

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

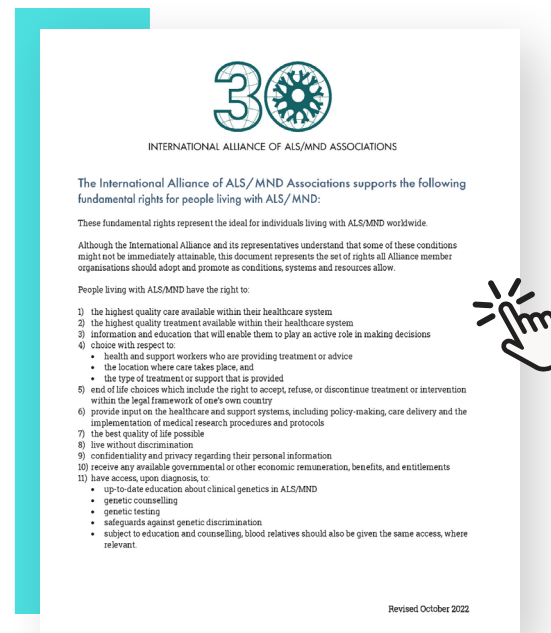
## Our Members

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.

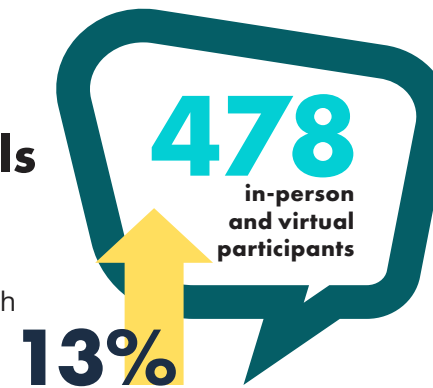
#### The Alliance Meeting

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  
OF ALS/MND ASSOCIATIONS

## 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

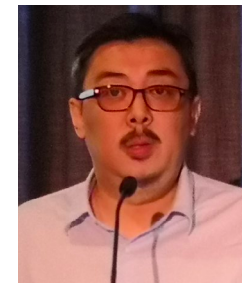
#### Directors



**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

Company registration number 3739783  
Charity registration number 1079504

# **The International Alliance of ALS/MND Associations**

## **Directors' Report and Financial Statements for the year ended 30 June 2023**

# International Alliance of ALS/MND Associations

## Reference and Administrative details

The International Alliance of ALS/MND Associations is a company limited by guarantee and a registered charity governed by its memorandum and articles of association. The Directors of the charity are its Trustees for the purposes of charity law and throughout this report are collectively referred to as the Directors.

Company registration number: 3739783

Charity registration number: 1079504

## Directors

Calaneet Balas  
David Ali  
Marcela Santos  
Gudjon Sigurdsson  
Evy Reviere  
Pablo Aquino  
Nick Goldup  
Andrea Pauls Backman (resigned 29<sup>th</sup> November 2022)  
Lung Kuo  
Dr Hilmi Uysal  
Yohei Yamada (appointed 29<sup>th</sup> November 2022)  
Sabine Turgeman (appointed 29<sup>th</sup> November 2022)

## Principal and Registered Office

Francis Crick House  
6 Summerhouse Road  
Moulton Park  
Northampton  
NN3 6BJ

## Professional Advisers

Independent Examiner	Jim Gourlay FCCA 11 Russell Place Busby G76 8JN
Solicitor	Bates Wells Brathwaite 10 Queen Street Place London EC4R 1BE
Bankers	Lloyds Bank PLC Public & Community Sector 3rd Floor 25 Gresham Street London EC2V 7HN

# **International Alliance of ALS/MND Associations**

## **Directors' Report**

### **For the Year Ended 30 June 2023**

The Directors present their report together with the financial statements for the year ended 30 June 2023. Reference and administrative information set out on page 1 forms part of this report. The financial statements comply with current statutory requirements, the Memorandum and Articles of Association and the Statement of Recommended Practice Accounting and Reporting by Charities.

### **Objectives**

The International Alliance of ALS/MND Associations (the Alliance) is the lead body for organisations and associations representing people living with Motor Neurone Disease (MND), also known as Amyotrophic Lateral Sclerosis (ALS).

Member organisations and associations provide direct support and services for people living with the disease. Members are generally drawn from national bodies; however, in some countries there are multiple members, servicing segments of the ALS/MND population.

Our purpose, vision and value proposition are outlined below:

**PURPOSE:** The Alliance is a global network of ALS/MND associations informed by PALS/CALS, that builds capability for its members and connects to external stakeholders.

**VISION:** A World Free of ALS

**VALUE PROPOSITION:** 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, PALS and CALS, internal, and external stakeholders connect.

Our two main strategic focuses are Community and Capability, and we do this by building and sustaining our Capacity. The International Alliance aspires to:

### **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 (PD) 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.

### **Achievements**

The Alliance continues to find the balance between allocation of our limited resources and maximizing services to the ALS Community. We are an enabler of global Collaboration on ALS/MND for Education, Advocacy and Research.

# International Alliance of ALS/MND Associations

## Directors' Report

### For the Year Ended 30 June 2023

- Exchange and disseminate information:
  - After two years of 100 percent virtual due to the COVID 19 pandemic, the Alliance Meeting and Allied Professionals Forum returned in a hybrid format with the in-person portion being done in San Diego, California. The Alliance Meeting had 241 registrants with 136 in-person / 105 virtual and the Allied Professionals Forum has 478 registrants 201 in-person / 277 virtual. The Alliance must always hold their meetings in a hybrid format to support the community of people living with ALS/MND and their caregivers for accessibility.
  - The Alliances successful roundtable series continued in this year with roundtables on Emergency Preparedness for People Living with ALS/MND and Business Continuity for our member organizations. In addition, a roundtable was done on Optimizing Clinical Trials: Outcome Measures.
  - Our webinar series continued with Apps Demonstration; Innovation in Clinical Trial Design; Voice Banking; Genetic Counselling; First annual global clinical trials update; What do I need to know about clinical trials; Sharing success: A fireside chat with the 2022 award winners; Genetic counselling and testing; Maintaining my independence; Scientific Advisory Council update and Q&A.
- Increasing awareness of ALS/MND:
  - An Advocacy and Public Policy Committee was formed to create global strategies that integrate with local work to leverage the strength and data of the global community for advancement for all.
  - The Alliance has worked to raise awareness and engagement globally through the use of Facebook, Twitter, LinkedIn, and YouTube.
  - The Alliance's website ([www.als-mnd.org](http://www.als-mnd.org)) was completely overhauled to take a person-centred approach in 2021 and is reviewed each year by our PALS & CALS Advisory Council.
- Improve the quality of care:
  - The Alliance promotes improvement of quality of care through the exchange and dissemination of information, promoting and supporting attendance at the Alliance Meeting, Allied Professionals' Forum (APF) and International Symposium. We have an active Advisory Council of people living with ALS/MND and Carers of people with ALS/MND and they provide input into priorities.
- Stimulate and support research:
  - The Allied Professionals' Forum (APF) has expanded to be a two-day meeting open to allied health professionals which provides an opportunity for new and emerging researchers in care and management of ALS/MND to present to an audience of fellow professionals.
  - ALSMND Connect is a two-hour meeting which brings leading researchers and people affected by the disease together in a forum where researchers can describe the most recent advances in clinical and scientific research. This event is live streamed and also archived for future viewing.
- Awards:
  - The Forbes Norris Award was presented to Professor Richard Bedlack for his decades-long contribution to the management of and advances in understanding ALS/MND.
  - Sally Light, Chief Executive of the MND Association in England, Wales and Northern Ireland, was 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 ALS/MND.
  - Richard Cave was this year's Allied Health Professional Award winner. He was recognized for his outstanding work in the field of voice banking for people living with ALS/MND.

# **International Alliance of ALS/MND Associations**

## **Directors' Report**

### **For the Year Ended 30 June 2023**

#### **Our goals for the year included:**

- Retain our current membership and increase the number of ALS/MND Associations worldwide.
- Provide meaningful opportunities for exchange of information at the Alliance Meeting, Allied Professionals Forum and webinars and roundtables.
- Increase awareness through Global Day, social media and advocacy that is helpful to our members.
- Have an actionable research strategy in place by 2024.
- Grow the capacity of the Alliance to support these strategies and to ensure its sustainability.

#### **Our achievements for the year included:**

- In the 2022 – 2023 Membership Year we grew by 2 affiliate members, Global Neuro YCare (formerly Luka Youth Foundation) and NEALS, new member – ALS Society of British Columbia, and retained 100% of our former members.
- Delivery of the Alliance Meeting in hybrid format.
- Delivery of the Allied Professionals Forum in hybrid format.
- Delivered 2 stakeholder roundtables.
- Delivering 11 webinars
- Ongoing growth and development of social media networks.
- Delivering statements/programs regularly from our Advisory Councils.
- New member associations in underserved regions; engaging and partnering with other international ALS/MND organisations focusing on research and clinical trial development, including NEALS, PACTALS and ENCALS; working with regional networks such as EuPALS and UNELA.

#### **Review of Financial Activities**

The charity is a company limited by guarantee, governed by its Memorandum and Articles of Association, and is registered with the Charity Commission (Charity No. 1079504).

The results for the year to 30 June 2023 are set out in the Statement of Financial Activities, as shown on page 8.

There were net resources of £47,913 (2022 – net outgoing resources £29,249). The Directors are satisfied that the charity's financial position is adequate to fulfil its obligations.

The format of the financial statements is in accordance with Statement of Recommended Practice - Accounting and Reporting by Charities.

The Reserves Policy requires the Directors to hold sufficient funds to cover the following:

#### **Designated Funds**

Funds within the Operating Reserve that have been identified by the Board to be used for a specific purpose, and where the Board maintains flexibility to change the purpose if circumstances require reconsideration.

#### **Restricted Funds**

Grants or contributions received for a specific goal or purpose which cannot be accessed for any purpose other than that for which they are intended.

#### **Operating Reserve**

The Operating Reserve is intended to provide long-term stability by ensuring that sufficient funds are available to cover unexpected, unbudgeted or one-time costs. The Operating Reserve may also be used to cover expenses resulting from anticipated revenues or grants being delayed or cancelled.

# **International Alliance of ALS/MND Associations**

## **For the Year Ended 30 June 2023**

### **Risk Management**

The Directors have in place a formal risk management process and risk register to assess business risk and implement risk management strategies. They are able to report that all identifiable major risks to which the charity is exposed have been regularly reviewed in respect of potential impact, likelihood of occurrence and means of mitigation.

The following have been identified as the key risks:

- Loss of major subscription income,
- Incapacity or loss of key Staff
- Loss of key Directors
- Loss of IT infrastructure and support
- Security of IT systems
- Breaches of governance and compliance requirements
- Breach of privacy.

The Directors are pleased to report that systems have been strengthened to properly manage these risks.

### **Public Benefit**

The trustees have referred to the guidance contained in the Charity Commission's general guidance on public benefit when reviewing the charity's aims and objectives and in planning its future activities. The Alliance provides unrestricted access to information and resources to all people and organisations associated with ALS/MND, and additional opportunities to those organisations who become members of the Alliance. The Directors believe that the Alliance and its operations satisfy the public benefit requirement of the Charities Act 2006.

### **Assets**

The assets of the charity are held in pursuance of the governing document's objectives and are represented by unrestricted funds in the sum of £211,494 and restricted funds of £Nil.

### **Directors**

For the purposes of company law, the Directors listed on page 1 are the Directors of the company.

Directors are elected by the Alliance's membership at the Annual General Meeting. The maximum number of Directors is eleven and the minimum number is five.

Induction and ongoing training for Directors is provided through the Alliance solicitors and advice and guidance from existing Directors. An orientation session was held in January 2023 facilitated by Bates, Wells Brathwaite on the duties of Directors.

### **Directors' Responsibilities for the Financial Statements**

Company law requires the Directors to prepare financial statements for each financial year that give a true and fair view of financial activities of the charitable company during the year and of its financial position at the end of the year.



# **International Alliance of ALS/MND Associations**

## **Directors' Report**

### **For the Year Ended 30 June 2023**

#### **Directors' Responsibilities for the Financial Statements**

In preparing those financial statements, the Directors should follow best practice and:

- select suitable accounting policies and then apply them consistently.
- make judgments and estimates that are reasonable and prudent.
- state whether applicable accounting standards and statements of recommended practice have been followed, subject to any material departures disclosed and explained in the financial statements.
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charity will continue in operation.

The Directors are responsible for keeping adequate accounting records which disclose with reasonable accuracy the financial position of the charitable company which enable them to ascertain their financial position and to ensure that the financial statements comply with the Companies Act 2006, the Charities Act 1993 and regulations there under. They are also responsible for safeguarding the assets of the charitable company and for taking reasonable steps for the prevention and detection of fraud and other irregularities.

Members of the charitable company guarantee to contribute an amount not exceeding £1 to the assets of the charitable company in the event of winding up. The total number of such guarantees at 30 June 2023 was 57. Members have no beneficial interest in the charitable company.

#### **Appointment of Independent Examiner**

A resolution to appoint Jim Gourlay FCCA as the examiner will be proposed at the 2023 Annual General Meeting.



**Calaneet Balas**

**Chair**

Date: November 10, 2023

# **International Alliance of ALS/MND Associations**

## **Independent Examiner's Report to the Directors**

I report on the accounts of the charity for the year ended 30 June 2023, which comprise the statement of financial activities, balance sheet, statement of accounting policies and related notes. These financial statements have been prepared on the basis of the accounting policies set out therein.

This report is made solely to the Directors as a body, in accordance with section 145 of the Charities Act 2011. My examination has been undertaken so that I might state to the Directors those matters I am required to state to them in an independent examiner's report and for no other purpose. To the fullest extent permitted by law, I do not accept or assume responsibility to anyone other than the charity and the Directors as a body, for my examination, for this report, or for the opinions I have formed.

## **Respective Responsibilities of Directors and Examiner**

The charity's trustees are responsible for the preparation of the accounts. The charity's trustees consider that an audit is not required for this year under section 144 of the Charities Act 2011 (the Charities Act) and that an independent examination is needed.

It is my responsibility to:

- examine the accounts under section 145 of the Charities Act,
- to follow the procedures laid down in the general Directions given by the Charity Commission (under section 145(5)(b) of the Charities Act, and
- to state whether particular matters have come to my attention.

## **Basis of Independent Examiner's Report**

My examination was carried out in accordance with the general directions given by the Charity Commission. An examination includes a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also includes consideration of any unusual items or disclosures in the accounts and seeking explanations from you as Directors concerning any such matters. The procedures undertaken do not provide all the evidence that would be required in an audit, and consequently no opinion is given as to whether the accounts present a 'true and fair view' and the report is limited to those matters set out in the statement below.

## **Independent Examiner's Statement**

In connection with my examination, no matter has come to my attention:

1. which gives me reasonable cause to believe that in, any material respect, the requirements:
  - to keep accounting records in accordance with section 130 of the Charities Act; and
  - to prepare accounts which accord with the accounting records and comply with the accounting requirements of the Charities Acthave not been met; or
2. to which, in my opinion, attention should be drawn in order to enable a proper understanding of the accounts to be reached.

*Jim Gourlay*

**Jim Gourlay**

Date: November 14, 2023

# International Alliance of ALS/MND Associations

## Statement of Financial Activities (incorporating an Income and Expenditure Account) For the Year Ended 30 June 2023

	Notes	Unrestricted Funds £	Restrict ed Funds £	Total Funds 2023	Total Funds 2022
<b>Income and Expenditure</b>					
<b>Income</b>					
<b>Donations and legacies:</b>					
Donations and gifts		90,634	-	<b>90,634</b>	5,295
Grants and Sponsorships	1	129,153	-	<b>129,153</b>	183,199
Subscriptions	2	112,704	-	<b>112,704</b>	94,668
<b>Investment Income:</b>					
Interest Receivable		-	-	-	-
<b>Charitable activities:</b>					
Conference income		301,380	-	<b>301,380</b>	91,652
<b>Total income</b>		<b>633,871</b>	<b>-</b>	<b>633,871</b>	<b>374,814</b>
<b>Expenditure</b>					
<b>Charitable activities:</b>					
Awareness raising and publicity	3 & 4	585,958	-	<b>585,958</b>	345,565
<b>Total expenditure</b>	5 & 6	<b>585,958</b>	<b>-</b>	<b>585,958</b>	<b>345,565</b>
<b>Net income &amp; net movement in funds</b>		<b>47,913</b>	<b>-</b>	<b>47,913</b>	<b>29,249</b>
<b>Reconciliation of funds</b>					
Fund balance brought forward at 1 July		163,581	-	163,581	134,332
<b>Fund balance carried forward at 30 June</b>	9	<b>211,494</b>	<b>-</b>	<b>211,494</b>	<b>163,581</b>

The statement of financial activities includes all gains and losses recognised in the year. All incoming resources and resources expended derive from continuing activities. The notes contained in pages 10 to 17 of this report form part of the financial statements.

# International Alliance of ALS/MND Associations

## Balance Sheet

As at 30 June 2023

	Notes	2023 £	2022 £
<b>Current Assets</b>			
Debtors & Prepayments	7	16,124	15,400
Cash at Bank		213,742	167,585
		<b>229,866</b>	182,985
<b>Creditors:</b>			
Amounts falling due within one year	8	18,372	19,404
<b>Net Current Assets</b>		<b>211,494</b>	163,581
<b>Accumulated Funds</b>			
Restricted Funds	10	-	-
Unrestricted Funds:			
General Fund		211,494	163,581
	9	<b>211,494</b>	163,581

The opinion of the Directors is that the company is entitled to the exemptions conferred by Section 477 of the Companies Act 2006 in respect of the year ended 30 June 2023.

Directors' responsibilities:

- i) the Directors have not required the company to obtain an audit of its accounts for the year in accordance with section 476.
- ii) the Directors acknowledge their responsibilities for complying with the requirements of the Act with respect to accounting records and the preparation of the accounts.

The accounts have been prepared in accordance with the special provisions applicable to companies' subject to the small companies' regime.

The financial statements on pages 8 to 17 were approved by the Board of Directors on 2nd December 2023 and were signed on their behalf by:



**David Ali**  
Honorary Treasurer  
Date: November 10, 2023

# **International Alliance of ALS/MND Associations**

## **Statement of Accounting Policies**

### **Principal accounting policies**

The financial statements have been prepared in accordance with the Statement of Recommended Practice: Accounting and Reporting by Charities preparing their Accounts in accordance with Financial Reporting Standard 102 (effective January 2019), the Companies Act 2006 and the Charities Act 2011.

### **Basis of accounting**

The financial statements are prepared in accordance with the historical cost convention.

### **Recognition of income and expenditure**

Income from all sources is credited to the Statement of Financial Activities when receivable. Expenditure is accounted for on an accruals basis, inclusive of any VAT which cannot be recovered.

Income for membership subscriptions is recognised in the Statement of Financial Activities in the financial period to which it relates. Any such income relating to a future financial period is not recognised in the Statement of Financial Activities but is treated as deferred income and included as a liability in the Balance Sheet.

Unrestricted funds are donations and other incoming resources received or generated for expenditure on the general objectives of the charity.

Income receivable to which a specific purpose has been defined by the donor is included in restricted funds. Expenditure which meets the defined purpose of the donation is matched to the income and charged to that restricted fund.

### **Restricted funds**

There are no restricted funds at this time.

### **Donations and legacies**

Donations are recognised when the charity has evidence of entitlement to the gift, receipt is probable, and its amount can be measured reliably. Entitlement usually arises immediately upon receipt, however, in the event that a donation is subject to conditions that require a level of performance before the charity is entitled to the funds, the income is deferred and not recognised until either those conditions are fully met, or the fulfilment of those conditions is wholly within the control of the charity and it is probable that those conditions will be fulfilled in the reporting period.

### **Investment income**

Interest on funds held on deposit is included when receivable and the amount can be measured reliably by the charity; this is normally upon notification of the interest paid or payable by the bank.

### **Income from charitable activities**

Income from charitable activities is recognised as earned (as the related goods or services are provided).

### **Charitable activities**

Expenditure on charitable activities includes all costs incurred by the charity in undertaking activities that further its charitable aims for the benefit of its beneficiaries, including those support costs and costs relating to the governance of the charity apportioned to charitable activities. The cost of charitable activities presented in the Statement of Financial Activities includes the costs of direct service provision.

# **International Alliance of ALS/MND Associations**

## **Statement of Accounting Policies (continued)**

### **Allocation of costs incurred in respect of more than one activity**

Support costs are allocated to activities on the basis of time spent by people involved in the activities. Support costs are the costs of general management, accounting and budgeting, payroll administration, information and communications technology, human resources and facilities provision. Allocations are made across the charitable activity of awareness raising and publicity and also to costs of governance.

It is the nature of the Alliance 's activities that certain costs are incurred in respect of more than one activity. Where these costs, primarily staff, travel and associated expenses and premises costs cannot be directly attributed to a single activity, they are allocated on a time spent basis across the activities of awareness raising and publicity, and governance.

Governance costs relate to the costs of running the Alliance, such as the costs of statutory compliance, meetings and the employment and establishment costs of the staff involved.

### **Taxation**

As a registered charity, the Alliance benefits from being exempt from corporation tax on its charitable income, as all income is applied for charitable purposes.

### **Support costs**

Support costs are incurred supporting the charity's activities and include expenditure associated with administrative and finance functions, business support, HR, IT and governance. These support functions are shared across the charity's activities and are apportioned across those activities in order to arrive at the full cost for each reported activity. The method of apportionment adopted by the charity is outlined in the notes to the financial statements.

### **Governance costs**

Governance costs (which are included as a component of support costs in accordance with SORP) comprise all costs involving the public accountability of the charity and its compliance with regulation and good practice. These costs include those related to constitutional and statutory requirements, external scrutiny (audit or independent examination), strategic management, and other legal and professional fees.

### **Financial instruments**

The charity only has financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and subsequently measured at their settlement value with the exception of bank loans which are subsequently measured at the carrying value plus accrued interest less repayments. The financing charge to expenditure is at a constant rate calculated using the effective interest method.

### **Judgements**

In preparing the financial statements, the Trustees have made judgements regarding the allocation of support costs to the individually reported activities of the charity. Details of the apportionment basis are included in the notes to the financial statements.

## International Alliance of ALS/MND Associations

### 1 Grants and sponsorships receivable

There were Grants and Sponsorship worth £129,153 receivable during the year (2021/22: £183,199).

### 2 Income from subscriptions

	2023 £	2022 £
United Kingdom	15,600	16,087
Europe	31,353	26,088
Africa	100	100
Asia	2,823	3,579
North America	49,544	40,863
South America	1,104	847
Australasia	12,180	7,103
	<hr/> 112,704	<hr/> 94,668

### 3 Charitable activities

Expenditure on charitable activities includes:

	2023 £	2022 £
Independent Examiner's remuneration	<hr/> 800	<hr/> 750

### 4 Directors' remuneration and expenses

No remuneration was paid or payable to any director or to any person(s) known to be connected to a director. No expenses were reimbursed to any of the directors in relation to travel and accommodation costs incurred in the course of their duties.



## International Alliance of ALS/MND Associations

### 5 Total expenditure

#### Community Expenditure

	Unrestricted Funds £	Restricted Funds £	<b>2023 £</b>	2022 £
Membership	8,644	-	<b>8,644</b>	19,367
PALS & CALS	-	-	-	10,960
SAC	-	-	-	8,463
Stakeholder Development Costs	29,979	-	<b>29,979</b>	19,135
	<b>38,623</b>	-	<b>38,623</b>	57,924

#### Capability Expenditure

	Unrestricted Funds £	Restricted Funds £	<b>2023 £</b>	2022 £
Advocacy	6,851	-	<b>6,851</b>	4,239
Annual Meeting	273,021	-	<b>273,021</b>	145,466
Education & Awareness	125,611	-	<b>125,611</b>	32,509
Partnership Programme Costs	5,760	-	<b>5,760</b>	13,602
	<b>411,243</b>	-	<b>411,243</b>	195,816

## International Alliance of ALS/MND Associations

### Capacity Expenditure

	Unrestricted Funds £	Restricted Funds £	2023 £	2022 £
Administration	105,308	-	<b>105,308</b>	40,617
Governance*	28,578	-	<b>28,578</b>	37,334
Other	1,407	-	<b>1,407</b>	472
	135,293	-	<b>135,293</b>	78,423
<b>Total Expenditure</b>	<b>585,159</b>	<b>-</b>	<b>585,159</b>	<b>332,163</b>

\*Governance costs include costs for the AGM, director travel and subsistence, board meetings and administrative support.

## 6 Employee and trustee information

The average number of persons (FTE) employed by the charity during the year was 1.25. (2022: 1.25).

### Employment costs for the year were:

	Unrestricted Funds £	Restricted Funds £	2023 £	2022 £
Gross wages and salaries	64,363	-	<b>64,363</b>	61,172
Social security costs / taxation	30,640	-	<b>30,640</b>	30,575
Pension costs	0	-	<b>0</b>	0
Healthcare insurance	4,294	-	<b>4,294</b>	0
	99,297	-	<b>99,297</b>	91,747

### Key Management Personnel

The key management personnel of the charity comprise the trustees and the executive director. Total employee benefits of the key management personnel for the charity were £99,297 (2021: £91,747).

## International Alliance of ALS/MND Associations

The number of officers who received emoluments over £60,000 was in the following ranges:

	2023 Number	2022 Number
£60,001 to £70,000	1	1
£70,001 to £80,000	-	-
£80,001 to £90,000	-	-

### 7 Debtors & prepayments

	2023 £	2022 £
Prepayments	16,124	7,112
Accrued Income	-	8,288
Accrued Bank interest	-	-
	<hr/> 16,124	<hr/> 15,400

### 8 Creditors: Amounts falling due within one year

	2023 £	2022 £
Accruals	3,123	19,404
Salary costs	-	-
Deferred income	15,249	-
	<hr/> 18,372	<hr/> 19,404

## International Alliance of ALS/MND Associations

### 9 Movements of funds

	General Fund £	Restricted Funds (Note 10) £	<b>2023 £</b>	2022 £
As at 1 July 2022	163,581		<b>163,581</b>	134,332
Net income / (expenditure)	47,913		<b>47,913</b>	29,249
<b>As at 30 June 2023</b>	<b>211,494</b>	<b>-</b>	<b>211,494</b>	163,581

### 10 Analysis of net assets - movement in funds

	<b>2022 Bfwd £</b>	Restricted £	Unrestricted £	<b>2023 Total £</b>
Current Assets	182,985	-	46,881	229,866
Net Current Liabilities	<u>(19,404)</u>	-	1,032	<u>(18,372)</u>
<b>Total Net Assets</b>	<b><u>163,581</u></b>	<b>-</b>	<b><u>47,913</u></b>	<b><u>211,494</u></b>
Bfwd funds 1 <sup>st</sup> July 2022		-	163,581	<b>163,581</b>
<b>Cfwd funds 30<sup>th</sup> June 2023</b>		<b><u>-</u></b>	<b><u>211,494</u></b>	

## International Alliance of ALS/MND Associations

### Statement of Financial Activities (incorporating an Income and Expenditure Account) For the Year Ended 30 June 2022

	Notes	Unrestricted Funds £	Restricted Funds £	Total Funds 2022	Total Funds 2021
<b>Income and Expenditure</b>					
<b>Income</b>					
<b>Donations and legacies:</b>					
Donations and gifts		5,295	-	<b>5,295</b>	662
Grants and Sponsorships	1	183,199	-	<b>183,199</b>	24,691
Subscriptions	2	94,668	-	<b>94,668</b>	81,255
<b>Investment Income:</b>					
Interest Receivable		-	-	-	44
<b>Charitable activities:</b>					
Conference income		91,652	-	<b>91,652</b>	57,549
<b>Total income</b>		<b>374,814</b>	<b>-</b>	<b>374,814</b>	164,202
<b>Expenditure</b>					
<b>Charitable activities:</b>					
Awareness raising and publicity	3 & 4	332,163	13,402	<b>345,565</b>	228,139
<b>Total expenditure</b>	5 & 6	<b>332,163</b>	<b>13,402</b>	<b>345,565</b>	228,139
<b>Net income / (expenditure) &amp; net movement in funds</b>		<b>42,651</b>	<b>(13,402)</b>	<b>29,249</b>	(63,937)
<b>Reconciliation of funds</b>					
Fund balance brought forward at 1 July		120,930	13,402	<b>134,332</b>	198,239
<b>Fund balance carried forward at 30 June</b>	9	<b>163,581</b>	<b>-</b>	<b>163,581</b>	134,332

Company registration number 3739783  
Charity registration number 1079504

# **The International Alliance of ALS/MND Associations**

## **Directors' Report and Financial Statements for the year ended 30 June 2023**

# International Alliance of ALS/MND Associations

## Reference and Administrative details

The International Alliance of ALS/MND Associations is a company limited by guarantee and a registered charity governed by its memorandum and articles of association. The Directors of the charity are its Trustees for the purposes of charity law and throughout this report are collectively referred to as the Directors.

Company registration number: 3739783

Charity registration number: 1079504

## Directors

Calaneet Balas  
David Ali  
Marcela Santos  
Gudjon Sigurdsson  
Evy Reviere  
Pablo Aquino  
Nick Goldup  
Andrea Pauls Backman (resigned 29<sup>th</sup> November 2022)  
Lung Kuo  
Dr Hilmi Uysal  
Yohei Yamada (appointed 29<sup>th</sup> November 2022)  
Sabine Turgeman (appointed 29<sup>th</sup> November 2022)

## Principal and Registered Office

Francis Crick House  
6 Summerhouse Road  
Moulton Park  
Northampton  
NN3 6BJ

## Professional Advisers

Independent Examiner	Jim Gourlay FCCA 11 Russell Place Busby G76 8JN
Solicitor	Bates Wells Brathwaite 10 Queen Street Place London EC4R 1BE
Bankers	Lloyds Bank PLC Public & Community Sector 3rd Floor 25 Gresham Street London EC2V 7HN



# **International Alliance of ALS/MND Associations**

## **Directors' Report**

### **For the Year Ended 30 June 2023**

The Directors present their report together with the financial statements for the year ended 30 June 2023. Reference and administrative information set out on page 1 forms part of this report. The financial statements comply with current statutory requirements, the Memorandum and Articles of Association and the Statement of Recommended Practice Accounting and Reporting by Charities.

### **Objectives**

The International Alliance of ALS/MND Associations (the Alliance) is the lead body for organisations and associations representing people living with Motor Neurone Disease (MND), also known as Amyotrophic Lateral Sclerosis (ALS).

Member organisations and associations provide direct support and services for people living with the disease. Members are generally drawn from national bodies; however, in some countries there are multiple members, servicing segments of the ALS/MND population.

Our purpose, vision and value proposition are outlined below:

**PURPOSE:** The Alliance is a global network of ALS/MND associations informed by PALS/CALS, that builds capability for its members and connects to external stakeholders.

**VISION:** A World Free of ALS

**VALUE PROPOSITION:** 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, PALS and CALS, internal, and external stakeholders connect.

Our two main strategic focuses are Community and Capability, and we do this by building and sustaining our Capacity. The International Alliance aspires to:

### **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 (PD) 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.

### **Achievements**

The Alliance continues to find the balance between allocation of our limited resources and maximizing services to the ALS Community. We are an enabler of global Collaboration on ALS/MND for Education, Advocacy and Research.

# International Alliance of ALS/MND Associations

## Directors' Report

### For the Year Ended 30 June 2023

- Exchange and disseminate information:
  - After two years of 100 percent virtual due to the COVID 19 pandemic, the Alliance Meeting and Allied Professionals Forum returned in a hybrid format with the in-person portion being done in San Diego, California. The Alliance Meeting had 241 registrants with 136 in-person / 105 virtual and the Allied Professionals Forum has 478 registrants 201 in-person / 277 virtual. The Alliance must always hold their meetings in a hybrid format to support the community of people living with ALS/MND and their caregivers for accessibility.
  - The Alliances successful roundtable series continued in this year with roundtables on Emergency Preparedness for People Living with ALS/MND and Business Continuity for our member organizations. In addition, a roundtable was done on Optimizing Clinical Trials: Outcome Measures.
  - Our webinar series continued with Apps Demonstration; Innovation in Clinical Trial Design; Voice Banking; Genetic Counselling; First annual global clinical trials update; What do I need to know about clinical trials; Sharing success: A fireside chat with the 2022 award winners; Genetic counselling and testing; Maintaining my independence; Scientific Advisory Council update and Q&A.
- Increasing awareness of ALS/MND:
  - An Advocacy and Public Policy Committee was formed to create global strategies that integrate with local work to leverage the strength and data of the global community for advancement for all.
  - The Alliance has worked to raise awareness and engagement globally through the use of Facebook, Twitter, LinkedIn, and YouTube.
  - The Alliance's website ([www.als-mnd.org](http://www.als-mnd.org)) was completely overhauled to take a person-centred approach in 2021 and is reviewed each year by our PALS & CALS Advisory Council.
- Improve the quality of care:
  - The Alliance promotes improvement of quality of care through the exchange and dissemination of information, promoting and supporting attendance at the Alliance Meeting, Allied Professionals' Forum (APF) and International Symposium. We have an active Advisory Council of people living with ALS/MND and Carers of people with ALS/MND and they provide input into priorities.
- Stimulate and support research:
  - The Allied Professionals' Forum (APF) has expanded to be a two-day meeting open to allied health professionals which provides an opportunity for new and emerging researchers in care and management of ALS/MND to present to an audience of fellow professionals.
  - ALSMND Connect is a two-hour meeting which brings leading researchers and people affected by the disease together in a forum where researchers can describe the most recent advances in clinical and scientific research. This event is live streamed and also archived for future viewing.
- Awards:
  - The Forbes Norris Award was presented to Professor Richard Bedlack for his decades-long contribution to the management of and advances in understanding ALS/MND.
  - Sally Light, Chief Executive of the MND Association in England, Wales and Northern Ireland, was 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 ALS/MND.
  - Richard Cave was this year's Allied Health Professional Award winner. He was recognized for his outstanding work in the field of voice banking for people living with ALS/MND.

# **International Alliance of ALS/MND Associations**

## **Directors' Report**

### **For the Year Ended 30 June 2023**

#### **Our goals for the year included:**

- Retain our current membership and increase the number of ALS/MND Associations worldwide.
- Provide meaningful opportunities for exchange of information at the Alliance Meeting, Allied Professionals Forum and webinars and roundtables.
- Increase awareness through Global Day, social media and advocacy that is helpful to our members.
- Have an actionable research strategy in place by 2024.
- Grow the capacity of the Alliance to support these strategies and to ensure its sustainability.

#### **Our achievements for the year included:**

- In the 2022 – 2023 Membership Year we grew by 2 affiliate members, Global Neuro YCare (formerly Luka Youth Foundation) and NEALS, new member – ALS Society of British Columbia, and retained 100% of our former members.
- Delivery of the Alliance Meeting in hybrid format.
- Delivery of the Allied Professionals Forum in hybrid format.
- Delivered 2 stakeholder roundtables.
- Delivering 11 webinars
- Ongoing growth and development of social media networks.
- Delivering statements/programs regularly from our Advisory Councils.
- New member associations in underserved regions; engaging and partnering with other international ALS/MND organisations focusing on research and clinical trial development, including NEALS, PACTALS and ENCALS; working with regional networks such as EuPALS and UNELA.

#### **Review of Financial Activities**

The charity is a company limited by guarantee, governed by its Memorandum and Articles of Association, and is registered with the Charity Commission (Charity No. 1079504).

The results for the year to 30 June 2023 are set out in the Statement of Financial Activities, as shown on page 8.

There were net resources of £47,913 (2022 – net outgoing resources £29,249). The Directors are satisfied that the charity's financial position is adequate to fulfil its obligations.

The format of the financial statements is in accordance with Statement of Recommended Practice - Accounting and Reporting by Charities.

The Reserves Policy requires the Directors to hold sufficient funds to cover the following:

#### **Designated Funds**

Funds within the Operating Reserve that have been identified by the Board to be used for a specific purpose, and where the Board maintains flexibility to change the purpose if circumstances require reconsideration.

#### **Restricted Funds**

Grants or contributions received for a specific goal or purpose which cannot be accessed for any purpose other than that for which they are intended.

#### **Operating Reserve**

The Operating Reserve is intended to provide long-term stability by ensuring that sufficient funds are available to cover unexpected, unbudgeted or one-time costs. The Operating Reserve may also be used to cover expenses resulting from anticipated revenues or grants being delayed or cancelled.

# **International Alliance of ALS/MND Associations**

## **For the Year Ended 30 June 2023**

### **Risk Management**

The Directors have in place a formal risk management process and risk register to assess business risk and implement risk management strategies. They are able to report that all identifiable major risks to which the charity is exposed have been regularly reviewed in respect of potential impact, likelihood of occurrence and means of mitigation.

The following have been identified as the key risks:

- Loss of major subscription income,
- Incapacity or loss of key Staff
- Loss of key Directors
- Loss of IT infrastructure and support
- Security of IT systems
- Breaches of governance and compliance requirements
- Breach of privacy.

The Directors are pleased to report that systems have been strengthened to properly manage these risks.

### **Public Benefit**

The trustees have referred to the guidance contained in the Charity Commission's general guidance on public benefit when reviewing the charity's aims and objectives and in planning its future activities. The Alliance provides unrestricted access to information and resources to all people and organisations associated with ALS/MND, and additional opportunities to those organisations who become members of the Alliance. The Directors believe that the Alliance and its operations satisfy the public benefit requirement of the Charities Act 2006.

### **Assets**

The assets of the charity are held in pursuance of the governing document's objectives and are represented by unrestricted funds in the sum of £211,494 and restricted funds of £Nil.

### **Directors**

For the purposes of company law, the Directors listed on page 1 are the Directors of the company.

Directors are elected by the Alliance's membership at the Annual General Meeting. The maximum number of Directors is eleven and the minimum number is five.

Induction and ongoing training for Directors is provided through the Alliance solicitors and advice and guidance from existing Directors. An orientation session was held in January 2023 facilitated by Bates, Wells Brathwaite on the duties of Directors.

### **Directors' Responsibilities for the Financial Statements**

Company law requires the Directors to prepare financial statements for each financial year that give a true and fair view of financial activities of the charitable company during the year and of its financial position at the end of the year.

# **International Alliance of ALS/MND Associations**

## **Directors' Report**

### **For the Year Ended 30 June 2023**

#### **Directors' Responsibilities for the Financial Statements**

In preparing those financial statements, the Directors should follow best practice and:

- select suitable accounting policies and then apply them consistently.
- make judgments and estimates that are reasonable and prudent.
- state whether applicable accounting standards and statements of recommended practice have been followed, subject to any material departures disclosed and explained in the financial statements.
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charity will continue in operation.

The Directors are responsible for keeping adequate accounting records which disclose with reasonable accuracy the financial position of the charitable company which enable them to ascertain their financial position and to ensure that the financial statements comply with the Companies Act 2006, the Charities Act 1993 and regulations there under. They are also responsible for safeguarding the assets of the charitable company and for taking reasonable steps for the prevention and detection of fraud and other irregularities.

Members of the charitable company guarantee to contribute an amount not exceeding £1 to the assets of the charitable company in the event of winding up. The total number of such guarantees at 30 June 2023 was 57. Members have no beneficial interest in the charitable company.

#### **Appointment of Independent Examiner**

A resolution to appoint Jim Gourlay FCCA as the examiner will be proposed at the 2023 Annual General Meeting.



**Calaneet Balas**

**Chair**

Date: November 10, 2023

# **International Alliance of ALS/MND Associations**

## **Independent Examiner's Report to the Directors**

I report on the accounts of the charity for the year ended 30 June 2023, which comprise the statement of financial activities, balance sheet, statement of accounting policies and related notes. These financial statements have been prepared on the basis of the accounting policies set out therein.

This report is made solely to the Directors as a body, in accordance with section 145 of the Charities Act 2011. My examination has been undertaken so that I might state to the Directors those matters I am required to state to them in an independent examiner's report and for no other purpose. To the fullest extent permitted by law, I do not accept or assume responsibility to anyone other than the charity and the Directors as a body, for my examination, for this report, or for the opinions I have formed.

## **Respective Responsibilities of Directors and Examiner**

The charity's trustees are responsible for the preparation of the accounts. The charity's trustees consider that an audit is not required for this year under section 144 of the Charities Act 2011 (the Charities Act) and that an independent examination is needed.

It is my responsibility to:

- examine the accounts under section 145 of the Charities Act,
- to follow the procedures laid down in the general Directions given by the Charity Commission (under section 145(5)(b) of the Charities Act, and
- to state whether particular matters have come to my attention.

## **Basis of Independent Examiner's Report**

My examination was carried out in accordance with the general directions given by the Charity Commission. An examination includes a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also includes consideration of any unusual items or disclosures in the accounts and seeking explanations from you as Directors concerning any such matters. The procedures undertaken do not provide all the evidence that would be required in an audit, and consequently no opinion is given as to whether the accounts present a 'true and fair view' and the report is limited to those matters set out in the statement below.

## **Independent Examiner's Statement**

In connection with my examination, no matter has come to my attention:

1. which gives me reasonable cause to believe that in, any material respect, the requirements:
  - to keep accounting records in accordance with section 130 of the Charities Act; and
  - to prepare accounts which accord with the accounting records and comply with the accounting requirements of the Charities Acthave not been met; or
2. to which, in my opinion, attention should be drawn in order to enable a proper understanding of the accounts to be reached.

*Jim Gourlay*

**Jim Gourlay**

Date: November 14, 2023

# International Alliance of ALS/MND Associations

## Statement of Financial Activities (incorporating an Income and Expenditure Account) For the Year Ended 30 June 2023

	Notes	Unrestricted Funds £	Restrict ed Funds £	Total Funds 2023	Total Funds 2022
<b>Income and Expenditure</b>					
<b>Income</b>					
<b>Donations and legacies:</b>					
Donations and gifts		90,634	-	<b>90,634</b>	5,295
Grants and Sponsorships	1	129,153	-	<b>129,153</b>	183,199
Subscriptions	2	112,704	-	<b>112,704</b>	94,668
<b>Investment Income:</b>					
Interest Receivable		-	-	-	-
<b>Charitable activities:</b>					
Conference income		301,380	-	<b>301,380</b>	91,652
<b>Total income</b>		<b>633,871</b>	<b>-</b>	<b>633,871</b>	<b>374,814</b>
<b>Expenditure</b>					
<b>Charitable activities:</b>					
Awareness raising and publicity	3 & 4	585,958	-	<b>585,958</b>	345,565
<b>Total expenditure</b>	5 & 6	<b>585,958</b>	<b>-</b>	<b>585,958</b>	<b>345,565</b>
<b>Net income &amp; net movement in funds</b>		<b>47,913</b>	<b>-</b>	<b>47,913</b>	<b>29,249</b>
<b>Reconciliation of funds</b>					
Fund balance brought forward at 1 July		163,581	-	163,581	134,332
<b>Fund balance carried forward at 30 June</b>	9	<b>211,494</b>	<b>-</b>	<b>211,494</b>	<b>163,581</b>

The statement of financial activities includes all gains and losses recognised in the year. All incoming resources and resources expended derive from continuing activities. The notes contained in pages 10 to 17 of this report form part of the financial statements.

# International Alliance of ALS/MND Associations

## Balance Sheet

As at 30 June 2023

	Notes	2023 £	2022 £
<b>Current Assets</b>			
Debtors & Prepayments	7	16,124	15,400
Cash at Bank		213,742	167,585
		<b>229,866</b>	182,985
<b>Creditors:</b>			
Amounts falling due within one year	8	18,372	19,404
<b>Net Current Assets</b>		<b>211,494</b>	163,581
<b>Accumulated Funds</b>			
Restricted Funds	10	-	-
Unrestricted Funds:			
General Fund		211,494	163,581
	9	<b>211,494</b>	163,581

The opinion of the Directors is that the company is entitled to the exemptions conferred by Section 477 of the Companies Act 2006 in respect of the year ended 30 June 2023.

Directors' responsibilities:

- i) the Directors have not required the company to obtain an audit of its accounts for the year in accordance with section 476.
- ii) the Directors acknowledge their responsibilities for complying with the requirements of the Act with respect to accounting records and the preparation of the accounts.

The accounts have been prepared in accordance with the special provisions applicable to companies' subject to the small companies' regime.

The financial statements on pages 8 to 17 were approved by the Board of Directors on 2nd December 2023 and were signed on their behalf by:



**David Ali**  
Honorary Treasurer  
Date: November 10, 2023



# **International Alliance of ALS/MND Associations**

## **Statement of Accounting Policies**

### **Principal accounting policies**

The financial statements have been prepared in accordance with the Statement of Recommended Practice: Accounting and Reporting by Charities preparing their Accounts in accordance with Financial Reporting Standard 102 (effective January 2019), the Companies Act 2006 and the Charities Act 2011.

### **Basis of accounting**

The financial statements are prepared in accordance with the historical cost convention.

### **Recognition of income and expenditure**

Income from all sources is credited to the Statement of Financial Activities when receivable. Expenditure is accounted for on an accruals basis, inclusive of any VAT which cannot be recovered.

Income for membership subscriptions is recognised in the Statement of Financial Activities in the financial period to which it relates. Any such income relating to a future financial period is not recognised in the Statement of Financial Activities but is treated as deferred income and included as a liability in the Balance Sheet.

Unrestricted funds are donations and other incoming resources received or generated for expenditure on the general objectives of the charity.

Income receivable to which a specific purpose has been defined by the donor is included in restricted funds. Expenditure which meets the defined purpose of the donation is matched to the income and charged to that restricted fund.

### **Restricted funds**

There are no restricted funds at this time.

### **Donations and legacies**

Donations are recognised when the charity has evidence of entitlement to the gift, receipt is probable, and its amount can be measured reliably. Entitlement usually arises immediately upon receipt, however, in the event that a donation is subject to conditions that require a level of performance before the charity is entitled to the funds, the income is deferred and not recognised until either those conditions are fully met, or the fulfilment of those conditions is wholly within the control of the charity and it is probable that those conditions will be fulfilled in the reporting period.

### **Investment income**

Interest on funds held on deposit is included when receivable and the amount can be measured reliably by the charity; this is normally upon notification of the interest paid or payable by the bank.

### **Income from charitable activities**

Income from charitable activities is recognised as earned (as the related goods or services are provided).

### **Charitable activities**

Expenditure on charitable activities includes all costs incurred by the charity in undertaking activities that further its charitable aims for the benefit of its beneficiaries, including those support costs and costs relating to the governance of the charity apportioned to charitable activities. The cost of charitable activities presented in the Statement of Financial Activities includes the costs of direct service provision.

# **International Alliance of ALS/MND Associations**

## **Statement of Accounting Policies (continued)**

### **Allocation of costs incurred in respect of more than one activity**

Support costs are allocated to activities on the basis of time spent by people involved in the activities. Support costs are the costs of general management, accounting and budgeting, payroll administration, information and communications technology, human resources and facilities provision. Allocations are made across the charitable activity of awareness raising and publicity and also to costs of governance.

It is the nature of the Alliance 's activities that certain costs are incurred in respect of more than one activity. Where these costs, primarily staff, travel and associated expenses and premises costs cannot be directly attributed to a single activity, they are allocated on a time spent basis across the activities of awareness raising and publicity, and governance.

Governance costs relate to the costs of running the Alliance, such as the costs of statutory compliance, meetings and the employment and establishment costs of the staff involved.

### **Taxation**

As a registered charity, the Alliance benefits from being exempt from corporation tax on its charitable income, as all income is applied for charitable purposes.

### **Support costs**

Support costs are incurred supporting the charity's activities and include expenditure associated with administrative and finance functions, business support, HR, IT and governance. These support functions are shared across the charity's activities and are apportioned across those activities in order to arrive at the full cost for each reported activity. The method of apportionment adopted by the charity is outlined in the notes to the financial statements.

### **Governance costs**

Governance costs (which are included as a component of support costs in accordance with SORP) comprise all costs involving the public accountability of the charity and its compliance with regulation and good practice. These costs include those related to constitutional and statutory requirements, external scrutiny (audit or independent examination), strategic management, and other legal and professional fees.

### **Financial instruments**

The charity only has financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and subsequently measured at their settlement value with the exception of bank loans which are subsequently measured at the carrying value plus accrued interest less repayments. The financing charge to expenditure is at a constant rate calculated using the effective interest method.

### **Judgements**

In preparing the financial statements, the Trustees have made judgements regarding the allocation of support costs to the individually reported activities of the charity. Details of the apportionment basis are included in the notes to the financial statements.

## International Alliance of ALS/MND Associations

### 1 Grants and sponsorships receivable

There were Grants and Sponsorship worth £129,153 receivable during the year (2021/22: £183,199).

### 2 Income from subscriptions

	2023 £	2022 £
United Kingdom	15,600	16,087
Europe	31,353	26,088
Africa	100	100
Asia	2,823	3,579
North America	49,544	40,863
South America	1,104	847
Australasia	12,180	7,103
	<hr/> 112,704	<hr/> 94,668

### 3 Charitable activities

Expenditure on charitable activities includes:

	2023 £	2022 £
Independent Examiner's remuneration	<hr/> 800	<hr/> 750

### 4 Directors' remuneration and expenses

No remuneration was paid or payable to any director or to any person(s) known to be connected to a director. No expenses were reimbursed to any of the directors in relation to travel and accommodation costs incurred in the course of their duties.

## International Alliance of ALS/MND Associations

### 5 Total expenditure

#### Community Expenditure

	Unrestricted Funds £	Restricted Funds £	<b>2023 £</b>	2022 £
Membership	8,644	-	<b>8,644</b>	19,367
PALS & CALS	-	-	-	10,960
SAC	-	-	-	8,463
Stakeholder Development Costs	29,979	-	<b>29,979</b>	19,135
	<b>38,623</b>	-	<b>38,623</b>	57,924

#### Capability Expenditure

	Unrestricted Funds £	Restricted Funds £	<b>2023 £</b>	2022 £
Advocacy	6,851	-	<b>6,851</b>	4,239
Annual Meeting	273,021	-	<b>273,021</b>	145,466
Education & Awareness	125,611	-	<b>125,611</b>	32,509
Partnership Programme Costs	5,760	-	<b>5,760</b>	13,602
	<b>411,243</b>	-	<b>411,243</b>	195,816

## International Alliance of ALS/MND Associations

### Capacity Expenditure

	Unrestricted Funds £	Restricted Funds £	2023 £	2022 £
Administration	105,308	-	<b>105,308</b>	40,617
Governance*	28,578	-	<b>28,578</b>	37,334
Other	1,407	-	<b>1,407</b>	472
	135,293	-	<b>135,293</b>	78,423
<b>Total Expenditure</b>	<b>585,159</b>	<b>-</b>	<b>585,159</b>	<b>332,163</b>

\*Governance costs include costs for the AGM, director travel and subsistence, board meetings and administrative support.

## 6 Employee and trustee information

The average number of persons (FTE) employed by the charity during the year was 1.25. (2022: 1.25).

### Employment costs for the year were:

	Unrestricted Funds £	Restricted Funds £	2023 £	2022 £
Gross wages and salaries	64,363	-	<b>64,363</b>	61,172
Social security costs / taxation	30,640	-	<b>30,640</b>	30,575
Pension costs	0	-	<b>0</b>	0
Healthcare insurance	4,294	-	<b>4,294</b>	0
	99,297	-	<b>99,297</b>	91,747

### Key Management Personnel

The key management personnel of the charity comprise the trustees and the executive director. Total employee benefits of the key management personnel for the charity were £99,297 (2021: £91,747).

## International Alliance of ALS/MND Associations

The number of officers who received emoluments over £60,000 was in the following ranges:

	2023 Number	2022 Number
£60,001 to £70,000	1	1
£70,001 to £80,000	-	-
£80,001 to £90,000	-	-

### 7 Debtors & prepayments

	2023 £	2022 £
Prepayments	16,124	7,112
Accrued Income	-	8,288
Accrued Bank interest	-	-
	<hr/>	<hr/>
	16,124	15,400

### 8 Creditors: Amounts falling due within one year

	2023 £	2022 £
Accruals	3,123	19,404
Salary costs	-	-
Deferred income	15,249	-
	<hr/>	<hr/>
	18,372	19,404

## International Alliance of ALS/MND Associations

### 9 Movements of funds

	General Fund £	Restricted Funds (Note 10) £	<b>2023 £</b>	2022 £
As at 1 July 2022	163,581		<b>163,581</b>	134,332
Net income / (expenditure)	47,913		<b>47,913</b>	29,249
<b>As at 30 June 2023</b>	<b>211,494</b>	<b>-</b>	<b>211,494</b>	163,581

### 10 Analysis of net assets - movement in funds

	<b>2022 Bfwd £</b>	Restricted £	Unrestricted £	<b>2023 Total £</b>
Current Assets	182,985	-	46,881	229,866
Net Current Liabilities	<u>(19,404)</u>	-	1,032	<u>(18,372)</u>
<b>Total Net Assets</b>	<b><u>163,581</u></b>	<b>-</b>	<b><u>47,913</u></b>	<b><u>211,494</u></b>
Bfwd funds 1 <sup>st</sup> July 2022		-	163,581	<b>163,581</b>
<b>Cfwd funds 30<sup>th</sup> June 2023</b>		<b><u>-</u></b>	<b><u>211,494</u></b>	

## International Alliance of ALS/MND Associations

### Statement of Financial Activities (incorporating an Income and Expenditure Account) For the Year Ended 30 June 2022

	Notes	Unrestricted Funds £	Restricted Funds £	Total Funds 2022	Total Funds 2021
<b>Income and Expenditure</b>					
<b>Income</b>					
<b>Donations and legacies:</b>					
Donations and gifts		5,295	-	<b>5,295</b>	662
Grants and Sponsorships	1	183,199	-	<b>183,199</b>	24,691
Subscriptions	2	94,668	-	<b>94,668</b>	81,255
<b>Investment Income:</b>					
Interest Receivable		-	-	-	44
<b>Charitable activities:</b>					
Conference income		91,652	-	<b>91,652</b>	57,549
<b>Total income</b>		<b>374,814</b>	<b>-</b>	<b>374,814</b>	164,202
<b>Expenditure</b>					
<b>Charitable activities:</b>					
Awareness raising and publicity	3 & 4	332,163	13,402	<b>345,565</b>	228,139
<b>Total expenditure</b>	5 & 6	<b>332,163</b>	<b>13,402</b>	<b>345,565</b>	228,139
<b>Net income / (expenditure) &amp; net movement in funds</b>		<b>42,651</b>	<b>(13,402)</b>	<b>29,249</b>	(63,937)
<b>Reconciliation of funds</b>					
Fund balance brought forward at 1 July		120,930	13,402	<b>134,332</b>	198,239
<b>Fund balance carried forward at 30 June</b>	9	<b>163,581</b>	<b>-</b>	<b>163,581</b>	134,332