Annual General Meeting
Minutes
November 29, 2025, 7:00 am to 8:30 am

Land acknowledgement
We acknowledge that we are meeting today in Toronto, on the traditional territory of many Nations, including the Mississaugas of the Credit, the Anishinaabe, the Chippewa, the Haudenosaunee, and the Wendat peoples. This land is covered by Treaty 13 signed with the Mississaugas of the Credit, and the Williams Treaties signed with multiple Mississaugas and Chippewa bands.

We also recognize that many participants are joining us virtually from locations across Turtle Island and around the world. Each of us is situated on lands with their own Indigenous histories, Nations, and treaties. I invite you to take a moment to reflect on the land you are on today and the longstanding relationships between Indigenous peoples and their territories.

1. Welcome
The new chair of the Board of Trustees, Tammy Moore welcomed everyone to the meeting and shared the history of the Alliance.

2. Call to Order
The meeting was called to order at 7:09 am

3. Confirmation of Quorum
As per the bylaws, quorum was confirmed.

4. Announcement of Election Results
Calaneet Balas, Gethin Thomas and Angela Harris were thanked for their service on the Board of Trustees.

5. Review: 2024 - 2025 Programs
In 2024-2025, the Alliance expanded to 68 member associations across 39 countries and maintained 100% member retention. The Alliance welcomed seven new members last year, including organizations from Canada, India, Kenya, Italy, Luxembourg, and the United States.

In addition, the Alliance:
- Provided secretariat support to ALS Africa Network and ELATAM
- Continued strong collaboration with NEALS, PACTALS, ENCALS
- And worked closely with regional networks such as EUpALS and UNELA

Information was shared on the newly launched ALS/MND Health Literacy Map, which includes four domains: Understanding ALS/MND, living with ALS/MND, Treating ALS/MND and Taking Action.

6. Approval of 2024 AGM Minutes
On a motion duly proposed by Marcela Santos, seconded by Limore Noach, and carried, the minutes

of the 2024 Annual General meeting were approved as presented.

7. Appointment of new Trustees

The following new Trustees were appointed for 2026: Pablo Aquino, Valeria Gerbino, and Jennifer Hjelle and Yohei Yamada returning for a second term. The Alliance is working toward a skilled based Board for the future.

8. Treasurer's Report

The year-end financial statements were presented.

a) Receive the accounts

On a motion duly proposed by Tanner Hockensmith, and seconded by Marcela Santos, and carried, the examined financial statements, as approved by the Board of Trustees, for the period ending June 30, 2025, were approved.

b) Appointment of Independent Reviewer

On a motion duly proposed by Pablo Aquino, and seconded by Evy Reviers, and carried, that the Board appoint Dunkley's as the Independent Examiner for the 2025-2026 fiscal year.

c) Fixing of the annual subscriptions

An outline of the increase in Alliance membership fees was shared along with how those changes will affect different organizations. The membership fees have not increased in more than a decade.

On a motion duly proposed by Pablo Aquino, and seconded by Limore Noach, and carried, that the Alliance membership fees for 2026-2027 be increased as outlined below:

- *That membership fees will remain at 0.2% of member organization revenue for the previous year.*
- *The minimum fee for Full Members be raised to £125 commencing from the 2026-2027 financial year and adjusted for inflation each year thereafter by equivalent to the global inflation rate.*
- *That the fee cap for Full Members be raised to £12,500 from the 2026-2027 membership year and then adjusted for inflation each year by equivalent to the global inflation rate (currently 2.75%) commencing from the 2027-2028 membership year.*
- *That members in countries in the lowest income tier as defined by the World Bank may apply to be granted a fee waiver.*
- *That members in the lower-middle-income as defined by the World Bank be granted 50% fee relief if they apply for it.*
- *That for the new Affiliate Membership categories, the following membership fees apply for 2026-2027:*
    - *Emerging Associations – 0.2% of member organization revenue for the previous year, although it is likely that Emerging Associations may not have received any or minimal. revenue in the previous year, and in any case, may apply for a membership fee waiver.*
    - *Network – 0.1% of revenue for the previous year. Less developed networks may*

apply to be granted a fee waiver.
- *Education and Research – 0.2% if have own revenue, or minimum fee of £125 if have no direct income given operate within a non-profit entity such as a university.*
- *Fiscal Sponsorship/Hosting Arrangement - minimum fee of £125.*

9. Adjournment

On a motion moved by Evy Reviers and carried the Annual General Meeting was adjourned.

10. Looking to the Future

The Alliances continues to be guided by the three pillars — Community, Capability, and Capacity.

Community - In 2025–2026, the Alliance will continue working to retain a strong global membership and welcome new organizations that share the vision of a world free of ALS/MND. This will include supporting associations in regions where ALS/MND structures are emerging. The goal is to ensure that every member, regardless of size or geography, feels supported and connected.

Capability - The Alliance advocacy goals for the coming year include:

- Promoting equitable access to therapies for all
- Ensuring people with lived experience remain meaningfully involved in Alliance initiatives.
- Strengthening global recognition of ALS/MND within international health and policy forums

Education will include strengthening health literacy to aid in informative decision making.

With the Health Literacy Map as the guide, programs will be developed to help members, health professionals and people with lived experience make informed decisions throughout the ALS/MND journey.

The Alliance Meeting and Allied Professionals Forum will continue to build on global dialogue to learn from and support each other while individually supporting local communities.

The Alliance is committed to supporting collaborative, inclusive research, and to ensuring that scientific information reaches members in clear and accessible ways.

Capacity - In 2025–2026, the Alliance will continue strengthening the organizational support offered to members, including tools, resources, and opportunities for collaboration and learning.

The Alliance will also focus on maintaining and expanding internal capacity, working with staff contractors.

Work will be done to develop the Alliance's next three-year strategic plan.

Together, the Alliance continues to build a stronger, more connected ALS/MND community and move closer to a world free of ALS/MND.