



INTERNATIONAL ALLIANCE  
OF ALS/MND ASSOCIATIONS

# 2023-2024 ANNUAL REPORT





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OF ALS/MND ASSOCIATIONS

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## MESSAGE FROM THE CHAIR & THE CEO

This year has been one of growth and collaboration as we work toward our vision of a world free of ALS/MND. We're excited to have welcomed seven new member associations, bringing our global network to 64 associations in 38 countries. We're especially proud to be making meaningful strides in under-represented regions like Kenya and Vietnam.

Connecting the ALS/MND community is at the heart of what we do. In 2023, our annual Alliance Meeting and Allied Professionals Forum brought together over 550 people — people who are eager to make a difference in the ALS/MND community, supporting each other with their knowledge, experiences and innovations. We also launched the Global Clinic Locator, an interactive map to help people with ALS/MND and their caregivers find nearby clinics to get the care they need.

Our focus on coordinating research efforts around the world continues to grow. We established a new Research Directors' Forum to drive initiatives that help our members understand and implement scientific research, and promote the inclusion of under-represented populations in studies. We also strengthened our relationships with global organizations like the World Health Organization to have ALS/MND needs heard at the international level.

Finally, 2024 marks the 10th anniversary of the Ice Bucket Challenge, which continues to raise awareness and drive action for better research, care and support. In addition to honouring its history, we created a special video of members worldwide taking the Challenge for Global ALS/MND Awareness Day. These initiatives help us spread awareness — and hope — across the globe, and reinforce the importance of our work every single day.



A handwritten signature in black ink.

**Calaneet Balas**  
Chair



A handwritten signature in black ink.

**Catherine Cummings,**  
CAE, MBA  
CEO





## WHO WE ARE

The International Alliance of ALS/MND Associations was founded in 1992 to provide an international community for individual ALS/MND associations globally. 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 connect people living with ALS (PALS) and their caregivers (CALs) to internal and external collaborators.

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



**Our Vision:** A world free of ALS/MND.

## Our Strategic Priorities to 2025

1. **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 and CALs. Be the gateway for relevant external collaborators.
2. **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 collaborators to the network of domestic associations.
3. **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, technological and financial resources to be able to deliver member value and ensure sustainability of a viable Alliance into the future. Focus on disseminating information in a concise manner that delivers the value-add of the Alliance. Build capacity to harmonize member communications across the organization and present a strong brand for the Alliance.



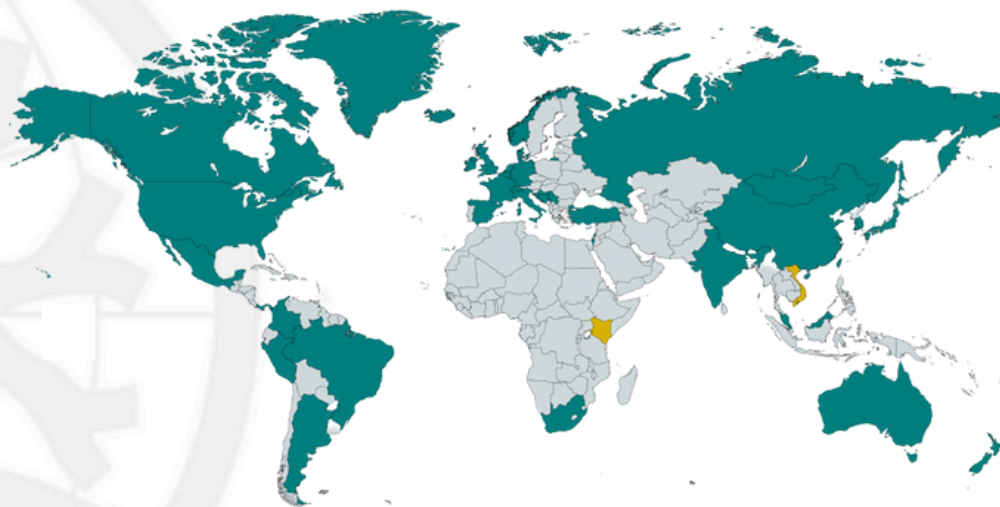


# COMMUNITY

## Global Network

Our vision is to unite members from around the world in working toward a world free of ALS/MND. This past year, we were excited to welcome seven new members from England, India, Luxembourg and the USA, bringing our total membership to 64 associations across 38 countries.

We're proud to see our geographic reach expanding, especially in under-represented countries. We're actively helping new associations take root in Kenya and Vietnam, and we've been approached by the Democratic Republic of the Congo to assist in establishing an association there.



- Countries where we have member associations
- Countries where new member associations are being established



## March of Faces

We all know how important it is for the voices of PALS and CALS to be heard if we're going to achieve our vision.

Every year, the March of Faces — a visual display of the courageous people, past and present, living with ALS/MND — is a powerful reminder of why our efforts matter so much.



## COMMUNITY

### The 2023 Award Winners

Every year, we present three awards to recognize excellence in the ALS/MND community. In 2023, we introduced a fourth, the Student Innovation Award, to inspire the next generation of researchers and innovators.



#### Student Innovation Award Lauri Desai & Zineb Flahy

Lauri Desai and Zineb Flahy, second-year Computer Science students at University College London, are the recipients of the inaugural Student Innovation Award. Their project, an eye-gaze solution compatible with standard webcams on Windows machines, offers a new level of accessibility for individuals living with ALS/MND. This innovative project not only exemplifies technical creativity but also has the potential to make a meaningful impact on the lives of people affected by ALS/MND.



#### Humanitarian Award Dr. Lucie Bruijn

With over three decades of work, including her tenure as Chief Scientist of The ALS Association, Dr. Lucie Bruijn has driven groundbreaking initiatives like the TREAT ALS program and the Pre-fALS study, which laid the foundation for critical trials like ATLAS. Her collaborative efforts have amplified research impact worldwide, creating lasting progress in understanding and treating ALS/MND.



## COMMUNITY

### The 2023 Award Winners



#### Allied Health Professional Award Dr. Deirdre Murray

As a Research Fellow and Clinical Specialist Physiotherapist at Beaumont Hospital in Dublin, Dr. Deirdre Murray has been a key figure in advancing clinical care and management practices. Her efforts in developing Ireland's "HSCP Deliver: Strategic Guidance Framework" and her participation in the REVEALS study have greatly influenced our understanding of respiratory function in ALS/MND patients. Her dedication is further reflected in her co-founding of an international ALS/MND therapy network, which continues to foster global collaboration.



#### Forbes Norris Award Dr. Jeremy M. Shefner

Over the course of his career at institutions such as Brigham and Women's Hospital, SUNY Upstate Medical University and the Barrow Neurological Institute, Dr. Jeremy M. Shefner has profoundly impacted the lives of patients and advanced clinical research. His leadership in clinical trials and co-founding of the Northeast ALS Consortium (NEALS) has been instrumental in expanding treatment options and enhancing patient care globally. His compassion and dedication continue to inspire both his patients and colleagues, cementing his legacy in the fight against ALS/MND.





# CAPABILITY

## The 2023 International Meetings



One of our main roles is to serve as a gateway for global collaboration. The annual Alliance Meeting and Allied Professionals Forum truly highlight the spirit of teamwork in the ALS/MND community. In 2023, these events were held in Basel, Switzerland, and offered virtually.

› **The Annual Alliance Meeting brought together 166 representatives from our member associations around the world.** This was their chance to connect and discuss everything from organizational development and patient care to funding and ongoing activities.



"We are fighting the same fight against ALS, but we have contextual differences that make us stronger when we come together."

- Marcela Santos, Asociación Colombiana de Esclerosis Lateral Amiotrófica, at the 2023 Alliance Meeting



## CAPABILITY

### The 2023 International Meetings

› **The Allied Professionals Forum drew 391 international healthcare professionals, along with PALS and CALS.** This educational event offers a unique space for sharing best practices and innovations in ALS/MND care, treatment and research.

Last year, we also reimagined our traditional Poster Hall, turning it into dynamic virtual galleries featuring both new posters and those previously shown at other conferences during the year. This approach gave research presentations a bigger reach and sparked meaningful discussion on recent findings and what the future may hold among healthcare professionals worldwide.

"This has been very informative. It's been fascinating to know what we do have in America, and what they may not have somewhere else, and to see the spirit of collaboration for people to work together to make everything accessible all around the globe."

- Linda Levine, caregiver to her husband who has ALS/MND, at the 2023 Allied Professionals Forum

#### THANK YOU TO OUR 2023 SPONSORS

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Silver



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Contributors





# CAPABILITY

## Collaborative Research

We know that increasing research capability globally requires us to work together. That’s why we created the Research Directors’ Forum, composed of research directors from our member associations. We currently have 11 members from six countries, and we’re expanding as our membership grows.

The group’s mission is to produce resources such as guidelines and publications to support organizations without dedicated research expertise. We’re also focused on promoting the inclusion of under-represented populations in all aspects of ALS/MND research.

### Research Directors' Forum

**Chair:** Bec Sheean, PhD


**Members:**

- Raquel Barajas-Azpeleta, PhD
- Nicholas Cole, PhD
- Kuldip Dave, PhD
- Amy Easton, PhD
- Jane Haley, PhD
- Jessica Lee
- Martina de Majo, PhD
- Gethin Thomas, PhD
- David Taylor, PhD
- Fernando Vieira, MD

## Knowledge Sharing

To extend the reach of our own projects, we’ve also focused on increasing our submissions of posters, presentations and publications.

Over the past year, these efforts have led to our inclusion in six international conferences, where we presented more than 10 posters.



### Global Access to Voice Preservation in ALS/MND Populations

Jarnall Chudge<sup>1</sup>, Jessica Mabe<sup>1</sup>, Martina de Majo<sup>1</sup>, Catherine Cummings<sup>1</sup>, Julia Simon<sup>1</sup>

<sup>1</sup>International Alliance of ALS/MND Associations

#### BACKGROUND

OpenStim is among the most common symptoms of people living with Amyotrophic Lateral Sclerosis (ALS). It is characterized by difficulty in articulation and intelligibility of speech. Voice preservation (VP) technologies involve recording samples of a person's speech to generate their virtual voice and assist with communication. From these recordings, a synthetic voice can be created with the aim of enhancing quality of life.

Although voice banking is not the most ideal solution for everyone, it can provide the most realistic, natural-sounding voice for people with ALS. It is available in many languages, including in limited access, often to other and English-speaking countries.

The International Alliance of ALS/MND Associations is currently leading a pilot project in Colombia, working with PALS and caregivers of people living with ALS/MND to help deliver a communication solution that is cost-effective and reflects the significance of voice to a person's self-identity while being sensitive to the cultural aspects of language such as accents, dialects, and idioms.

In Colombia, 90% of PALS are in urban areas, and it takes an average of two years to go from symptoms to diagnosis due to a lack of awareness and access to experts. However, the need for voice banking is increasing significantly during the pandemic. In addition, the need of knowledge and aid in using technology varies greatly.

#### METHOD

Through an international network, the National University Hospital (NUEVA), the Colombian Association of Amyotrophic Lateral Sclerosis (ACALA), and the Alliance, this pilot project seeks to establish a broader understanding of the current state of voice and recording of these systems and deliver a pilot service aimed at people with ALS. The project aims to provide a more accessible and affordable service for people with ALS, and their family and friends, go through the process. We aim to align with some of the technology knowledge that can be used to expand the current resources, allowing the service will be for the people and aligned to the socio-cultural and linguistic characteristics of Colombia.

ACALA supported the PALS participants in the project and NUNA have ensured ethical compliance and developed a research protocol and clinical governance process specifically for the pilot. Access to the VP technology has been provided by Acoustic's MyVoiceNet desktop application (MyVoiceNet.com).

#### DISCUSSION

To fully the objective of making VP technology available everywhere, the project will develop a range of services, that can be provided to people with ALS. The delivery of these services is to provide a more accessible and affordable service for people with ALS, and their family and friends, go through the process. We aim to align with some of the technology knowledge that can be used to expand the current resources, allowing the service will be for the people and aligned to the socio-cultural and linguistic characteristics of Colombia.

#### RESULTS

Table 1: Summary of the results of the pilot project in Colombia. The table shows the number of participants, the number of recordings, and the number of people who have used the service.

Category	Sub-category	Value
Participants	Total	10
	Male	6
	Female	4
	Age range (years)	45-75
Recordings	Total	100
	Male	60
	Female	40
	Age range (years)	45-75
Service use	Total	10
	Male	6
	Female	4
	Age range (years)	45-75

Figure 1: A line graph showing the number of participants who have used the service over time. The x-axis represents time in months, and the y-axis represents the number of participants. The graph shows a steady increase in the number of participants using the service over the 12-month period.

Figure 2: A bar chart showing the number of recordings made by participants over time. The x-axis represents time in months, and the y-axis represents the number of recordings. The chart shows a steady increase in the number of recordings made over the 12-month period.

Figure 3: A bar chart showing the number of people who have used the service over time. The x-axis represents time in months, and the y-axis represents the number of people. The chart shows a steady increase in the number of people using the service over the 12-month period.

Figure 4: A bar chart showing the number of recordings made by participants over time. The x-axis represents time in months, and the y-axis represents the number of recordings. The chart shows a steady increase in the number of recordings made over the 12-month period.

## Global Clinic Locator



Thanks to the efforts of the Mappers, we added a Global Clinic Locator to our website. This interactive map helps PALS and CALS find ALS/MND clinics near them. It will be continually updated to include new clinics as we learn about them.





## CAPABILITY

### Global Advocacy

Throughout the year, we've been using the results of the 2023 Fundamental Rights Survey to guide our advocacy efforts. The first two rights — access to care and access to treatment — were the focus of the member roundtables.

Not every country can meet the basic needs of PALS, and in some places, care and treatment are limited or difficult to access. These roundtables were designed to help us better understand the challenges different regions and countries face, and what tools they need to make progress.

On a global level, we've strengthened our advocacy efforts by collaborating with major organizations like the World Health Organization, the World Rehabilitation Alliance, the World Patients Alliance and the International Neuropalliative Care Society, ensuring ALS/MND needs are heard at the international level.

In addition, recognizing the lack of networks in the Global South to advocate for and advance ALS/MND clinical trials, we're providing secretariat services to support the development of ALS/MND networks in Africa and Latin America — ALS Africa and ELATAM — aimed at fostering collaboration in these regions.



### Global Awareness Day

Each year, we celebrate Global ALS/MND Awareness Day on June 21. ALS/MND affects people in every country, regardless of race, ethnicity or socioeconomic status. For every person diagnosed, the impact will be forever felt by their loved ones and friends.

This year, we marked the day by spreading awareness — and ice-cold water — in honour of the 10th anniversary of the Ice Bucket Challenge. Since 2014, this event has raised vital awareness and funds for research, care, support and assistive technology. We created a special video featuring our members from around the globe participating in the Challenge to continue to spread HOPE to every corner of the world.



## CAPACITY

### Alliance Staff

Over the past five years, we've steadily integrated new projects and initiatives as part of our strategic plan, with many launched in just the past year. To support this growth, we've expanded our team.

While our CEO remains our only full-time employee, we now have eight dedicated contractors who help drive our vision forward.

**CEO:** Cathy Cummings, CAE, MBA

**Program Coordinator:** Jessica Mabe

**Scientific Director:** Martina de Majo, PhD

**Advocacy & Membership Lead:** David Ali

**Innovation & Technology Lead:** Jarnail Chudge

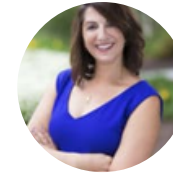
**Events Coordinator:** Angèle Gilchrist Blanchard

**Executive Assistant:** Liana Maltby

**Strategic Project Manager:** Julia Simon

**Communications Manager:** Lynne Yryku

## 2023-2024 Board of Trustees



**CHAIR**  
Calaneet Balas



**VICE-CHAIR**  
Marcela Santos



**TREASURER**  
Tammy Moore



**TRUSTEE**  
Pablo Aquino



**TRUSTEE**  
Mary Ellen Bench



**TRUSTEE**  
Angela Harris



**TRUSTEE**  
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**TRUSTEE**  
Gudjon Sigurdsson



**TRUSTEE**  
Gethin Thomas



**TRUSTEE**  
Sabine Turgeman



**TRUSTEE**  
Hilmi Uysal



**TRUSTEE**  
Yohei Yamada



# CAPACITY

## 2023-2024 Advisory Councils



### Scientific Advisory Council

This council is a centralized resource to review and provide global perspective on scientific and biomedical announcements, information and opportunities relating to ALS/MND.

**Chair:** Nicholas Cole, PhD

#### Council Members :

Adriano Chiò, MD  
Martina de Majo, PhD  
Kuldip Dave, PhD  
Jeannine Heckmann, MD, PhD  
Caroline Ingre, MD, PhD  
Qing Liu, MD, PhD  
Christopher J. McDermott, MD, PhD  
Piera Pasinelli, PhD  
Martha Peña Preciado, MD  
Nadia Sethi, DDS  
Bec Sheean, PhD  
David Taylor, PhD

**Board Liaison:** Pablo Aquino



### PALS & CALS Advisory Council

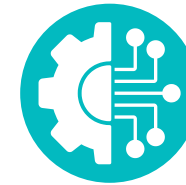
This council helps the Board of Directors consider and include in its work the wide-ranging opinions and ideas of people with ALS/MND (PALS) and their caregivers (CALS) from around the world.

**Chair:** Sara Feldman, PT, DPT, ATP

#### Council Members:

Stacy Lewin Farber, MD  
Phil Green  
Ajay Gupta  
Alper Kaya, MD  
Albert Koo Tee Yih  
Norman MacIsaac  
Felipe Ocampo, MD  
Orlando Ruiz  
Leanne Sklavenitis  
Leah Stavenhagen  
Paula Trefiak  
Angélique van der Lit-van Veldhuizen  
Bruce Virgo

**Board Liaison:** Gudjon Sigurdsson



### Innovation & Technology Council

This council makes recommendations regarding technology and innovation strategies in line with the Alliance's strategic goals and principles which will benefit those living and affected by ALS/MND globally.

**Chair:** Blair Casey

#### Council Members:

Richard Cave  
Jarnail Chudge  
John Costello  
Sara Feldman, PT, DPT, ATP  
Mike Gardner  
Phil Green  
Catherine Holloway

**Board Liaison:** Gethin Thomas, PhD



### Advocacy & Public Policy Advisory Council

This council provides advice on matters of advocacy and public policy at the global level. Where possible, it also provides global support to local issues where it would be impactful to advancing legislation or policy.

**Chair:** David Ali

#### Council Members:

Kielan Arblaster  
Nguyen Tran Minh Duc, MD  
Lung Kuo  
Evy Reviers  
Marcela Santos  
Gudjon Sigurdsson  
Sabine Turgeman  
Ilayda Ulgenalp  
Hilmi Uysal, MD

**Board Liaison:** Tammy Moore







**[ALS-MND.ORG](http://ALS-MND.ORG)**