

INTERNATIONAL ALLIANCE  
OF ALS/MND ASSOCIATIONS

**2022-2023**  
**ANNUAL REPORT**



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## MESSAGE FROM THE CHAIR & THE EXECUTIVE DIRECTOR

### Shaping the Future of ALS/MND Together

Our community is a mosaic, composed of diverse allies worldwide. We are advocacy organizations, researchers, allied health professionals, scientists, industry collaborators, and people living with ALS/MND and their caregivers. Each of you plays a pivotal role in our collective efforts, and together, we have accomplished remarkable feats.

In response to the pandemic's challenges in 2020 and 2021, the Alliance transitioned events like the annual International Meetings to virtual platforms, broadening global participation. When we returned to in-person events, your feedback on the importance of maintaining a virtual component resonated strongly. Hence, our 2022 Alliance Meeting and Allied Professionals Forum seamlessly combined in-person and virtual components, achieving record attendance.

These events serve as powerful reminders that our shared journey transcends geographical boundaries. Whether it's Dublin or Bogotá, universal truths unite us, binding us as a global community. Our member associations worldwide strive to address the gaps in access, research, healthcare and the daily needs of those affected by ALS/MND.

Prominent figures in our community like Professor Orla Hardiman and Dr. Adriano Chiò have underscored the need for global collaboration in research initiatives. Their insights illuminate the path forward: solving the ALS/MND puzzle requires international cooperation. Our 2022-2023 roundtables on genetics, optimizing clinical trials and emergency preparedness further highlighted the Alliance's role in facilitating collaborative research on a global scale.

As we look ahead, the Alliance remains committed to serving our community's needs. Our role as an enabler of global collaboration uniquely positions us to coordinate projects that advance our understanding, enhance access, promote fundamental rights, and improve the quality of life for people living with ALS/MND and their caregivers.

Reflecting on our accomplishments, we would like to convey our heartfelt appreciation for your unwavering support and dedication to our global ALS/MND community. Your support has been instrumental to our successes, and we look forward to continuing this remarkable journey with you. Together, we can create a world free of ALS/MND, making a lasting and meaningful impact on lives worldwide.



A handwritten signature in black ink.

**Calaneet Balas**  
Chair

A handwritten signature in black ink.

**Catherine Cummings,**  
**CAE, MBA**  
Executive Director

## 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 PALS and CALS to internal and external stakeholders.

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 stakeholders.
- 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 stakeholders 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, technology 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.



# A STRONG COMMUNITY

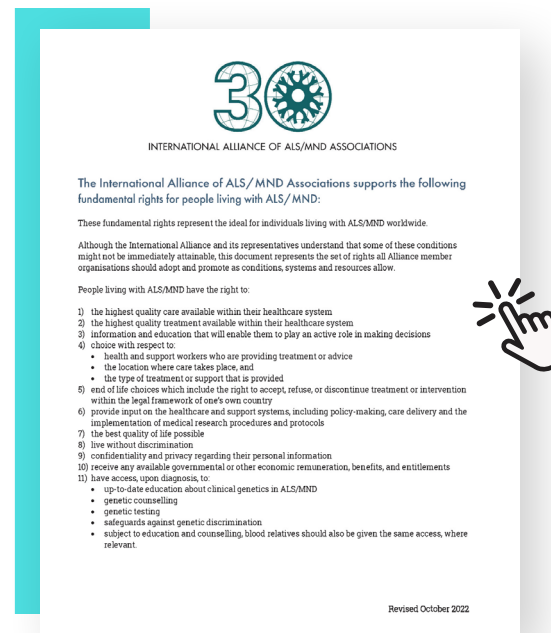
## Our Members

The Alliance began in 1992 with 14 founding members, representing 17 countries. We have since grown to more than double in both size and reach. In 2022-2023, our global community included 54 organizations, representing 33 countries.

These organizations represent not only the Alliance membership but also — and importantly — the global community of researchers, clinicians, PALS, CALS and so many more, who are all united in our fight against ALS/MND.

Our member organizations are also the guardians of the Fundamental Rights of People Living with ALS/MND and Caregivers. These fundamental rights represent the ideal for individuals living with ALS/MND worldwide that should be adopted and promoted as conditions, systems and resources allow.

We are only where we are today because of member organizations, whose dedication and commitment remain unwavering year over year. Thank you to all for continuing to strive for a world free of ALS/MND.



## GLOBAL ALS/MND AWARENESS DAY

As everyone in this community knows, ALS/MND does not discriminate; it affects people regardless of sex, race, ethnicity or socioeconomic status, and it doesn't concern itself with nationality or borders.

However, we also know the most common challenges we face are around the lack of awareness in government, professional circles and the public related to ALS/MND in each country, which means fewer resources and less funding for a disease that has the potential to impact everyone.

That is why every June 21 our community comes together to celebrate Global ALS/MND Awareness Day to raise the profile of this debilitating disease, and 2023 was exceptional. We saw an unprecedented amount of collaboration and sharing of each other's events and news on social media (#ALSMNDWithoutBorders) from early May until the end of June, with engagement from thousands of individuals, countries, clinicians, researchers, industry collaborators and, most importantly, people living with ALS/MND and their caregivers.

Thank you to everyone who helped make this day a resounding success, demonstrating we remain united in the worldwide fight against ALS/MND.

A few highlights from Global Day 2023

## The 2022 Award Winners

### ALLIED HEALTH PROFESSIONAL AWARD

#### Richard Cave

More than 80% of people living with ALS/MND develop difficulties with their speech, losing not only a functional means of communication but also a display of their individual and social identity through their vocal characteristics. Most of these people eventually use an augmentative and alternative communication device; however, the synthesized voices of these devices are often viewed as impersonal and do not match the age or accent of the individual. Voice banking creates an approximation of the person's own voice that can be used in these devices to help preserve their self-identity and perhaps even their dignity.

Richard Cave is a leader in the field of voice banking in the UK and globally. He has trained over 1,000 other therapists in the process of voice banking, has written and presented internationally on the subject, and regularly hosts free training sessions online. He also continues to personally help individuals living with ALS/MND who do not have access to a therapist or cannot voice bank by themselves record their voices each week.

"Richard is an international figurehead in the fight against ALS/MND," says Nick Goldup of the MND Association. "He literally gives thousands of people living with ALS/MND a voice."



**Richard Cave**

## The 2022 Award Winners

### FORBES NORRIS AWARD

#### Dr. Richard Bedlack

American Professor of Neurology Dr. Richard Bedlack operates from the belief that everyone living with ALS/MND should receive the highest quality of care possible. It is with this philosophy in mind that he created and directs the Duke ALS Clinic in the US. By adhering to best practices, he offers families the resources of a large interdisciplinary care team, presenting all available treatment options, so they can approach the disease in the way that is best for them.

One of his most notable public contributions is the creation of the ALSUntangled™ website. A tremendous resource to the ALS/MND community, it provides scientific reviews of alternative and off label treatments to help people make informed decisions about their care.

“What began with seeing his first person with ALS/MND and a desire to ‘do better’ has led to a 20-year career of striving to continuously offer better care and treatments for those living with ALS/MND,” says colleague Stacey Asnani. “During this time, Dr. Bedlack has built a world-class ALS clinic, made significant contributions to clinical research, and engaged in advocacy that has advanced initiatives leading to positive changes in care provision, education, benefits and research.”



**Dr. Richard Bedlack**



## The 2022 Award Winners

### HUMANITARIAN AWARD

#### Sally Light

Sally Light, Chief Executive of the MND Association in England, Wales and Northern Ireland, has been awarded the 2022 Humanitarian Award from the International Alliance of ALS/MND Associations. This prestigious award honours Light's leadership in raising awareness and action around Amyotrophic Lateral Sclerosis/Motor Neurone Disease (ALS/MND), a group of diseases in which the nerve cells that control muscles undergo degeneration and die, to enhance the quality of life of those affected.

When Sally Light joined the MND Association of England, Wales and Northern Ireland as Chief Executive (now retired) in 2012, multidisciplinary care of people living with ALS/MND was inconsistent in many parts of the UK. Thanks to her extensive experience in neurological care management, she successfully led a campaign to establish a national clinical guideline for ALS/MND, which has ultimately improved the quality and consistency of care within the UK and influenced service provision globally. She also understands the need for greater international co-operation in research and care in all areas of work; during her tenure, the MND Association participated and invested in numerous multinational programs and projects.

"Ms. Light has always put people with ALS/MND and their families at the centre of everything the Association has done and believed in the community that underpins and strengthens our cause," explains Chris James of the MND Association. "She has championed greater empowerment of volunteers, a more participative membership, and continuous development of co-production and co-creation of our work and priorities. Despite the growth in size and complexity, she has never lost sight of whom we exist to support."



**Sally Light**



## A GLOBAL CONNECTOR

### The 2022 International Meetings



Our International Meetings — the Alliance Meeting and the Allied Professionals Forum — are our biggest events of the year, and 2022 was no exception. Held in San Diego, California, in December, these meetings showcase the spirit of collaboration and innovation in the ALS/MND community, bringing together the brightest minds and most passionate advocates. In-person and virtual attendance were available.

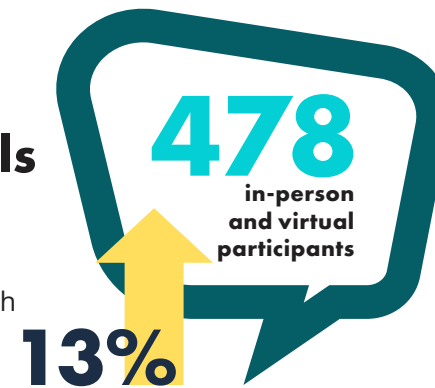
#### The Alliance Meeting

A venue for member associations to meet and share advances in supporting people living with ALS/MND



#### The Allied Professionals Meeting

An educational and training forum for health professionals who specialize in ALS/MND



*"It was global, diverse, incredibly engaging, and such a great forum to meet with advocacy groups and individuals from around the world."*

# The 2022 International Meetings

## HIGHLIGHTS

### Access

Access can mean many things to our community including access to clinical trials, access to healthcare, access to treatments and, in this context, access to community and education. With the goals of making the Alliance Meeting and the Allied Professionals Forum meet the access needs of our community, we worked hard to ensure the experience of those who participated in-person and virtually was equally engaging and informative.

### PALS Representation

We hit a record this year for the greatest number of PALS and CALS attending our meetings, with some 40 people living with ALS/MND registered. About 25% attended in-person and 75% online. We also had many PALS presenters, integrating their lived experience into our program.

### Global Representation

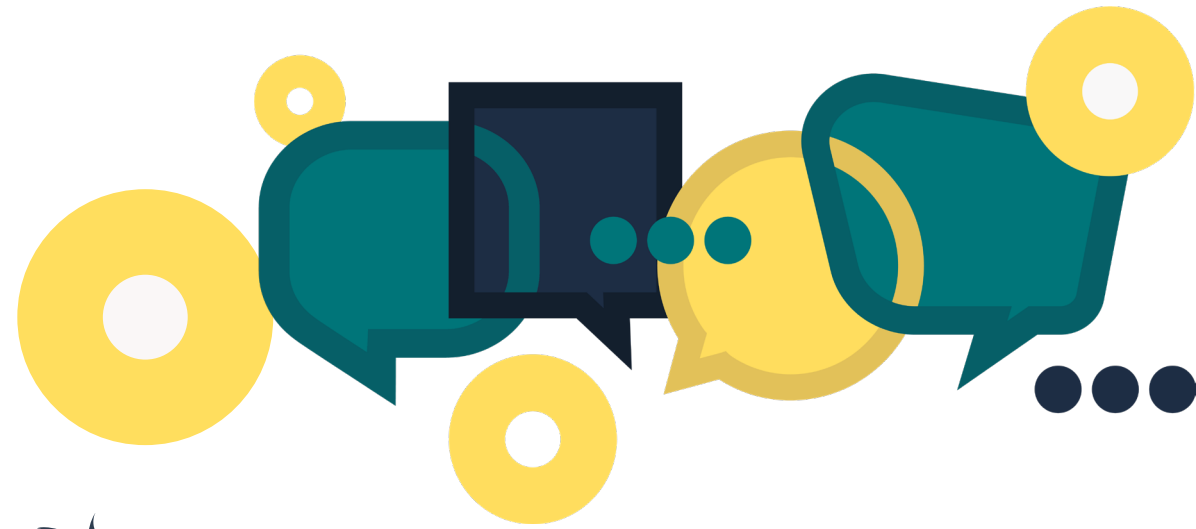
We had attendees joining us from 21 countries around the world for the Alliance Meeting, and attendees from 23 countries joining us for the Allied Professionals Forum. Both meetings had representatives from 6 continents!

*"The level of content and discussion was superb, and the stakeholders gathered in one room was truly impressive. It is wonderful to see a united and collegial patient community all committed to advancing research and sharing best practices."*

*"Cathy and her team put together perhaps the most patient-inclusive, globally inclusive, hybrid event I have been to. They even provided real-time translation to attendees! Not an easy feat and a great model for others."*

## The 2022 International Meetings

We would like to extend a great big thank you to our sponsors for their support of the 2022 International Meetings. We truly could not have done it without their support.



## Roundtables

## GENETICS SUMMIT

During the spring and summer of 2022, the Alliance brought together the foremost experts in the field of genetics, global leadership of ALS/MND associations and other health charities, and executives from industry collaborators to determine aspirational goals and action steps in the field of ALS/MND genetics.

Attendees were challenged to consider how all stakeholders can collaborate in advancing tangible action steps that will improve opportunities for people living with ALS/MND. To say the discussions were robust would be an understatement. It is abundantly evident that everyone participating in the summit wanted the same thing — a world free of ALS/MND — to be solved one step at a time as urgently as possible. There were 14 projects suggested, with action plans currently being developed.

Thank you to our sponsors for this event: Biogen, Ionis, Amylyx, Apellis, Mitsubishi Tanabe Pharma and Cytokinetics.

## OPTIMIZING CLINICAL TRIALS: OUTCOME MEASURES FOR ALS/MND

In the fall of 2022, we examined the history, strengths and weaknesses of ALSFRS-R and focused on opportunities for improvement that can be undertaken in the community. We also looked at research being done to create and validate alternative measures and self-reported ALSFRS-R scores. Our focus was on how we can harmonize standard operating procedures and identify other opportunities for improvement.

There was a long list of action items from this roundtable, but the first steps are to conduct an inventory of what measures are being used as primary and exploratory endpoints in all ongoing trials; and create an Outcomes Measures Consortium to include patients, advocates, clinicians, investigators, regulators and payers.

Thank you to our sponsors for this event: Biogen, Amylyx, Apellis, Mitsubishi Tenabe Pharma and Cytokinetics.



## Roundtables

### EMERGENCY PREPAREDNESS

Recent worldwide events have highlighted the need for a proactive approach to help ALS/MND communities prepare for emergencies. The Alliance has surveyed our members, and the results showed that 77% don't have an emergency preparedness plan. In response to this feedback, in the spring of 2023, we held a roundtable discussion for our members to talk about emergency preparedness.

We included global input from different perspectives, including emergency experts, lived experiences and a global understanding of what is possible. Out of this information, we created an emergency plan template for our member organizations and an emergency preparedness toolkit for PALS and CALS.

Thank you to our sponsors for this event: Amylyx, Cytokinetics, MTPharma and Sanofi.



INTERNATIONAL ALLIANCE  
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## EMERGENCY PREPAREDNESS TOOLKIT

The unique needs of a person living with ALS/MND are important to consider on any given day, and even more so in the event of an emergency. Please consider this list of items in preparing your plan.

### WHERE TO START?

- ☐ Understand emergencies that could happen near you.
- ☐ Complete a personal ability plan.
  - What you will be able to do.
  - What help will you need before, during and after an emergency?
- ☐ Build your support network.
- ☐ Prepare a list of emergency contacts.
- ☐ Collect all medical information:
  - Medications
  - Medical conditions
  - Special equipment
  - Allergies
  - Health insurance information
- ☐ Communication difficulties instructions
- ☐ Medication supplies
- ☐ Emergency supply kit (home and car)



# Webinars



The global ALS/MND community is made up of many groups — people living with ALS/MND and their caregivers, advocacy organizations, researchers, allied health professionals, scientists, and industry collaborators. Each of us plays an important role in educating and supporting each other. We are an inclusive community, and our full potential is only realized when we are all working together and united in our efforts to create a world free of ALS/MND.

## MARCH OF FACES

The ALS/MND March of Faces is a visual display of courageous women and men, both past and present, with ALS/MND. Kyle Hahn, a person living with ALS/MND, conceived the banner in July 1997 as an advocacy and awareness tool.

Each year, we display the printed March of Faces banner at our Alliance Meeting. We also transform the banner into a video, which we display year-round on our website, with the permission of those pictured or their families. It is a powerful reminder of our collective vision: a world free of ALS/MND.

We thank all involved for supporting the Alliance and helping us raise awareness of ALS/MND worldwide.

[Click here for the 2022 video](#)



## 2022-2023 BOARD & ADVISORY COUNCILS

### Board of Directors

#### Chair



**Calaneet Balas**  
The ALS Association

#### Directors



**Pablo Aquino**  
ALS Association  
of Argentina



**Nick Goldup**  
MND Association of  
England, Wales and  
Northern Ireland



**Lung Kuo**  
Taiwan MND  
Association



**Evy Reviere**  
ALS Liga België

#### Vice-Chair & Honorary Treasurer



**David Ali**  
MND Australia



**Marcela Santos**  
ALS Association of  
Colombia



**Gudjon  
Sigurdsson**  
MND Association  
of Iceland



**Hilmi Uysal**  
ALS MNH Derneği



**Yohei Yamada**  
Japan ALS Association



# Advisory Councils

## SCIENTIFIC ADVISORY COUNCIL

The Scientific Advisory Council is a centralized resource to review and provide global perspective on scientific and biomedical announcements, information and opportunities relating to ALS/MND.

**Chair:** Dr. Gethin Thomas, Australia  
**Board Liaison:** Pablo Aquino, Argentina  
Dr. Adriano Chiò, Italy  
Dr. Nicholas Cole, England  
Dr. Kuldip Dave, USA  
Dr. Jeannine Heckmann, South Africa  
Dr. Caroline Ingre, Sweden  
Dr. Qing Liu, China  
Dr. Christopher McDermott, UK  
Dr. Piera Pasinelli, USA  
Dr. Nadia Sethi, USA  
Dr. David Taylor, Canada

## PALS & CALS ADVISORY COUNCIL

The PALS & CALS Advisory Council helps the Board of Directors consider and include in its work the wide-ranging opinions and ideas of people with ALS/MND and caregivers to people living with ALS/MND from across the globe.

**Chair:** Sara Feldman, USA  
**Board Liaison:** Gudjon Sigurdsson, Iceland  
Phil Green, USA  
Ajay Gupta, India  
Alper Kaya, Turkey  
Albert Koo Tee Yih, Malaysia  
Norman MacIsaac, Canada  
Dr. Felipe Ocampo, USA  
Orlando Ruiz, Colombia  
Angélique van der Lit-van Veldhuizen, Netherlands  
Bruce Virgo, Scotland

## INNOVATION AND TECHNOLOGY ADVISORY COUNCIL

The Innovation and Technology Advisory 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, USA  
**Board Liaison:** Nick Goldup, UK  
Richard Cave, UK  
Jarnail Chudge, UK  
John Costello, USA  
Sara Feldman, USA  
Mike Gardner, Canada  
Phil Green, USA  
Stuart Moss, UK