INTERNATIONAL ALLIANCE
OF ALS/MND ASSOCIATIONS

Annual Report

2025–2026



Evidence into Action

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Message from the Chair and the CEO

Thank you. Everything in this report happened because you showed up: in Toronto, in our forums and webinars, in the survey you shared with your communities, and in the daily work of supporting people living with ALS/MND and the people who care for them.

This year also set our direction for the next three. In March, the Board adopted the 2026–2028 Strategy. Its six priorities share one purpose: accelerating outcomes on the fundamental rights of people affected by ALS/MND, everywhere in the world.

Our community grew. We welcomed 12 new members and, as of June 30, 2026, brought together 81 organizations in 40 countries. Nearly 460 people joined us in Toronto, in person and online, from 30 countries.

Your work shows in the results. In the 2025 Fundamental Rights Survey, 2,232 people from 51 countries responded, in 16 languages. One finding we can all be proud of: people connected to an ALS/MND association reported stronger support on 10 of the 11 rights. The survey is just as clear about what remains: access to treatment, care, trials and genetic testing is far weaker in the Global South, and caregivers are still under-supported.

That is where this year's new work points. The SEED (Supporting Excellence, Equity, and Discovery for ALS/MND) Grant Program, launched on Global ALS/MND Awareness Day, drew 26 applications from 18 countries in its first round. Our Genetics Task Force brought 22 experts to consensus on genetic counselling and testing. And the 2027 Caregiver Calendar put caregivers at the centre of Global Day.

The pages that follow show what we delivered under each priority and where the work goes next. We are grateful to every member, volunteer, partner and person with lived experience who made this year possible, and we look forward to continuing to collaborate with you in the coming year.



Tammy Moore, ICD.D
Chair



Cathy Cummings, CAE
CEO

Alliance Strategy 2026–2028

Our Vision

A world free of ALS/MND.

Our Aspiration

To drive global collaboration.

Our Reach

We work globally, serving the entire ALS/MND community.

Our Purpose

Everything we do is oriented around one purpose: accelerating outcomes on the fundamental rights of people affected by ALS/MND, everywhere in the world.

Our Priorities

Bring focus to quality of life for PALS and their community: We advocate more effectively to improve outcomes by understanding what people living with ALS/MND (PALS) and their community identify as important.

Facilitate research coordination: By bringing people together and facilitating research coordination across the globe, we deepen our understanding of ALS/MND and accelerate research.

Increase awareness of ALS/MND: By raising awareness of ALS/MND and the Alliance, we strengthen our advocacy efforts at the global level, which supports our members at the local level.

Leverage collective capacity: By coordinating with our members and partnering in strategic international collaborations, we leverage collective knowledge and resources — positioning the Alliance as a trusted source of evidence-based information, best practices and tools.

Include under-represented communities: By working alongside under-represented communities, we ensure meaningful inclusion across the globe so geography does not dictate destiny.

Grow the community: By identifying and inviting ALS/MND organizations not yet part of the Alliance, and by supporting the creation and development of new organizations, we expand the community working toward a world free of ALS/MND.

Quality of Life for PALS and their Community

We now have the strongest evidence yet on what people living with ALS/MND and caregivers need, and where support falls short.

- **2025 Fundamental Rights Survey.** An independent research firm ran the survey in 16 languages, and 2,232 people living with ALS/MND, caregivers and blood relatives responded from 51 countries. The results inform our advocacy, our quality-of-life work and the priorities in the new strategy. While some of the rights have improved since 2023, the right to live without discrimination has not: at least one third of people living with ALS/MND reported discrimination.
- **Choice drives quality of life.** Autonomy over providers, place of care and end-of-life decisions showed the strongest link to quality of life, stronger than treatment or care. This finding is the basis for a project to determine quality-of-life drivers. Early findings were accepted as a poster at ALS Nexus in August 2026.
- **Caregivers are under-supported.** Only 26% of caregivers received palliative care support, 12% received bereavement support, and 22% received no support at all. The 2027 Caregiver Calendar made caregivers the focus of our Global Day campaign.
- **Patient Fellows Program.** Twenty-two people living with ALS/MND, former and current caregivers, and gene carriers from 11 countries joined the 2025 International Symposium on ALS/MND. Their January webinar, “Nothing About Us, Without Us,” shared what they brought back. Twenty-two new Fellows from 17 countries were selected for 2026.
- **AI and quality of life.** Through the ElevenLabs Impact Program, anyone living with ALS/MND can get a free Pro voice clone licence: an AI copy of their own voice for use on a communication device. We also asked our global community where they see the most potential in AI and what concerns them. With University College London, we are researching how AI can support quality of life, drawing on our Patient Needs Matrix and Maslow’s hierarchy of needs.



Facilitate Research Coordination

We brought researchers, clinicians and associations to common positions on questions that affect care worldwide.

- **Genetic counselling and testing.** The Alliance's Genetics Task Force brought together 22 international experts, supported by working groups of clinicians, researchers, genetic counsellors, ethicists, advocates and people with lived experience. They met in Toronto in December 2025 and reached consensus on recommendations for genetic counselling and testing in ALS/MND. The recommendations were presented at ENCALS in June 2026 and published in *Brain*: "Global best practice recommendations for genetic counselling and testing in amyotrophic lateral sclerosis."



- **Outcome Measures Task Force.** The first phase reviewed 10 years of ALS/MND clinical trials. It confirmed that the field has no standard set of outcome measures. The next phase will develop a multilingual, at-home version of the ALSFRS-R that regulators can accept as a trial endpoint, so more people can take part in trials from home.
- **Global presence.** This year, CEO Cathy Cummings and Scientific Director Dr. Martina de Majo represented the Alliance at many conferences, including the AFTD Holloway Summit, Precision ALS, the TRICALS Masterclass and the Packard Meeting at Johns Hopkins. These meetings connect the Alliance with researchers, clinicians, people living with ALS/MND and experts in related conditions, and open up new opportunities to collaborate.
- **Publications.** Alongside the genetics recommendations, Dr. Martina de Majo co-authored "TDP-43-Associated Neurodegenerative Disease Conceptualization and Integrated Staging: A Review," published in *JAMA Neurology*. In addition, Cathy Cummings co-authored "Third sector organisations unite to advance neuropalliative care" in *The Lancet Neurology* and "The World Federation of Neurology Specialty Group in ALS/MND: toward strategic partnership and new frontiers" in *Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration.*

Increase Awareness of ALS/MND

We raised the profile of ALS/MND with the public and with the health professionals who see people first.

- **Advocacy Plan 2026–2028.** After consulting members on global advocacy priorities, the Advocacy & Public Policy Forum developed a three-year plan and began putting it into action. It sets three priorities: recognition of ALS/MND as a public health priority by the World Health Organization and in other global health agendas; equitable access to affordable treatments, with transparent drug pricing; and representation of people living with ALS/MND and caregivers in health policy and governance.
- **Global ALS/MND Awareness Day.** On June 21, 2026, we revealed the 2027 ALS/MND Caregiver Calendar. Member associations submitted 48 images, and nearly 1,000 public votes from around the world chose the featured artwork. Proceeds from calendar sales help people with lived experience take part in ALS/MND events.
- **R.A.C.E. to Diagnose ALS/MND.** Timely, accurate diagnosis is an Alliance priority. We created this education program, funded by My Name'5 Doddie Foundation, to help healthcare professionals such as neurologists, therapists, ENT specialists and early-career physicians recognize possible ALS/MND, assess it, communicate clearly and expedite referral.
- **March of Faces.** The annual March of Faces banner and video feature people living with ALS/MND and people remembered by their families. The 2025 edition honoured 53 people from 22 countries.





Leverage Collective Capacity

We gave members more ways to learn from each other and more tools to use in their own organizations.

- **Alliance Meeting and Allied Professionals Forum.** Nearly 460 people from 30 countries took part in Toronto, November 29 to December 2, 2025, in person and online. The Alliance Meeting drew 153 delegates and the Forum 305, with 34 people living with ALS/MND at each. We offered real-time translation into 15 languages, and we had 39 virtual posters from around the world in our Poster Hall. People living with ALS/MND and caregivers led four sessions, and one keynote was delivered entirely in Spanish. The expanded “Day in the Life Of” Suite let attendees test wheelchairs, lifts and hospital beds, and taste dysphagia-friendly foods. Nearly 90% of survey respondents for each event said it met or exceeded their expectations.



- **More member forums.** We expanded member forums in 2025–2026, with a session almost every month. Topics included tofersen and the ATLAS trial, advocacy campaigns, and fundraising.
- **Understanding how members collaborate.** A research project with Concordia University, Montreal, ran three focus groups and workshops with community members from several regions to inform how the Alliance puts its strategic priorities into practice.
- **ALS/MND Health Literacy Map.** The Map organizes information about ALS/MND by what people need to know. It now shapes our webinars, roundtables and website. It was presented as a poster at the Allied Professionals Forum in Toronto, where it was the second most viewed of 39 virtual posters. So far, we have rebuilt the “Understanding ALS/MND” and “About Us” sections of our website based on the Map.

Include Under-Represented Communities

The survey confirmed that where people live still shapes their access to diagnosis, treatment and trials. This year, we put resources behind closing that gap.

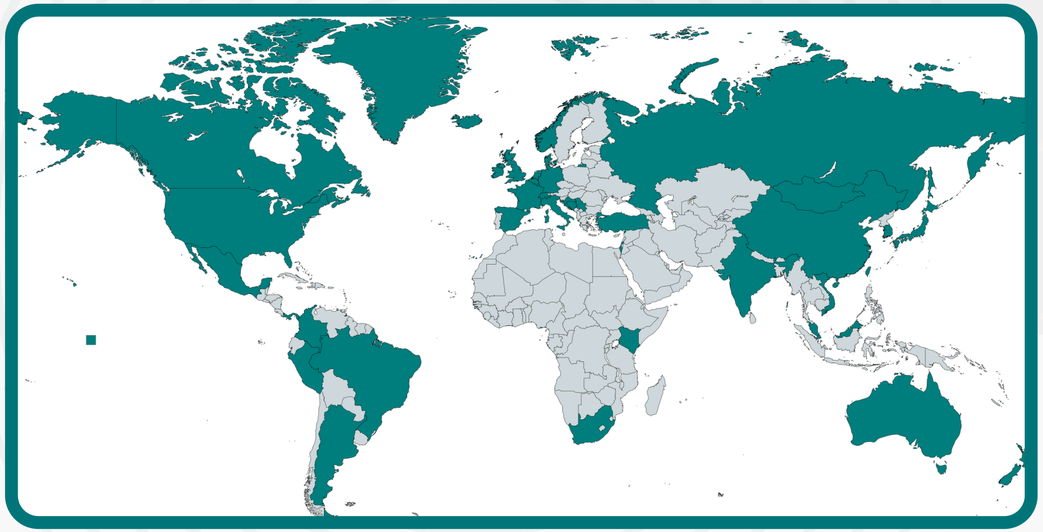
- **SEED Grant Program.** Launched on Global Day, June 21, 2026, SEED is the Alliance's first grant program. It funds early-stage research infrastructure in low-, lower-middle- and upper-middle-income countries. The inaugural round closed on September 1 with 26 complete applications from 18 countries: 8 from Africa, 10 from Asia and 8 from Latin America. The program is possible because of founding support from FightMND and ALS Canada. It also receives support from the ALS Society of Alberta, ALS Therapy Development Institute, LifeArc, My Name'5 Doddie Foundation, Stichting ALS Nederland and The ALS Association.
- **Closing the diagnostic gap.** A 2025 literature review and gap analysis documented wide regional differences in diagnostic capacity. Our April 15 Global Roundtable focused on practical strategies to close them.
- **Equitable access to therapies.** Our February webinar, "Approved Treatments in ALS/MND," showed that approval does not mean access: riluzole, edaravone and tofersen are available unevenly across regions. We supported individual countries seeking access, including tofersen in Norway, and began mapping approved treatments worldwide, starting with tofersen.
- **Language access.** Webinars and member forums run with captions in multiple languages, and each member forum is held at two times to accommodate different time zones. In addition, the Fundamental Rights Survey was offered in Swahili, Vietnamese and Traditional Chinese for the first time.



Grow the Community

As of June 30, 2026, the Alliance brought together 81 member organizations in 40 countries. We also opened new ways for individuals to learn and lead within the community.

- **New members.** We welcomed 12 organizations: ALSWiki.org and ALS Action Canada Society (Canada); Hellenic ALS Association (Greece); Viva La Vita Italia (Italy); Motor Neuron Disease Association of Kenya (Kenya); Stichting Patiënten voor Patiënten (Netherlands); ALS Vietnam (Vietnam); the Pan-Asian Consortium for Treatment and Research in ALS (PACTALS), a regional body based in Malaysia; the Packard Center for ALS Research (United States); Her ALS Story (United States); North Star ALS (United States); and Genetic ALS & FTD: End the Legacy (United States).



- **Alliance Fellows Program.** This program is an evolution of the Global Clinical Research Learning Institute we launched in 2024. It is a virtual program for people affected by ALS/MND worldwide who want to understand research, treatment development and advocacy. In 2025, we had 13 participants from nine countries.
- **Volunteer leadership.** New chairs took office on the Board and three councils and forums: Tammy Moore (Board), Dr. Kuldip Dave (Scientific Advisory Council), Bruce Virgo (PALS & CALS Advisory Council) and Jessica Lee (Research Directors Forum). Guðjón Sigurðsson continued as Chair of the Advocacy & Public Policy Forum. We thank Calaneet Balas, Dr. David Taylor, Dr. Gethin Thomas, Dr. Nicholas Cole, Dr. Bec Sheean, Rachael Marsden and Dr. Sara Feldman for their years as chairs.

2025 Award Recipients

These awards recognize people whose work changes what is possible for people living with ALS/MND.

Forbes Norris Award



Dr. Philip Van Damme is a professor at KU Leuven and Director of the Neuromuscular Reference Centre. His neurofilament biomarker research was pivotal to FDA and EMA approval of tofersen for SOD1-ALS. He helped lead Project MinE, one of the largest genetic studies in ALS/MND.

Allied Health Professional Award



Alberto Fontana founded the NeMO Clinical Centres, Italy's national network for neuromuscular care. Its eight centres serve more than 7,500 people a year, offering integrated, person-centred care at no cost to families. In 2024, NeMO took part in 24 ALS/MND clinical studies.

Humanitarian Award



Dr. Alper Kaya has lived with ALS/MND since 1990 and chairs the ALS/MND association in Türkiye. He founded the country's first national ALS/MND research database, helped establish a parliamentary research commission, and coordinated support for about 700 people living with ALS/MND after the 2023 earthquake.

Student Innovation Award



Apaala Basak, a doctoral student in biological engineering, is developing an optogenetic therapy that uses light to activate tongue muscles and preserve swallowing in ALS/MND.



Dr. Sadegh Ghaderi, in his doctoral research, built a framework that uses widely available MRI to identify new biomarkers for ALS/MND diagnosis and monitoring.

Thank You

Thank you to our members, volunteers, funders and partners.

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