Richard Cave, Dr. Richard Bedlack, and Sally Light.

The Alliance's 2022-2023 achievements were reviewed. There were several roundtables including Genetics, Optimizing Clinical Trials, and Emergency Preparedness as well as numerous webinars.

The meeting in 2022 was held in San Diego with 241 attendees and nearly 500 attended the APF in person and virtual. It was the largest meeting held to date.

Global Awareness Day is June 21 with many events planned including the 10th Anniversary of the Ice Bucket Challenge.

4. Approval of 2022 AGM Minutes

On a motion duly proposed by Tammy Moore and seconded by Evy Reviere, and carried, the minutes of the 2022 Annual General Meeting be approved as presented.

5. Announcement of Director Elections

Four new candidates and one candidate for re-election put their names forward for three positions. The successful candidates in the Director Election were announced – returning member Marcela Santos, and Tammy Moore and Gethin Thomas.

6. Treasurer's Report

The financial statements from July 1, 2022, to June 30, 2023, were presented.

The Committee members, staff, MND Association and James Gourlay were thanked for their support and commitment to the Committee.

A comparison of statement of profit and loss overview. The Alliance is a registered charity in the UK so the funds are in pounds. A surplus of £48,000 against a planned deficit of £16,000. The budgeted expectations were higher than expected with 100 percent retention of members along with a new member British Columbia and two affiliate members, Global Neuro Y Care and NEALS. There are several other discussions occurring with other potential new members.

A review of the income was shared. Work is being done to increase revenue through sponsorship. Donations and gifts were £190,000 which is 85,000 more than the previous year.

The expenses for the 2022 Alliance meeting and APF were higher than usual due to the cost of audio-visual services and support. They are critical services that are required for the meeting to run smoothly.

Educational service expenses were also higher but offset by other expense lines that were budgeted.

The Balance Sheet was reviewed, and the Alliance is in a good financial position.

James Gourlay, Accounts Reviewers reviewed the accounts and found that there was no matter that came to his attending during the review.

A fund development plan is being developed to ensure The Alliance continues to receive appropriate funding to offer services.

7. Resolutions

a. Receive Accounts

On a motion duly proposed by Sara Feldman and seconded by Pablo Aquino, and carried, the examined financial statements, as approved by the Board of Directors, for the period ending June 30, 2022, were approved.

b. Appoint the Independent Examiners

An explanation was given regarding the change of Examiners for the 2022-2023 fiscal year. James Gourlay was recommended by the MNDA and conducted the examination.

On a motion duly proposed by David Ali and seconded by Evy Reviere, and carried, James Gourlay was appointed as examiner for the 2023/2024 fiscal year.

c. Fixing of Membership Fees

The membership fees were discussed at length by the Committee and several options were considered. Discussions were had with various groups and a decision was made to leave the membership fees as is.

On a motion duly proposed by David Ali and seconded by Wendy Toyer, and carried the annual subscriptions were fixed at the current rate of 0.2 per cent for full members, with a minimum of £100 and a maximum of £10,000 per year; and at a fee of £100 for affiliates.

d. Special Resolution

The Policy Review Committee reviewed the Articles and recommended changes. The changes were mostly clean up and consistency of language. A few sections were updated to remove “the use of post” and moving to electronic communication. There was a change for the Board of Directors/Trustees that outlines if a Trustee is absent from three meetings in a calendar year, the Trustee can be removed. The chairs of the Governance and Budget & Finance Committee changed with the removal of tying the role to the Vice Chair position. The language around the appointment of the Chairperson was cleaned up and simplified to “two terms”.

On a motion duly proposed by Gudjon Sigurdsson, seconded by Sara Feldman, and carried the draft Articles of Association attached hereto were approved and 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.

8. Other Business

9. Adjournment

On a motion moved by Lauren Webb, seconded by Marcela Santos, and carried the Annual General Meeting be adjourned.

8:40 am (CET)

Next meeting: December 3, 2024