



Annual General Meeting

Minutes

October 29, 2024, 7:00 am to 8:30 am

1. Call to Order

The meeting was called to order at 7:04 am.

2. Confirmation of Quorum

As per the bylaws, quorum was confirmed.

3. Welcome & 2023 - 2024 In Review

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

The Board of Trustees and staff were thanked for their service.

Recognition and thanks were given to retiring Board of Trustees members: Pablo Aquino, Gudjon Sigurdsson, Hilmi Uysal, Lung Kuo (Kolo), Sabine Turgeman and Mary Ellen Bench.

The vision of the Alliance is to unite members from around the world. The global community has increased to 64 members across 38 countries. New members include organizations from England, India, Luxembourg, and the USA. Progress has been made in unrepresented countries specifically in Kenya and Vietnam. Assistance is being given to the Democratic Republic of the Congo as they work toward establishing an association.

The 2023 Alliance Meeting was held in Basel, Switzerland with 166 attendees and 361 international healthcare professional and PALS & CALS attending the APF in person and virtually.

The 2023 Award winners were honoured: Student Innovation Award Lauri Desai & Zineb Flahy; Humanitarian Award – Dr. Lucie Bruijn; Allied Health Professional Award - Dr. Deirdre Murray; and the Forbes Norris Award – Dr. Jeremy M. Shefner.

An outline was given regarding the newly formed Research Directors Forum that included 11 Directors from 6 different countries. The group will produce resources such as guidelines, and publications to support organizations and research programs across the globe.

A global clinic locator was created and added to the website.



The 2023 Fundamental Rights Survey has guided advocacy efforts including collaboration with the World Health Organization (WHO), the World Rehabilitation Alliance (WRA), the World Patients Alliance (WPA), and the International Neuropalliative Care Society, Secretariate service to ALS Africa & ELATAM.

This year, celebrations were held for the 10th Anniversary of the Ice Bucket Challenge. It was an opportunity to celebrate awareness and the impact on the community.

4. Approval of the Minutes

On a motion duly proposed by Evy Reviers, and seconded by Angela Harris, and carried, the minutes of the 2023 Annual General Meeting were approved as presented.

5. Announcement of Election Results

Six candidates put their name forward for four Board of Trustee positions. The successful candidates were announced – Jennifer Bedford, Evy Reviers, Clair Sullivan and Riccardo Zuccarino.

6. Treasurer's Report

As approved by the Board of Trustees, the financial statements from July 1, 2023, to June 30, 2024, were presented.

There was a deficit due to investment in capacity and resources and not meeting the revenue targets as budgeted. Three part-time staff were added to the organization to give the CEO more time to spend on fund development.

The Alliance took over the Patients Fellows Program this year with the hope to expand the program, keep it sustainable and more globally focused.

A strategy has been developed to increase funds. Reserves can be used should there be a small deficit in 2024-2025.

7. Ordinary Resolutions

a) Receive the Accounts

On a motion duly proposed by Marcela Santos, and seconded by Gethin Thomas, and carried, the examined financial statements, as approved by the Board of Trustees, for the period ending June 30, 2024, were approved.



b) Appointment of Independent Reviewer

On a motion duly proposed by Evy Reviere, and seconded by Pablo Aquino, and carried, that the Board be charged with appointing an Independent Examiner for the 2023/2024 fiscal year.

c) Fixing of the annual subscriptions

On a motion duly proposed by Pablo Aquino, and seconded by Evy Reviere, 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.

8. Adjournment

On a motion moved by Marcela and seconded by Angela and carried the Annual General Meeting be adjourned.

7:31 am (CET)

9. Looking Ahead

A presentation was shared on the plans for the future of the Alliance to continue building a global support system for members. Focus will continue to grow the communities with further attention to the Global South and supporting research, especially for those without research expertise. The newly established Research Forum will be coordinating projects on topics such as genetics counselling and testing consensus guidelines. Work will continue in promoting the inclusion of underrepresented communities. There will be a showcase of innovation and technology at the Alliance meeting in Montreal, and the patient needs framework will be updated and form the base of a roundtable in 2025

Connection and conversation are important and through member forums and asking the question what was keeping members up at night, work continues.

2025 the Alliance meeting and Allied Health Professionals meetings will be held in Montreal, Quebec.

Palliative care and the role of caregivers will be at the top of the list of items that will be worked on in 2024 – 2025.

New projects have been steadily increasing and now there are eight amazing contractors who work at the Alliance.



The Alliance is building a stronger partnership around the world while ensuring the Alliance stays strong.

Thanks were given to everyone who participates in the Alliance.

Next meeting: November 2025