



INTERNATIONAL ALLIANCE
OF ALS/MND ASSOCIATIONS

Annual Report

2024-2025



Discover Our Impact



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This year reminded us of the power of connection: how collaboration and mutual support can turn good ideas into meaningful progress for people affected by ALS/MND.

We saw our global community continue to grow, now representing 68 member organizations across almost 40 countries. We welcomed new associations from Luxembourg, India, the UK, the USA, Canada, and Italy, while emerging groups in Kenya, Greece, and Vietnam took important steps toward full membership. Each new member brings valuable experience and fresh insight to our shared mission.

Two of our projects stood out this year: the Emergency Preparedness Toolkit and the “Day in the Life Of” Experience Suite. Both received international recognition at the 2025 Associations World Summit, winning awards for “Best Member Engagement Initiative” and “Best New Event,” respectively. These achievements celebrate what happens when our community comes together to create practical tools that truly make a difference.

Engagement also reached new levels. The Alliance Meeting and Allied Professionals Forum in Montreal brought together more than 500 people, while our first Spanish-language regional session connected members across Latin America. The Patient Fellows Program — now managed directly by the Alliance — gave 23 people with lived experience a voice in global research discussions.

This year’s progress reflects the collective strength of our members and partners. Thank you for your continued commitment to collaboration and care.



CALANET BALAS
Chair



CATHERINE CUMMING,
CAE, MBA
CEO



OUR VISION: A WORLD FREE OF ALS/MND

The International Alliance of ALS/MND Associations was founded in 1992 to create a global community for ALS/MND associations. We help members thrive by adding value to existing and future associations through curation and creation of information and by acting as a global gateway through which Alliance Members, people living with ALS (PALS) and their communities, including caregivers and families (CALs), and internal and external contributors connect.

Our two main focuses are Community and Capability and we can do this as we build our Capacity.

Our Strategic Priorities to 2025

- **Build Community:** Build a global community. Build membership in countries and regions which do not yet have membership representation. Coordinate the global voice of PALS & CALs. Be the gateway for relevant external stakeholders.
- **Build Capability:** Build capability in member associations. Deliver professional development that includes the annual Alliance Meeting, but also provides Member value throughout the year. Make our members stronger to advocate on behalf of individuals at the local level and provide a platform for global issues. Increase research capability globally. Identify, promote, and support meaningful and timely in person and virtual connections between Members. Facilitate member peer-to-peer support. Be a gateway for external stakeholders to the network of domestic associations.
- **Build Capacity:** Build internal capacity at the Alliance. Enhance Member Intelligence to deepen the relationship with and knowledge of Members to better understand their needs, offerings and aspirations. Develop our human, technology and financial resources to be able to deliver member value and to ensure sustainability of a viable Alliance into the future. Focus on disseminating information in a concise manner that delivers value add of the Alliance. Build capacity to harmonize Member communications across the organization and present a strong brand for the Alliance.

Who we are



The creation and launch of the ALS/MND Health Literacy Map was one of the most significant developments of the year.

Developed through extensive consultation with our collaborators, particularly our PALS & CALS Advisory Council (PCAC), the Map defines what people living with ALS/MND and their communities need to know and access throughout the disease journey. Designed as a living framework, it will evolve and adapt to stay practical and relevant for those navigating ALS/MND.

It organizes information into four domains:

- **Understanding ALS/MND:** disease knowledge, research, and diagnosis
- **Living with ALS/MND:** planning, physical and mental health, and quality of life
- **Treating ALS/MND:** care delivery, clinical trials, and therapies
- **Taking Action:** advocacy, rights, and awareness

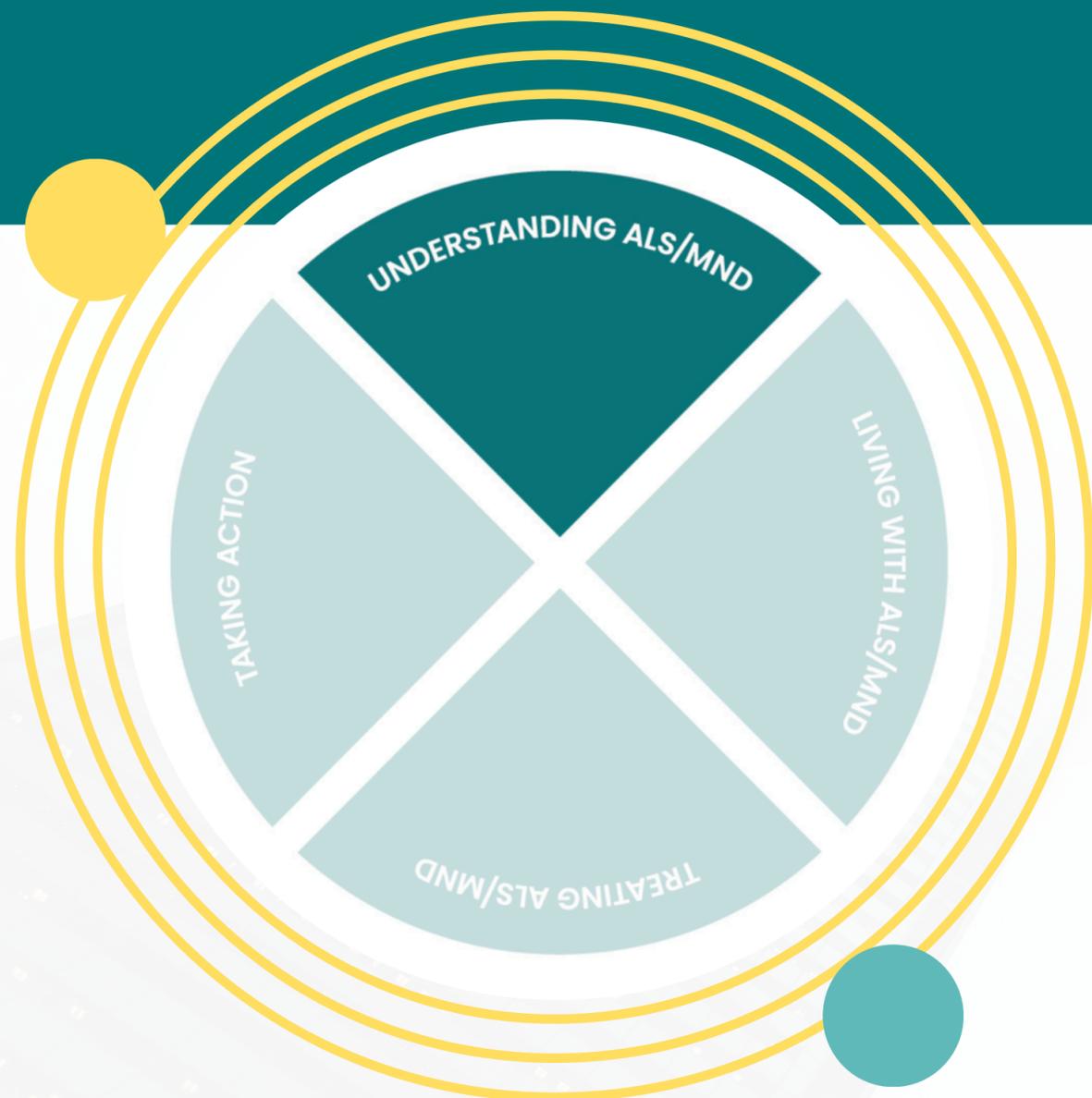
The Map was shared with members in December 2024 at the Alliance Meeting and published on our website in January 2025. It is already shaping how we organize our webinars, roundtables, and communications – including this Annual Report – to ensure consistent language and focus.

The Map is used internally to group all our projects and member initiatives by domain for strategic planning and content development. The framework is also being used to identify content gaps and plan future work.

Several member associations have expressed interest in adapting the Map for national use, demonstrating that it is becoming a shared tool for organizing ALS/MND information across regions.

Understanding ALS/MND

Our work in this area focused on connecting knowledge, improving information access, and strengthening collaboration between researchers, clinicians, and associations. This effort is essential to understanding ALS/MND in all its complexity: from genetics and diagnosis to lived experience and care delivery



Roundtables, Discovery Meetings and Webinars

Roundtables and discovery meetings enable us to gather perspectives and experiences across disciplines. In 2024–2025, five sessions were held:

- India Discovery Meeting (October 2024)
- (e)Quality of Life (February 2025)
- Diagnostic Delay in ALS/MND Discovery Meeting (February 2025)
- Clinical Trial Capacity in the Global South (April 2025)
- Palliative Care Integration (June 2025)

Each session drew participants from around the world and resulted in tangible outcomes – such as recommendations for trial expansion, frameworks for early palliative care, and updated principles for working with industry – that will guide upcoming projects.

Our quarterly public scientific webinars are also a key source of shared learning. Topics in 2024–2025 included:

- Annual Clinical Trials Update (November 2024)
- ALS/MND Platform Trials Update (March 2025)
- Scientific Advisory Council Mid-Year Review (June 2025)

Engagement with these sessions continued to grow, with hundreds of live and archived views across sessions.



Research: We shared research findings at the Northeast Amyotrophic Lateral Sclerosis (NEALS) Consortium's Meeting (October 2024), National Society of Genetic Counselors' (NSGC's) Conference (November 2024), International Symposium on ALS/MND (December 2024), and European Network to Cure ALS (ENCALS) Meeting (June 2025), presenting posters on topics including genetic counselling access, trial endpoint optimization, and quality-of-life measurement.

Building Networks to Improve Trials Capacity in the Global South

Jessica Mabe¹, Julia Simon¹, Martina de Majo¹, Catherine Cummings¹

¹International Alliance of ALS/MND Associations

BACKGROUND

ALS/MND is a fatal disorder with only a handful of disease-modifying treatments available, mainly in what is defined as the Global North by the United Nations. To date, clinical trials have shown a high failure rate and a focus on people living with ALS/MND (PALS) of European descent, excluding a large portion of the world population and potentially missing valuable information.

In 2023 the International Alliance of ALS/MND Associations ran its second survey focused on the fundamental rights for PALS and caregivers, receiving >2000 responses from 54 countries. Among them, 47% were PALS and their responses highlighted that:

- PALS in the Global South (GS), defined by the United Nations were less likely to be participating in a trial but more willing to.
- Globally, 36% of PALS were willing to participate in trials in the future however 32% stated they had no access to them. When analysed separately, 46% of respondents from the GS stated that they had no access to clinical trials or 26% in the GN.
- PALS who answered the survey perceived that they had access to the highest quality treatment only if they also had access to clinical trials (data not shown).

HYPOTHESIS

With more trials ongoing in the GN, the pool of treatment-naïve candidates in those regions is becoming limited, while underrepresented communities are left with scarce access to novel treatments. The Alliance identified two regions of the GS (Africa and Latin America) where no networks were available to run ALS/MND clinical trials.

RESULTS

Which of the following statements best describes your situation as it relates to clinical trials?

Statement	2023 (%)	2024 (%)
I am currently participating in a clinical trial	10%	10%
I have participated in a clinical trial in the past	13%	13%
I would like to participate in a clinical trial in the future	38%	38%
I have access to clinical trials, but I am not participating	9%	9%
I have no access to clinical trials	26%	26%

21. Which of the following statements best describes your situation as it relates to clinical trials?

Statement	2023 (%)	2024 (%)
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I have participated in a clinical trial in the past	13%	13%
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I have access to clinical trials, but I am not participating	9%	9%
I have no access to clinical trials	26%	26%

22. Disparities in clinical trials access between Global North and South. PALS respondents in the Global South were 47% less likely to participate in a clinical trial than those in the Global North. PALS in the Global South were 32% less likely to participate in a clinical trial in the future than those in the Global North. PALS in the Global South were 32% less likely to have access to clinical trials than those in the Global North.

Enhancing Quality of Life through Insights based on the ALS/MND Patient Needs Matrix

Jarnail Chudge¹, Catherine Cummings¹, Julia Simon¹

¹International Alliance of ALS/MND Associations

BACKGROUND

The International Alliance of ALS/MND Associations is leading a research project to explore the importance and significance of cultural activities in improving quality of life for people living with ALS/MND (PALS) and their caregivers (CALG). Through a "design thinking" approach, the project highlights tangible examples of how technological innovations support the creation of art, music, games, etc., enabling the pursuit of creative interests for PALS.

Drawing on Maslow's hierarchy of needs, insights from the Alliance's Fundamental Rights Survey, and the Alliance's Knowledge Map of the ALS/MND landscape, the aim is to provide personalized insights designed to enhance quality of life for each person. By bringing individual needs to the forefront, the Alliance looks to enhance quality of life, and provide guidance to help transform a person's life course based on their objectives and desires.

METHOD

Through the lens of personal, cultural, and social dimensions, the Alliance has adapted Maslow's expanded 8-layer model (encompassing the range of needs from physiological, safety, love and belonging, esteem, self-actualisation, cognitive, aesthetic, and transcendence) to develop the Patient Needs Matrix (PNM).

RESULTS

A key milestone in developing this framework took place in December 2024 at the Alliance's annual conference, through the creation of a "Day in the Life Of" experiential suite. This involved setting up an actual suite at the venue, showcasing a range of devices, technologies, adaptations, and innovations – all aimed at enhancing quality of life in daily living. The space included interactive zones focused on eating and drinking, hygiene, entertainment and creative expression, smart-home automation, rest and relaxation, intimacy, and clothing.

Global Analysis of Access to Genetic Counselling and Testing for People Living with ALS/MND

Jessica Mabe¹, Julia Simon¹, Martina de Majo¹, Catherine Cummings¹

¹International Alliance of ALS/MND Associations

BACKGROUND

Amyotrophic Lateral Sclerosis (ALS) or Motor Neuron Disease (MND) is an adult-onset neurodegenerative disorder characterized by progressive degeneration of motor neurons, resulting in loss of motor function and death, commonly by respiratory failure within 3-5 years from symptom onset. While most ALS/MND cases are apparently sporadic, recent studies have shown that up to 21% of people living with ALS/MND (PALS) carry variants in the ALS/MND gene panel independently of family history (Shimpfard et al. 2023).

METHODS

The survey was conducted by Bramm Research, an independent third party, and launched through our member organizations and social media in May 2023. Participants were given 60 days to respond. We received close to 2,000 responses from 54 countries and 47% of the respondents were PALS. The survey was available in 16 different languages.

OBJECTIVE

Access to genetic counselling and testing is one of the International Alliance of ALS/MND Associations' Fundamental Rights of people living with ALS/MND. Originally conceived in the late 1990s as the baseline of services for people living with ALS/MND, these rights represent the ideal for PALS and caregiver CALG worldwide. They are updated each year by the International Alliance of ALS/MND Advisory Council.

RESULTS

On a global scale, access to genetic counselling and testing is highly dependent on multifactorial interventions such as economics, healthcare systems and professional, and cultural. In April 2024, the International Alliance of ALS/MND Associations' Fundamental Rights Survey for PALS and CALG to assess, among many other parameters, access to genetic counselling and testing for PALS worldwide. In May 2024, a follow-up survey was launched to benchmark against the data captured in its first version.

Task Force-Global Effort: Optimizing ALS/MND Clinical Trial Endpoints

de Majo M(1), Pérodeau A (1), Van Damme P(2), Dave KD(3), van Eijk RPA(4), Sheehan B(5), Fournier C(6), Kaya A(1), Robinson M(1), Ocampo F(1), Cadavid F(1), Genge A(8), P Green(1), Cummings (1)

(1) International Alliance of ALS/MND Associations, (2) University of Leuven, (3) ALS Association, (4) UMC Utrecht, (5) MGH, (6) Emory University, (7) Verge Genomics, (8) Clinical Research Unit, Montreal Neurological Institute, Montreal, Canada

BACKGROUND

The International Alliance of ALS/MND Associations is a global network of Amyotrophic Lateral Sclerosis (ALS) and Motor Neuron Disease (MND) associations. Guided by the experiences of the European Network to Cure ALS (ENCALS) and their caregivers (CALG), the Alliance serves as a global gateway for ALS/MND advocacy and research collaboration.

METHODS

We also developed a survey to collect information and sponsor/industry opinions regarding outcome measures currently used to measure ALS/MND progression in clinical trials. We distributed the survey to the industry sponsors where we were able to reach in the field (43), collecting a total of 18 responses.

RESULTS

We conducted a literature review looking at clinical trials in the ALS/MND field run in the last 10 years. We used ClinicalTrials.gov, the World Health Organization's International Clinical Trials Registry Platform, and the ALS Therapy Institute's Clinical Trial Navigator.

We also developed a survey to collect information and sponsor/industry opinions regarding outcome measures currently used to measure ALS/MND progression in clinical trials. We distributed the survey to the industry sponsors where we were able to reach in the field (43), collecting a total of 18 responses.

DISCUSSION

The Alliance is helping to set up networks with secretariat services and global expertise across. These research networks are now recognized as ELATAM (Latin America - <https://elatom.org>) and ALS Africa (<https://alsafrikanet.org>).

CONCLUSION

By enabling establishment of clinical networks within Latin America and Africa, the Alliance is playing a pivotal role in providing the basis for expanding ALS/MND trials to geographic areas in the GS.

DISCUSSION

Genetic testing and counselling can provide PALS with important information to support their journey. Knowledge gained from genetic testing can help with treatment options and understanding the risk of passing it on to family members. Some interesting points from our 2023 survey are:

- Genetic counselling is perceived to be the most highly specialised professional in ALS/MND at 80% (followed by neurologists at 72% and respiratory therapists at 70%). Access to a genetic counsellor is needed as professionals specialised in ALS/MND to work in the interests for respondents who strongly agree with having access to high quality care (fundamental right #1).
- Access to genetic testing and counselling is lower in the Global South compared to the Global North.
- Access to genetic testing, counselling, and genetic counselling safeguards has remained the same since 2021, though in 2023 that remains higher with regards to having access to an ALS/MND association provides better alignment with this right.
- English-speaking respondents are more likely to have access to pre-date education about clinical genetics in ALS/MND.
- Approximately one quarter of PALS respondents reported that their blood relatives are given the same access to genetic counselling and testing.

CONCLUSION

While JAL is developing, the Alliance believes this novel approach will help each person understand where they are on their personal journey and connect with the different layers in a uniquely deep and meaningful way, with the goal of enhancing and enriching quality of life.

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DISCUSSION

Among the primary outcome measures, TEAS were the most frequently reported when all trial phases were considered. However, when focused specifically on phase II and III trials, CALS responses, representing a well-defined distribution across company sites—reflecting strong industry engagement with this topic. The findings highlight substantial variability in efficacy outcome measures, particularly in phase II and III trials. This analysis provides a comprehensive overview of current practices and supports efforts to establish a standardized core set of measures to accurately reflect disease progression in ALS/MND.

CONCLUSION

We conducted a survey of industry sponsors involved in ALS/MND clinical trials and received 18 responses, representing a well-defined distribution across company sites—reflecting strong industry engagement with this topic. The findings highlight substantial variability in efficacy outcome measures, particularly in phase II and III trials. This analysis provides a comprehensive overview of current practices and supports efforts to establish a standardized core set of measures to accurately reflect disease progression in ALS/MND.

Living with ALS/MND

Two of our initiatives that began as member-driven projects achieved international recognition this year for their practical impact.

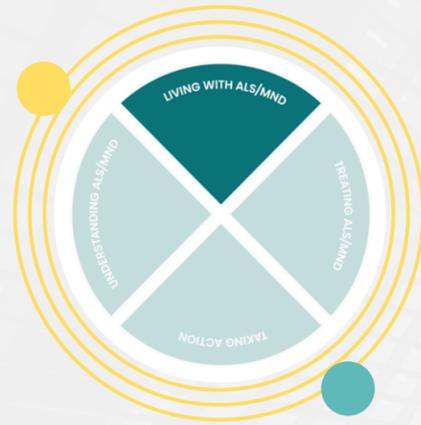


“Day in the Life Of” (DILo) Experience Suite

Created for the 2024 Allied Professionals Forum in Montreal, Canada, the DILo Suite allowed participants to experience the daily realities of ALS/MND through interactive stations featuring assistive devices, technologies, and adaptive environments.

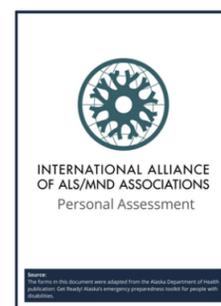
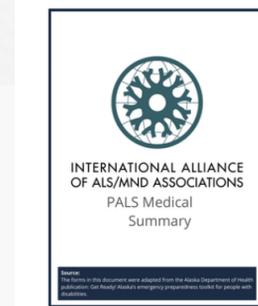
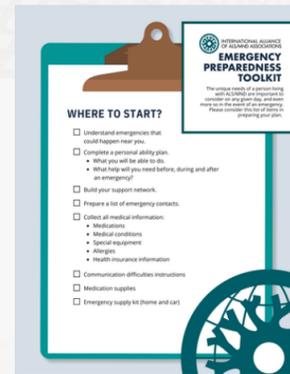
The inaugural suite included stations on communication and voice banking, transfers and mobility, daily living aids, and home modifications. Large and small industry partners collaborated to demonstrate accessible solutions, and Post-event feedback showed that 92% of participants said the suite improved their understanding of assistive technology options and caregiver needs.

The concept was awarded **“Best New Event”** at the 2025 Associations World Summit in June.



Emergency Preparedness Toolkit: Developed with member input as a result of major natural disasters around the world, the Toolkit was recognized as **“Best Member Engagement Initiative”** at the same awards. It provides step-by-step guidance to help associations and families prepare for disruptions in care or access to services.

Many members have since adapted it for local use, confirming its long-term value as a flexible planning resource. For example, the ALS Society of Canada and FightMND developed localized versions, each tailored to their national emergency protocols and health-system structures.



- << Checklist
- << Medical Emergency Card
- << Emergency Telephone List
- << Medical Summary
- << Medicine Chart
- << Personal Support Network
- << Emergency Supplies Checklist
- << Personal Assessment
- << Disability-related Supplies & Special Equipment



Patient Fellows Program: The Patient Fellows Program enables people living with ALS/MND and caregivers to attend the International Symposium on ALS/MND, share their experiences, and contribute directly to research discussions. This was the first year we managed the program, coordinating selection, travel, and accessibility support. We had 23 people affected by ALS/MND take part (12 in person and 11 virtually). Fellows from 14 countries participated, marking the broadest regional representation to date.

Post-event surveys showed 95% rated their experience as excellent or very good, highlighting accessibility, engagement with researchers, and feeling represented as key strengths. Their feedback is now shaping plans for future events to ensure lived experience remains central to global discussions.



Treating ALS/MND

We continued to bring members, clinicians, researchers, and allied health professionals together to improve care and accelerate knowledge sharing.



"The hybrid format worked perfectly. It made me feel connected even from thousands of miles away." (2024 Alliance Meeting)



"The sessions were inspiring and practical. I left with ideas I could use immediately in my own work." (2024 Allied Professionals Forum)



Alliance Meeting & Allied Professionals Forum: The annual Alliance Meeting and Allied Professionals Forum (APF) truly highlight the spirit of teamwork in the ALS/MND community. In 2024, these events were held in Montreal, Canada, and offered virtually. We welcomed 199 delegates (149 in person, 50 virtual) to the Alliance Meeting, and 427 participants (265 in-person, 162 virtual) to the APF.

Post-event surveys reflected strong satisfaction across both events, with over 90% of participants rating the content and speakers as good or excellent. Attendees praised the multidisciplinary discussions, practical takeaways, and inclusive hybrid delivery that enabled global participation.

As part of the APF, we also launched two pre-conference masterclasses, responding to participant requests for more in-depth content:

- **Engaging in Difficult News with PALS & CALS:** Delivering an ALS/MND diagnosis is only the beginning of many difficult conversations that allied health professionals must navigate. This class explored how to improve interactions with patients and families at every stage.
- **Upstream with a Paddle:** Healthcare professionals often find themselves working tirelessly downstream. The risk of burnout often feels inevitable, but it doesn't have to be. This class taught how to reclaim resilience and enhance well-being while continuing to care for others.

Sessions received an average rating of 4.3 out of 5, with attendees describing them as “the most valuable part of the Forum.”

“It was great to hear how different countries are tackling similar challenges. The discussions felt truly global.” (2024 Allied Professionals Forum)



Treatment Updates: In addition to webinars and conference sessions, our Scientific Advisory Council continued to maintain the treatment briefing notes and advise on clinical content for webinars and events, ensuring we are a trusted source of treatment information. Updated and new briefing notes on our website include drugs approved, in development, and no longer in development, providing a comprehensive snapshot for members and clinicians.

Taking Action

Our advocacy and awareness work this year focused on practical initiatives that reflect member priorities and strengthen the collective voice of people living with ALS/MND worldwide.



■ Countries where the Alliance has members

International Representation

We continued active participation in the World Rehabilitation Alliance (WRA) through its Emergencies, Research, Primary Care, and Workforce workstreams. This engagement helps integrate the needs of people living with ALS/MND into broader international health policy discussions. Our staff and members also contributed to global consultations on assistive technology, inclusive research, and ethical industry collaboration,

including presentations to the World Health Assembly side event on Rehabilitation for All.

Expanding Membership and Representation

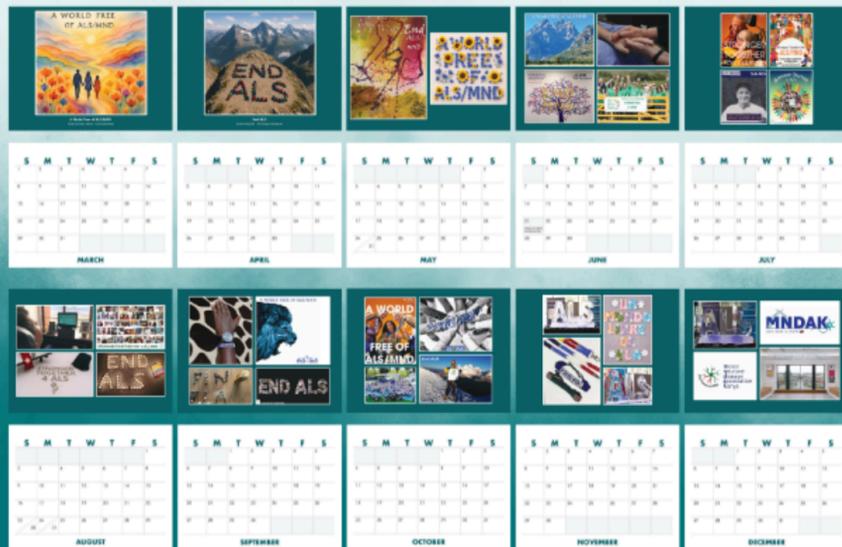
We expanded our Affiliate Membership with four categories: Emerging Associations, Networks, Education and Research Institutions, and Fiscal Sponsorship/Hosting Arrangements. This new structure recognizes the diversity of organizations contributing to ALS/MND efforts and creates clearer pathways for collaboration and engagement.



Awareness Campaigns

For Global ALS/MND Awareness Day 2025, we created and launched the 2026 ALS/MND Calendar. Members submitted artwork from their communities, and more than 2,300 public votes selected the winning images. The final calendar – produced in wall, desktop, and agenda formats – was unveiled by video and email on June 21. Promotion continues through social media, with proceeds supporting the participation of people with lived experience in ALS/MND events.

Our annual March of Faces banner and video featured portraits and tributes from across the community. The 2024 video showcased 60 faces from around the world and used the song “Won’t Give Up, My Friend,” by our own Alper Kaya, a PAL in Turkey. He created it for people living with ALS/MND and those who have lost loved ones to ALS/MND. He wrote the lyrics, and the music was created with Suno AI support.



2024 Award Winners

Congratulations to our award winners. Their achievements reflect the strength of our community and commitment to lasting impact.

Forbes Norris Award

Awarded to Dr. Glass and Dr. Simmons for their exceptional work in advancing clinical care and research in ALS/MND, translating scientific insight into improved patient outcomes.



DR. JONATHAN D. GLASS



DR. ZACHARY SIMMONS

Humanitarian Award

Recognizing Evy Reviere's advocacy and leadership in enhancing quality of life for people living with ALS/MND, including work on national care legislation in Belgium and international network building.



EVY REVIERS

Allied Health Professional Award

Awarded to Dr. Apreleva and Dr. Mesquita e Silva, whose innovations and outreach in therapy and rehabilitation have strengthened care practices globally.



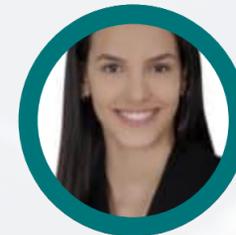
DR. ALISA APRELEVA



DR. TATIANA MESQUITA E SILVA

Student Innovation Award

These three medical students in Colombia developed digital tools to help patients, caregivers and clinicians manage ALS/MND more effectively, advancing our global cause.



VALERIA OTALORA GARCÉS



VALENTINA GONZALEZ



LUISA MARIA HORMIZDA INFANTE

Thank you!

As we look ahead to another year of collaboration and innovation, we remain grateful for every member, partner, and supporter who makes this global work possible.

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