

THE INTERNATIONAL ALLIANCE OF ALS / MND ASSOCIATIONS

England & Wales · Charity number 1079504

Details

Status Registered

Legal form Charitable company

Company number [03739783](#)

Registered 2000-02-23

Register [View on the Charity Commission register](#)

Contact

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6 Summerhouse Road
Moulton Park
Northampton
England
NN3 6BJ

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Email alliance@als-mnd.org

Website www.alsmndalliance.org

Activities

Objects: 1) FOR THE RELIEF OF PERSONS WORLDWIDE WHO ARE OR WHO ARE SUSPECTED OF BEING AFFECTED BY AMYOTROPHIC LATERAL SCLEROSIS (ALS)/ MOTOR NEURONE DISEASE (MND) AND ASSOCIATED CONDITIONS; AND2) THE ADVANCEMENT OF THE EDUCATION OF THE PUBLIC IN MATTERS RELATING TO ALS/MND

Activities: The International Alliance of ALS/MND Associations founded in November of 1992 to provide an international community for ALS/MND associations from around the world. Our vision is to engage our members, prospective members and other organizations in sharing resources globally, advancing awareness and supporting people with ALS/MND worldwide.

Classification

- **How:** Makes Grants To Organisations, Provides Advocacy/advice/information, Acts As An Umbrella Or Resource Body
- **What:** The Advancement Of Health Or Saving Of Lives
- **Who:** Other Charities Or Voluntary Bodies, Other Defined Groups

Geography

- Argentina
- Belgium
- Canada
- China
- Colombia
- Croatia
- France
- Germany
- Iceland
- India
- Ireland
- Israel
- Netherlands
- Russia
- Scotland
- South Africa
- Spain
- United States
- Northamptonshire

Finances

Period end	Income	Expenditure	Assets	Employees
2025-06-30	£699,821	£737,463	£75,337	0
2024-06-30	£595,025	£693,541	£112,978	1
2023-06-30	£633,871	£585,958	£211,494	1
2022-06-30	£374,814	£345,565	-	-
2021-06-30	£164,202	£228,139	-	-

Trustees

Name	Role	Appointed
Clare Sullivan		2025-01-01
Evy Reviere		2025-01-01
Jennifer Bedford		2025-01-01
Jennifer Hjelle		2025-11-29
Marcela Santos		2020-11-19
Mary Ellen Bench		2025-01-01
Nina Riffath Barakzai		2026-01-28
Pablo Aquino		2025-11-29
Riccardo Zuccarino		2025-01-01
Tammy Moore		2023-12-01
Valeria Gerbino		2025-11-29
Yohei Yomada		2022-11-29

THE INTERNATIONAL ALLIANCE OF ALS / MND ASSOCIATIONS

England & Wales - Charity number 1079504

Accounts

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 2025**

The 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. Day to day management of the charity is undertaken by Catherine Cummings.

Company registration number: 3739783

Charity registration number: 1079504

Directors

Calaneet Balas (appointed Chair 01/01/2019)

Jennifer Bedford (appointed 31/12/2024)

Mary Ellen Bench (appointed 01/01/2025)

Angela Harris (appointed 01/01/2024)

Tammy Moore (appointed 01/01/2024)

Evy Reivers (appointed 01/01/2025)

Marcela Santos (appointed 01/01/2021)

Clare Sullivan (appointed 01/01/2025)

Yohei Yamada (appointed 01/01/2023)

Riccardo Zuccarino (appointed 01/01/2025)

Pablo Aquino (resigned 31/12/2024)

Lung Kuo (resigned 31/12/2024)

Gudjon Sigurdsson (resigned 31/12/2024)

Gethin Thomas (resigned 05/03/2025)

Sabine Turgeman (resigned 31/12/2024)

Dr Hilmi Uysal (resigned 31/12/2024)

Principal and Registered Office

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

Professional Advisers

Independent Examiner	Dunkley's Accountants Woodlands Grange Woodlands Lane Bradley Stoke BS32 4JY
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Solicitor	Bates Wells Brathwaite 10 Queen Street Place London EC4R 1BE
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Bankers	Lloyds Bank PLC 2 George Row Northampton, NN1 1DJ
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The International Alliance of ALS/MND Associations

For the Year Ended 30 June 2025

The Directors present their report together with the financial statements for the year ended 30 June 2025. 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 including Care, Research, Advocacy and Public Policy.

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 as we build 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.

Build Capacity

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.

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.

The International Alliance of ALS/MND Associations

Directors' Report

For the Year Ended 30 June 2025

- Exchange and disseminate information
 - The Alliance Meeting and Allied Professionals Forum meetings were delivered in a hybrid format with the in-person portion being done in Montreal, Canada. The Alliance Meeting had some 199 registrants with 149 In person / 50 Virtual and the Allied Professionals Forum has some 427 registrants with 265 In person / 188 Virtual. The Alliance must always hold their meetings in a hybrid format to support accessibility for the community of people living with ALS/MND and their caregivers.
 - The Alliances successful roundtable series continued in this year with roundtables on Diagnostic Delay in ALS/MND, Fundamental Right: (e) Quality of Life, Fundamental Right: Increasing Clinical Trial Capacity in the Global South, ALS/MND Health Literacy Usability Session and Embedding Palliative Care Principles.
 - Our webinar series continued with Alliance Strategic Update, Annual Clinical Trials Update, ALS/MND Platform Trials Update, and SAC mid-year update and Q & A.
- Increasing awareness of ALS/MND
 - The Advocacy and Public Policy Advisory Council was changed to the Advocacy and Public Policy Forum and continued their work on creating 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, X, LinkedIn, and YouTube.
 - The Alliance works with the World Health Organization, The World Rehabilitation Alliance, and The World Patient Alliance.
- 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 the MND Association International Symposium. We have an active Advisory Council of people living with ALS/MND and Carers of people with ALS/MND, who provide input into priorities.
- Stimulate and support research
 - The Alliance research strategy is to enable global collaboration. We have added a Research Directors Forum that is comprised of member organization's Research Directors.
 - 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. Masterclasses on specific topics relevant to health professionals have been added to the forum. A Day in the Life Suite has been added to showcase technology and information for people living with ALS/MND.
 - ALSMND Connect is a four-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 archived for future viewing.
- Awards
 - The 2024 Forbes Norris Award was presented to Zachary Simmons and Johnathan D. Glass for contributions in research of ALS/MND.
 - The International Alliance of ALS/MND Associations proudly awarded Evy Reviers as the recipient of the 2024 Humanitarian Award, recognizing her unparalleled contributions to global research and advocacy on Amyotrophic Lateral Sclerosis/Motor Neurone Disease (ALS/MND).
 - The recipients of the 2024 Allied Professionals Award were Dr. Alisa Apreleva for her work in music therapy and Dra. Tatiana Mesquita e Silva for her work in Multidisciplinary Neurological Rehabilitation.
 - Student Innovation Award winners were Valeria Ojalora Garces, Valentina Gonzalez, Luisa Maria Hormizda infante, who worked selflessly participating in numerous research meetings trying to find the needs of patients affected by little-known diseases. The students have developed electronic applications that are available to the community.

The International Alliance of ALS/MND Associations

Directors' Report For the Year Ended 30 June 2025

Our goals for the year included

- Retain our current membership and increase the number of ALS/MND Association 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 2024 – 2025 Membership Year we grew by 7 members, ALS Society of Alberta, LifeArc, ALS Care and Support Foundation India, AriSLA-Fondazione Italiana de Ricerca per la SLA, Motor Neuron Disease Association of Kenya, Waertvult Liewen, and ALS United, Inc. 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 6 stakeholder roundtables
- Delivering a minimum of 4 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
- Supporting two emerging networks through secretariat called ALS Africa Network and ELATAM

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 2025 are set out in the Statement of Financial Activities, as shown on page 8.

There were net resources of £75,337 (2023.24 – £112,978). The Directors are satisfied that the charity's financial position is adequate to fulfil its obligations.

The Income in year £699,821 (2023.24 £595,025) – there were no new income streams

The expenditure in year £737,463 (2023.24 £693,541) – The charity expenditure was reflective of prior years with no new grants types issued (generic inflationary increase).

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 - £0 (2023.24 £0)

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 - £0 (2023.24 £0)

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 - £75,337 (2023.24 £112,978)

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.

The International Alliance of ALS/MND Associations

Directors' Report

For the Year Ended 30 June 2025

Plans for future periods

Our goals for the year included:

- Our plans for 2025 – 2026 include the fulfilment of our goals around Community, Capability and Capacity.
- In Community, we will strive to retain our membership and recruit new members who hold the vision of a World Free of ALS/MND!
- Our Capability Strategy has goals in Advocacy & Public Policy; Education; Research and supporting People with Lived Experience and those that care for them. Our education priority is to increase health literacy to aid in informative decision making. Advocacy and Public Policy priorities include – equitable access to therapies globally; inclusion of people with lived experience in Alliance initiatives; and, global recognition of ALS/MND. Through our Allied Professionals Forum each year we engage in a truly global conversation on the challenges and advancements in ALS/MND care.
- Lastly, we work to increase the capacity of all of our member organizations and the Alliance through organizational supports.

The International Alliance of ALS/MND Associations

Directors' Report

For the Year Ended 30 June 2025

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, especially due to the pandemic
- Incapacity or loss of key Staff
- Loss of key Directors
- Loss of IT infrastructure and support
- Breaches of governance and compliance requirements
- Breach of privacy.

The Directors are pleased to report that systems have been established 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 £75,337 and restricted funds of £0.00.

Structure, Governance & Management

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 2024 facilitated internally 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.

The International Alliance of ALS/MND Associations

Directors' Report For the Year Ended 30 June 2025

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 2011 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 2025 was 66. Members have no beneficial interest in the charitable company.

Appointment of Independent Examiner

A resolution to appoint Dunkleys Accountants as the examiner will be proposed at the 2025 Annual General Meeting.



Calaneet Balas
Chair

Date: November 13, 2025

The International Alliance of ALS/MND Associations

Independent Examiner's Report to the Directors

Independent examiner's report to the trustees of The International Alliance of ALS/MND Associations

I report to the charity trustees on my examination of the accounts of The International Alliance of ALS/MND Associations for the year ended 30 June 2025.

Responsibilities and basis of report

As the charity trustees of the Trust you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ('the Act').

I report in respect of my examination of the Trust's accounts carried out under section 145 of the Act and in carrying out my examination I have followed all applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

Independent examiner's statement

I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination giving me cause to believe that in any material respect:

1. accounting records were not kept in respect of the Trust as required by section 130 of the Act; or
2. the accounts do not accord with those records; or
3. the accounts do not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a true and fair view which is not a matter considered as part of an independent examination.

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.



Matthew Dobbins FCA
Dunkley's
Woodlands Grange
Woodlands Lane
Bradley Stoke
Bristol
BS32 4JY

Date: 13/11/2025

The International Alliance of ALS/MND Associations
Statement of Financial Activities (incorporating an Income and Expenditure Account)
For the Year Ended 30 June 2025

	Notes	Unrestricted Funds £	Restrict ed Funds £	Total Funds 2024.25	Total Funds 2023.24
Income and Expenditure					
Income					
Donations and legacies:					
Donations and gifts		29,343	-	29,343	29,170
Grants and Sponsorships	1	119,371	-	119,371	90,038
Subscriptions	2	141,625	-	141,625	115,769
Investment Income:					
Interest Receivable		7,758	-	7,758	3,585
Charitable activities:					
Conference income		401,725	-	401,725	356,463
Total income		<u>699,821</u>	<u>-</u>	<u>699,821</u>	<u>595,025</u>
Expenditure					
Charitable activities:					
Awareness raising and publicity	5	737,463	-	737,463	693,541
Total expenditure	5 & 6	<u>737,463</u>	<u>-</u>	<u>737,463</u>	<u>693,541</u>
Net (expenditure)/income & net movement in funds		(37,641)	-	(37,641)	(98,516)
Reconciliation of funds					
Fund balance brought forward at 1 July		<u>112,978</u>	<u>-</u>	<u>112,978</u>	<u>211,494</u>
Fund balance carried forward at 30 June	9 & 10	<u>75,337</u>	<u>-</u>	<u>75,337</u>	<u>112,978</u>

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 on pages 10 to 19 form part of these financial statements.

The International Alliance of ALS/MND Associations
Balance Sheet
As at 30 June 2025

	Notes	2024.25 £	2023.24 £
Current Assets			
Debtors & Prepayments	7	62,316	58,625
Cash at Bank		251,077	210,165
		313,393	268,790
Creditors:			
Amounts falling due within one year	8	238,057	155,812
Net Current Assets		75,337	112,978
Accumulated Funds			
Restricted Funds		-	-
Unrestricted Funds:		-	-
General Fund		75,337	112,978
	9	75,337	112,978

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 2025.

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 9 to 19 were approved by the Board of Directors on 13/11/2025 and were signed on their behalf by:



Tammy Moore
Honorary Treasurer

Date: November 13, 2025

The International Alliance of ALS/MND Associations Statement of Cashflow

	2024.25 £	2023.24 £
Cashflows from operating activities:		
Net cash provided by (used in) operating activities	33,155	(7,162)
Cash flows from investing activities:		
Dividends, interest and rents from investments	7,758	3,585
Net cash provided by (used in) investing activities	<u>7,758</u>	<u>(3,585)</u>
Cashflows from financing activities:		
Net cash provided by (used in) financing activities	<u>-</u>	<u>-</u>
Change in cash and cash equivalents in the reporting period	<u>40,912</u>	<u>(3,577)</u>
Cash and cash equivalents at the beginning of the reporting period	<u>210,165</u>	<u>213,742</u>
Cash and cash equivalents at the end of the reporting period	<u>251,077</u>	<u>210,165</u>

	2024.25 £	2023.24 £
Reconciliation of net income/(expenditure) to net cash flow from operating activities:		
Net income/(expenditure) for the reporting period (as per the statement of financial activities)	(37,641)	(98,516)
Adjustments for:		
Dividends, interest and rents from investments	(7,758)	(3,585)
(Increase)/decrease in debtors	(3,691)	(42,501)
Increase/(decrease) in creditors	82,245	137,440
Net cash provided by (used in) operating activities	<u>33,155</u>	<u>(7,162)</u>

Analysis of changes in net funds	At 01/07/24	Cash flow	At 30/06/2025
Net cash			
Cash at bank and in hand	210,165	40,912	251,077

The 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 from 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.

The 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.

The International Alliance of ALS/MND Associations

1 Grants and sponsorships receivable

There were Grants and Sponsorships worth £119,371 receivable during the year (2023/24: £90,038).

2 Income from subscriptions

	2024.25	2023.24
	£	£
United Kingdom	39,244	26,558
Europe	28,133	27,755
Africa	100	100
Asia	2,559	800
North America	57,925	48,094
South America	948	1,168
Australasia	12,716	11,294
	<u>141,625</u>	<u>115,769</u>

3 Charitable activities

Expenditure on charitable activities includes:

	2024.25	2023.24
	£	£
Independent Examiner's remuneration	<u>1,000</u>	<u>850</u>

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.

Director expenses amounting to £4,606 were paid to five directors. This amount consists of reimbursements for registration fees for the Alliance's internal conference, in line with the Alliance's policy. (2023.24 £0)

The International Alliance of ALS/MND Associations

5 Total expenditure

Community Expenditure

	Unrestricted Funds £	Restricted Funds £	2024.25 £	2023.24 £
Membership	27,720	-	27,720	25,621
PALS & CALS	18,823	-	18,823	13,671
SAC	-	-	-	-
Other	25,637	-	25,637	40,884
	72,180	-	72,180	80,176

Capability Expenditure

	Unrestricted Funds £	Restricted Funds £	2024.25 £	2023.24 £
Advocacy	23,876	-	23,876	19,461
Annual Meeting	332,325	-	332,325	279,179
Education & Awareness	83,805	-	83,805	111,437
Other	132,594	-	132,594	14,919
	572,601	-	572,601	424,997

The International Alliance of ALS/MND Associations

Capacity Expenditure

	Unrestricted Funds £	Restricted Funds £	2024.25 £	2023.24 £
Administration	55,383	-	55,383	64,895
Governance	37,182	-	37,182	113,998
Other	117	-	117	9,475
	<u>92,682</u>	<u>-</u>	<u>92,682</u>	<u>188,368</u>
Total Expenditure	<u>737,463</u>	<u>-</u>	<u>737,463</u>	<u>693,541</u>

Governance costs include costs of the AGM, directors 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 0.5. (2023.24 : 1.25) Employment costs for the year were:

	Unrestricted Funds £	Restricted Funds £	2024.25 £	2023.24 £
Gross wages and salaries	33,709	-	33,709	63,676
Social security costs				
Health insurance	<u>14,521</u>	<u>-</u>	<u>14,521</u>	<u>33,418</u>
	<u>48,230</u>	<u>-</u>	<u>48,230</u>	<u>97,094</u>

Key Management Personnel – The key management personnel comprise the Trustees and the Executive Director. Total employee benefits of the key management personnel for the charity was £48,230 (2023.24 = £97,094)

The number of officers who received emoluments over £60,000 was 0.5 in the range between £60,000 and £70,000. (2024 – 1)

The International Alliance of ALS/MND Associations

7 Debtors & prepayments

	2024.25 £	2023.24 £
Prepayments	49,022	58,626
Debtors	13,294	-
Accrued Bank interest	-	-
	<u>62,316</u>	<u>58,625</u>

8 Creditors: Amounts falling due within one year

	2024.25 £	2023.24 £
Accruals	59,840	9,619
Deferred income	<u>178,217</u>	<u>146,193</u>
	<u>238,057</u>	<u>155,812</u>

9 Movements of funds

	General Fund £	Restricted Funds (Note 10) £	2024.25 £	2023.24 £
As at 1 July 2024	112,978	-	112,978	211,494
Net (expenditure) / income	(37,641)	-	(37,641)	(98,516)
As at 30 June 2025	<u>75,337</u>	<u>-</u>	<u>75,337</u>	<u>112,978</u>

The International Alliance of ALS/MND Associations

10 Analysis of net assets - movement in funds

	2023.24 Bfwd £	Restricted £	Unrestricted £	2024.25 Total £
Current Assets	268,790	-	44,603	313,393
Net Current Liabilities	(155,812)	-	(82,245)	(238,057)
Total Net Assets	112,978	-	(37,642)	75,337
Bfwd funds 1 st July 2024		-	112,978	112,978
Cfwd funds 30 th June 2025			<u>75,337</u>	<u>75,337</u>

11. Related parties

Expenses were paid out of the funds of the charity to the CEO totalling £55,811. This amount consists of both operational expenses that were paid for on behalf of the Alliance, and reimbursement of travel and accommodation expenses incurred in the course of their duties. (2023.24 £0)

Director expenses amounting to £4,606 were paid to five directors. This amount consists of reimbursements for registration fees for the Alliance's internal conference, in line with the Alliance's policy. (2023.24 £0)

The International Alliance of ALS/MND Associations
Statement of Financial Activities (incorporating an Income and Expenditure Account)
For the Prior Year Ended 30 June 2024

	Notes	Unrestricted Funds £	Restricted Funds £	Total Funds 2023.24	Total Funds 2022.23
Income and Expenditure					
Income					
Donations and legacies:					
Donations and gifts		29,170	-	29,170	90,634
Grants and Sponsorships	1	90,038	-	90,038	129,153
Subscriptions	2	115,769	-	115,769	112,704
Investment income:					
Interest Receivable		3,585	-	3,585	-
Charitable activities:					
Conference income		356,463	-	356,463	301,380
Total income		595,025	-	595,025	633,871
Expenditure					
Charitable activities:					
Awareness raising and publicity	5	693,541	-	693,541	585,958
Total expenditure	5 & 6	693,541	-	693,541	585,958
Net income / (expenditure) & net movement in funds		(98,516)	-	(98,516)	47,913
Reconciliation of funds					
Fund balance brought forward at 1 July		211,494	-	211,494	163,581
Fund balance carried forward at 30 June	9	112,978	-	112,978	211,494

THE INTERNATIONAL ALLIANCE OF ALS / MND ASSOCIATIONS

England & Wales - Charity number 1079504

Accounts

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 2024

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 (resigned 1st December 23)

Marcela Santos

Gudjon Sigurdsson

Evy Reviere (resigned 1st December 23)

Pablo Aquino

Nick Goldup (resigned 15th December 23)

Lung Kuo

Hilmi Uysal

Yohei Yamada

Sabine Turgeman

Tammy Moore (appointed 1st December 23)

Gethin Thomas (appointed 1st December 23)

Angela Harris (appointed 1st January 24)

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 2 George Row Northampton UK NN1 1DJ

International Alliance of ALS/MND Associations

For the Year Ended 30 June 2024

The Directors present their report together with the financial statements for the year ended 30 June 2024.

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 including Care, Research, Advocacy and Public Policy.

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 2024

- Exchange and disseminate information
 - The Alliance Meeting and Allied Professionals Forum is delivered in a hybrid format with the in person portion being done in Basel, Switzerland. The Alliance Meeting had some 166 registrants with 110 In person / 56 Virtual and the Allied Professionals Forum has some 391 registrants 203 In person / 188 Virtual. The Alliance must always hold their meetings in a hybrid format to support accessibility for the community of people living with ALS/MND and their caregivers.
 - The Alliances successful roundtable series continued in this year with roundtables on Fundamental Right: Access to Treatment and Fundamental Right: Access to Care..
 - Our webinar series continued with Global fundamental rights survey results; Mental health support for people living with ALS/MND and caregivers; Annual global clinical trials update; Nutrition in ALS/MND; ALS/MND Platform trials update; Mental Health in ALS/MND; Respiratory Support in ALS/MND; Global Awareness Day.
- Increasing awareness of ALS/MND
 - An Advocacy and Public Policy Advisory Council 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, X, LinkedIn, and YouTube.
 - The Alliance works with the World Health Organization, The World Rehabilitation Alliance, and The World Patient Alliance.
- 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 , who provide input into priorities.
- Stimulate and support research
 - The Alliance research strategy is to enable global collaboration. We have added a Research Directors Forum that is comprised of member organization's Research Directors.
 - 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 four-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 archived for future viewing.
- Awards
 - The Forbes Norris Award was presented to Dr. Jeremy M. Shefner for his decades-long contribution to the management of and advances in understanding ALS/MND.
 - The International Alliance of ALS/MND Associations proudly awarded Dr. Lucie Bruijn as the recipient of the 2023 Humanitarian Award, recognizing her unparalleled contributions to global research and advocacy on Amyotrophic Lateral Sclerosis/Motor Neurone Disease (ALS/MND).
 - Dr. Deirdre Murray was the recipient of the prestigious Allied Health Professional Award for 2023. This recognition is a testament to Dr. Murray's outstanding contributions to the global fight against Amyotrophic Lateral Sclerosis/Motor Neurone Disease (ALS/MND). The winners of the inaugural Student Innovation Award were: Gauri Desai and Zineb Flahy, second-year Computer Science students at University College London whose work focused on a revolutionary eye-gaze solution.

International Alliance of ALS/MND Associations

Directors' Report

For the Year Ended 30 June 2024

Our goals for the year included

- Retain our current membership and increase the number of ALS/MND Association 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 2023 – 2024 Membership Year we grew by 3 members, ALS ONE (alsone.org), I AM ALS (iamals.org), Target ALS (targetals.org) 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 a minimum of 6 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
- Supporting two emerging networks through secretariat called ALS Africa Network and ELATAM

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 2024 are set out in the Statement of Financial Activities, as shown on page 8.

There were net outgoing resources of £(98,516) (2022.23 – outgoing resources £47,913). 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 2024

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, especially due to the pandemic
- Incapacity or loss of key Staff
- Loss of key Directors
- Loss of IT infrastructure and support
- Breaches of governance and compliance requirements
- Breach of privacy.

The Directors are pleased to report that systems have been established 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 £112,978 and restricted funds of £0.00.

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 2024 facilitated internally 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 2024

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 2011 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 2024 was 52. 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 2024 Annual General Meeting.



Calaneet Balas
Chair

Date: October 16 2024

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 2024, 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 Act

have 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.



Date: 18/10/2024

Jim Gourlay

International Alliance of ALS/MND Associations

Statement of Financial Activities (incorporating an Income and Expenditure Account) For the Year Ended 30 June 2024

	Notes	Unrestricted Funds £	Restrict ed Funds £	Total Funds 2023.24	Total Funds 2022.23
Income and Expenditure					
Income					
Donations and legacies:					
Donations and gifts		29,170	-	29,170	90,634
Grants and Sponsorships	1	90,038	-	90,038	129,153
Subscriptions	2	115,769	-	115,769	112,704
Investment Income:					
Interest Receivable		3,585	-	3,585	-
Charitable activities:					
Conference income		356,463	-	356,463	301,380
Total income		595,025	-	595,025	633,871
Expenditure					
Charitable activities:					
Awareness raising and publicity	3 & 4	693,541	-	693,541	585,958
Total expenditure	5 & 6	693,541	-	693,541	585,958
Net (expenditure)/income & net movement in funds		(98,516)	-	(98,516)	47,913
Reconciliation of funds					
Fund balance brought forward at 1 July		211,494	-	211,494	163,581
Fund balance carried forward at 30 June	9 & 10	112,978	-	112,978	211,494

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 on pages 10 to 17 form part of these financial statements.

International Alliance of ALS/MND Associations

Balance Sheet

As at 30 June 2024

	Notes	2023.24 £	2022.23 £
Current Assets			
Debtors & Prepayments	7	58,625	16,124
Cash at Bank		210,165	213,742
		268,790	229,866
Creditors:			
Amounts falling due within one year	8	155,812	18,372
Net Current Assets		112,978	211,494
Accumulated Funds			
Restricted Funds		-	-
Unrestricted Funds:			
General Fund		112,978	211,494
	9	112,978	211,494

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 2024.

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 29 October 2024 and were signed on their behalf by:

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2-89a6-
e705ab8ca207
Digitally signed by
f83a13c2-102c-42d2-89a6-
e705ab8ca207
Date: 2024.10.16 10:46:43 -04'00'

Tammy Moore

Honorary

Treasurer

Date 10/16/2024:

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 from 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 £90,038 receivable during the year (2022/23: £129,153).

2 Income from subscriptions

	2023.24 £	2022.23 £
United Kingdom	26,558	15,600
Europe	27,755	31,353
Africa	100	100
Asia	800	2,823
North America	48,094	49,544
South America	1,168	1,104
Australasia	11,294	12,180
	115,769	112,704

3 Charitable activities

Expenditure on charitable activities includes:

	2023.24 £	2022.23 £
Independent Examiner's remuneration	850	800

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. Expenses were paid out of the funds of the charity to three Directors for reimbursement of travel and accommodation expenses incurred in the course of their duties.

International Alliance of ALS/MND Associations

5 Total expenditure

Community Expenditure

	Unrestricted Funds £	Restricted Funds £	2023.24 £	2022.23 £
Membership	25,621	-	25,621	8,644
PALS & CALS	13,671	-	13,671	-
SAC	-	-	-	-
Other	40,884	-	40,884	29,979
	80,176	-	80,176	38,623

Capability Expenditure

	Unrestricted Funds £	Restricted Funds £	2023.24 £	2022.23 £
Advocacy	19,461	-	19,461	6,851
Annual Meeting	279,179	-	279,179	273,021
Education & Awareness	111,437	-	111,437	125,611
Other	14,919	-	14,919	5,760
	424,997	-	424,997	411,243

International Alliance of ALS/MND Associations

Capacity Expenditure

	Unrestricted Funds £	Restricted Funds £	2023.24 £	2022.23 £
Administration	64,895	-	64,895	105,308
Governance	113,998	-	113,998	28,578
Other	9,475	-	9,475	1,407
	<u>188,368</u>	<u>-</u>	<u>188,368</u>	<u>135,293</u>
Total Expenditure	<u>693,541</u>	<u>-</u>	<u>693,541</u>	<u>585,159</u>

Governance costs include costs of the AGM, directors 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. (2022.23 : 1.25) Employment costs for the year were:

	Unrestricted Funds £	Restricted Funds £	2023.24 £	2022.23 £
Gross wages and salaries	63,676	-	63,676	64,363
Social security costs	29,480	-	29,480	30,640
Health insurance	3,938	-	3,938	4,294
	<u>97,094</u>	<u>-</u>	<u>97,094</u>	<u>99,297</u>

Key Management Personnel – The key management personnel comprise the Trustees and the Executive Director. Total employee benefits of the key management personnel for the charity was £97,094 (2022.23 = £99,297)

The number of officers who received emoluments over £60,000 was 1 in the range between £60,000 and £70,000. (2023 – 1)

International Alliance of ALS/MND Associations

7 Debtors & prepayments

	2023.24 £	2022.23 £
Prepayments	58,625	16,124
Accrued Income	-	-
Accrued Bank interest		-
	58,625	16,124

8 Creditors: Amounts falling due within one year

	2023.24 £	2022.23 £
Accruals	9,619	3,123
Salary costs	-	-
Deferred income	146,193	15,249
	155,812	18,372

9 Movements of funds

	General Fund £	Restricted Funds (Note 10) £	2023.24 £	2022.23 £
As at 1 July 2023	211,494	-	211,494	163,581
Net (expenditure) / income	(98,516)	-	(98,516)	47,913
As at 30 June 2024	112,978	-	112,978	211,494

International Alliance of ALS/MND Associations

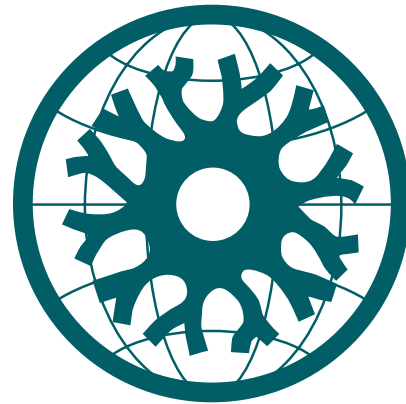
10 Analysis of net assets - movement in funds

	2022.23			2023.24
	Bfwd £	Restricted £	Unrestricted £	Total £
Current Assets	229,866	-	38,924	268,790
Net Current Liabilities	(18,372)	-	(137,440)	(155,812)
Total Net Assets	<u>211,494</u>	<u>-</u>	<u>(98,516)</u>	<u>112,978</u>
Bfwd funds 1 st July 2023			211,494	211,494
Cfwd funds 30 th June 2024		<u>-</u>	<u>112,978</u>	

THE INTERNATIONAL ALLIANCE OF ALS / MND ASSOCIATIONS

England & Wales - Charity number 1079504

Accounts



INTERNATIONAL ALLIANCE
OF ALS/MND ASSOCIATIONS

2022-2023
ANNUAL REPORT

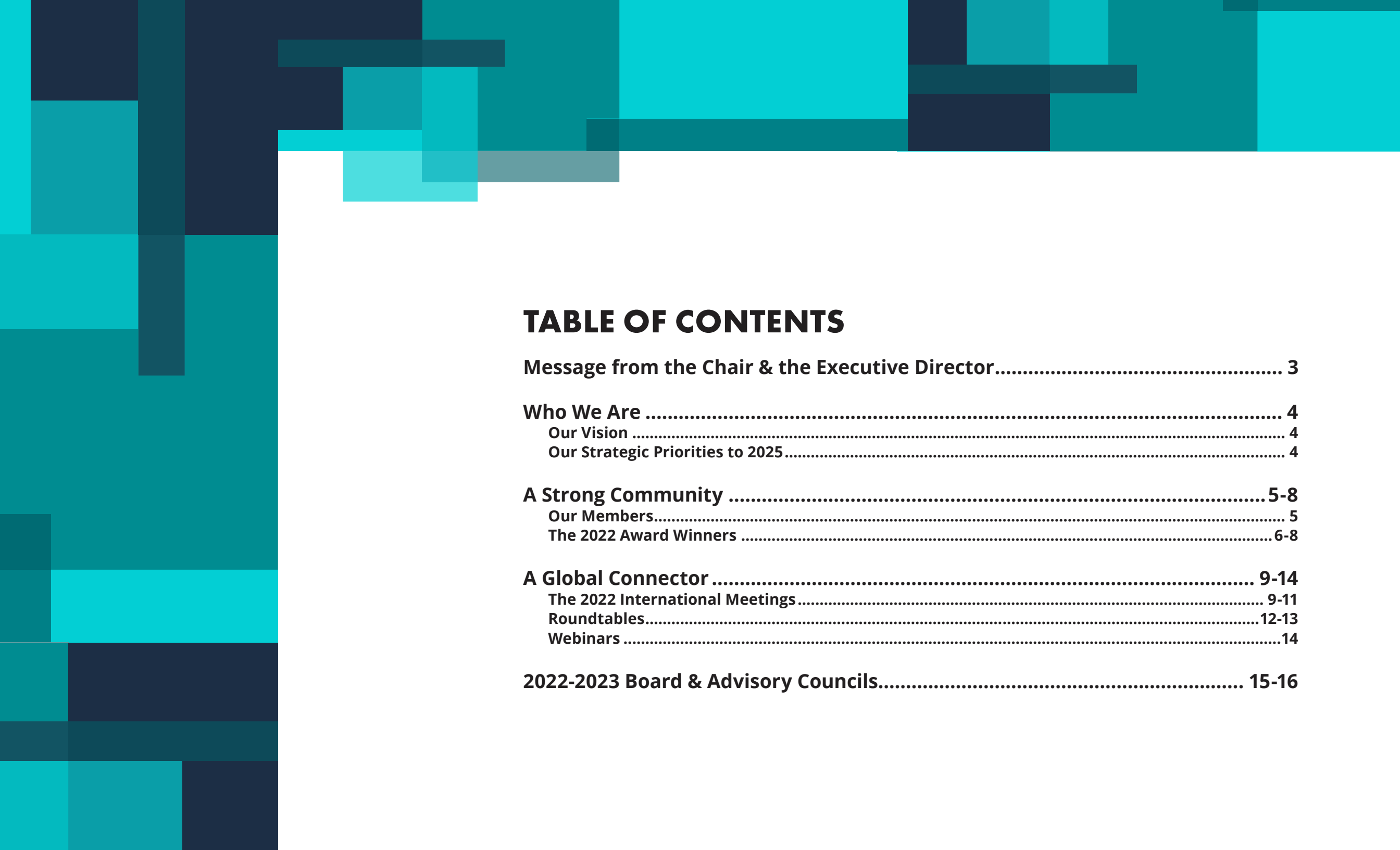


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MESSAGE FROM THE CHAIR & THE EXECUTIVE DIRECTOR

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

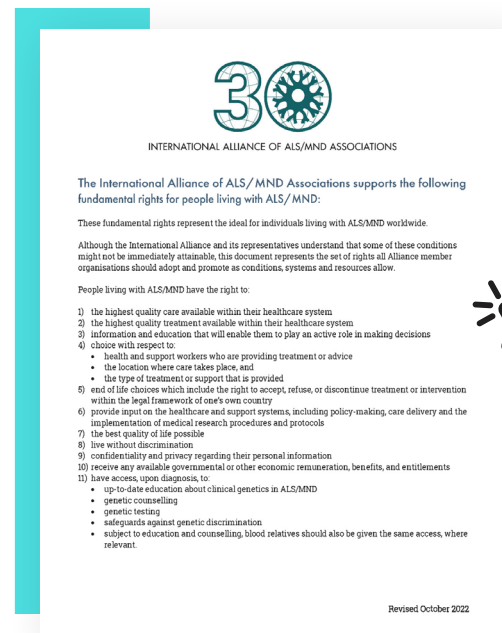
Our Members

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.

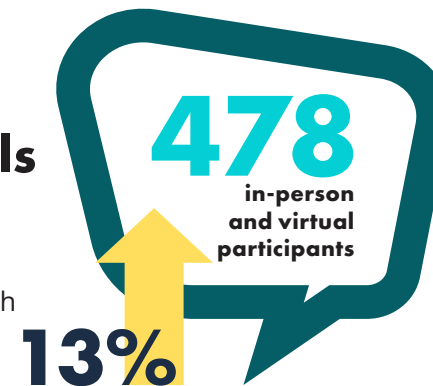
The Alliance Meeting

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 Tanabe 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 29th November 2022)
Lung Kuo
Dr Hilmi Uysal
Yohei Yamada (appointed 29th November 2022)
Sabine Turgeman (appointed 29th 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) 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
Income and Expenditure					
Income					
Donations and legacies:					
Donations and gifts		90,634	-	90,634	5,295
Grants and Sponsorships	1	129,153	-	129,153	183,199
Subscriptions	2	112,704	-	112,704	94,668
Investment Income:					
Interest Receivable		-	-	-	-
Charitable activities:					
Conference income		301,380	-	301,380	91,652
Total income		633,871	-	633,871	374,814
Expenditure					
Charitable activities:					
Awareness raising and publicity	3 & 4	585,958	-	585,958	345,565
Total expenditure	5 & 6	585,958	-	585,958	345,565
Net income & net movement in funds		47,913	-	47,913	29,249
Reconciliation of funds					
Fund balance brought forward at 1 July		163,581	-	163,581	134,332
Fund balance carried forward at 30 June	9	211,494	-	211,494	163,581

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 £
Current Assets			
Debtors & Prepayments	7	16,124	15,400
Cash at Bank		213,742	167,585
		229,866	182,985
Creditors:			
Amounts falling due within one year	8	18,372	19,404
Net Current Assets		211,494	163,581
Accumulated Funds			
Restricted Funds	10	-	-
Unrestricted Funds:			
General Fund		211,494	163,581
	9	211,494	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
	112,704	94,668

3 Charitable activities

Expenditure on charitable activities includes:

	2023 £	2022 £
Independent Examiner's remuneration	800	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 £	2023 £	2022 £
Membership	8,644	-	8,644	19,367
PALS & CALS	-	-	-	10,960
SAC	-	-	-	8,463
Stakeholder Development Costs	29,979	-	29,979	19,135
	38,623	-	38,623	57,924

Capability Expenditure

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

International Alliance of ALS/MND Associations

Capacity Expenditure

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

*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	-	64,363	61,172
Social security costs / taxation	30,640	-	30,640	30,575
Pension costs	0	-	0	0
Healthcare insurance	4,294	-	4,294	0
	99,297	-	99,297	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	-	-
	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	-
	18,372	19,404

International Alliance of ALS/MND Associations

9 Movements of funds

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

10 Analysis of net assets - movement in funds

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

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
Income and Expenditure					
Income					
Donations and legacies:					
Donations and gifts		5,295	-	5,295	662
Grants and Sponsorships	1	183,199	-	183,199	24,691
Subscriptions	2	94,668	-	94,668	81,255
Investment Income:					
Interest Receivable		-	-	-	44
Charitable activities:					
Conference income		91,652	-	91,652	57,549
Total income		374,814	-	374,814	164,202
Expenditure					
Charitable activities:					
Awareness raising and publicity	3 & 4	332,163	13,402	345,565	228,139
Total expenditure	5 & 6	332,163	13,402	345,565	228,139
Net income / (expenditure) & net movement in funds		42,651	(13,402)	29,249	(63,937)
Reconciliation of funds					
Fund balance brought forward at 1 July		120,930	13,402	134,332	198,239
Fund balance carried forward at 30 June	9	163,581	-	163,581	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 29th November 2022)
Lung Kuo
Dr Hilmi Uysal
Yohei Yamada (appointed 29th November 2022)
Sabine Turgeman (appointed 29th 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) 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
Income and Expenditure					
Income					
Donations and legacies:					
Donations and gifts		90,634	-	90,634	5,295
Grants and Sponsorships	1	129,153	-	129,153	183,199
Subscriptions	2	112,704	-	112,704	94,668
Investment Income:					
Interest Receivable		-	-	-	-
Charitable activities:					
Conference income		301,380	-	301,380	91,652
Total income		633,871	-	633,871	374,814
Expenditure					
Charitable activities:					
Awareness raising and publicity	3 & 4	585,958	-	585,958	345,565
Total expenditure	5 & 6	585,958	-	585,958	345,565
Net income & net movement in funds		47,913	-	47,913	29,249
Reconciliation of funds					
Fund balance brought forward at 1 July		163,581	-	163,581	134,332
Fund balance carried forward at 30 June	9	211,494	-	211,494	163,581

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 £
Current Assets			
Debtors & Prepayments	7	16,124	15,400
Cash at Bank		213,742	167,585
		229,866	182,985
Creditors:			
Amounts falling due within one year	8	18,372	19,404
Net Current Assets		211,494	163,581
Accumulated Funds			
Restricted Funds	10	-	-
Unrestricted Funds:			
General Fund		211,494	163,581
	9	211,494	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
	112,704	94,668

3 Charitable activities

Expenditure on charitable activities includes:

	2023 £	2022 £
Independent Examiner's remuneration	800	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 £	2023 £	2022 £
Membership	8,644	-	8,644	19,367
PALS & CALS	-	-	-	10,960
SAC	-	-	-	8,463
Stakeholder Development Costs	29,979	-	29,979	19,135
	38,623	-	38,623	57,924

Capability Expenditure

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

International Alliance of ALS/MND Associations

Capacity Expenditure

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

*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	-	64,363	61,172
Social security costs / taxation	30,640	-	30,640	30,575
Pension costs	0	-	0	0
Healthcare insurance	4,294	-	4,294	0
	99,297	-	99,297	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	-	-
	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	-
	18,372	19,404

International Alliance of ALS/MND Associations

9 Movements of funds

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

10 Analysis of net assets - movement in funds

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

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

THE INTERNATIONAL ALLIANCE OF ALS / MND ASSOCIATIONS

England & Wales - Charity number 1079504

Accounts

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 2022

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

Tammy Moore (until 10th November 2021)

Marcela Santos

Gudjon Sigurdsson

Evy Reviers

Gorrit Jan Blonk (until 10th November 2021)

Pablo Aquino

Nick Goldup

Andrea Pauls Backman

Lung Kuo (appointed 10th November 2021)

Dr Hilmi Uysal (appointed 10th November 2021)

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 Please note: Financial review examiner change was performed due to the growth in revenue and accounting governing body qualification requirements to perform a review of a business with this level of revenue
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 2022

The Directors present their report together with the financial statements for the year ended 30 June 2022.

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. The International Alliance aspires to:

Build Community

Build a global community. Identify, promote, and support meaningful and timely in person and virtual connections between Members. Prioritize building membership in countries and regions which do not yet have membership representation. Be the gateway for relevant external stakeholders. Coordinate the global voice of PALS & CALS.

Build Capability

Build capability in member associations by soliciting feedback to ensure we focus on issues that deliver impactful value. Encourage Member exchange of knowledge and facilitate discourse on issues. 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. Facilitate member peer-to-peer support. Be a gateway for external stakeholders to the network of domestic associations.

Achievements

This financial year was challenging due to the continuing impacts of COVID-19 and the Alliance continued to engage with and support its members through various opportunities such as roundtables and webinars.

International Alliance of ALS/MND Associations

Directors' Report

For the Year Ended 30 June 2022

- **Pandemic Response**
 - As the world went into lockdown in early 2020 the International Alliance very much adopted the motto “ALS /MND doesn't stop so neither will we!” The Alliance commenced holding webinars, roundtables and member meetings to discuss strategies to cope with the evolving situation and continue to deliver quality services to our community. As the pandemic continued through 2020 - 2021 the Alliance continued to meet virtually to provide member value including the Allied Professionals Forum and the Alliance Meeting. The spring of 2022 saw the reintroduction of in-person meetings.
- **Increasing awareness of ALS/MND**
 - 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) was completely overhauled to take a person centred approach in 2021 and reviewed mid-2022 to ensure that the changes made were validated through google analytics.
- **Exchange and disseminate information**
 - In December 2020, the Annual Meeting of the Alliance was held virtually. The Annual Meeting plays a key and enduring role in facilitating the exchange of information. The meeting was attended by 181 delegates representing organisational and individual members, as well as sponsors, observers and stakeholders.
 - In the 2020 – 2021 fiscal year a webinar series and member roundtables were introduced and continued in 2021- 2022. The webinars included: Sharing Success: Fireside Chat with 2021 Alliance Award Winner; Q&A with the Alliance's Scientific Advisory Council; Biomarkers in ALS/MND; Innovation and technology in ALS/MND; Youth and ALS/MND; Optimizing clinical trial design; Introduction to ALS/MND genetics; Genetics – Counselling & testing; Ethical considerations for genetics; Sharing Success: A Fireside chat with the 2021 Alliance winners; Global Survey Results; Care Part 1: What do I need to know at diagnosis; Care Part 2: What are my ongoing needs with ALS/MND?; Care Part 3: End of life; Cure Part 1: What do I need to know about clinical trials?. The roundtables were Improving Regulatory Pathways and Genetics Summit in October and June respectively.
 - The Alliance Meeting and the APF continued to be virtual in December 2021.
- **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 Dr Adriano Chio, a key contributor to the global understanding of ALS/MND and a leader in patient care! Adriano leads the Torino ALS Center
 - Canadian researcher, Dr. David Taylor, was awarded the 2021 Humanitarian Award from the International Alliance of ALS/MND Associations. This prestigious award honours Dr. Taylor's dedication to enhancing the quality of life for people living with ALS/MND around the world. There were two recipients of this year's Allied Health Professional Award: Dr. Melinda Kavanaugh and Sarah Solomon. Both are being recognized for the exceptional care they provide to people living with Amyotrophic Lateral Sclerosis/Motor Neurone Disease (ALS/MND)

International Alliance of ALS/MND Associations

Directors' Report

For the Year Ended 30 June 2022

Our goals for the year included

- Increase the number of ALS/MND Association worldwide
- The Annual International Alliance Meetings provide a unique opportunity for well-established member organisations to develop partnerships and collaborations with individuals interested in establishing an ALS/MND association in their own country or region.

Our achievements for the year included:

- Increasing membership by 2 associations
- Delivery of the Alliance Meeting virtually, in December 2021
- Delivery of the Allied Professionals Forum virtually in December 2021
- Ongoing growth and development of social media networks
- 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
- Delivering 3 stakeholder roundtables
- Delivering a minimum of 6 webinars
- Delivering statements/programs regularly from our Advisory Councils

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 2022 are set out in the Statement of Financial Activities, as shown on page 8.

There were net resources of £42,651 (2021 – net outgoing resources £59,661). 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 2022

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, especially due to the pandemic
- Incapacity or loss of key Staff
- Loss of key Directors
- Loss of IT infrastructure and support
- Breaches of governance and compliance requirements
- Breach of privacy.

The Directors are pleased to report that systems have been established 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 £163,581 and restricted funds of £0.00.

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 2022 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 2022

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 2022 was 62. Members have no beneficial interest in the charitable company.

Appointment of Independent Examiner

A resolution to appoint James Gourley as the examiner will be proposed at the 2022 Annual General Meeting.



Calaneet Balas
Chair

Date: November 21, 2022

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 2022, 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 Act

have 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.



Date: November 21, 2022

Jim Gourlay

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

The statement of financial activities includes all gains and losses recognised in the year. All incoming resources and resources expended derive from continuing activities.

International Alliance of ALS/MND Associations

Balance Sheet

As at 30 June 2022

	Notes	2022 £	2021 £
Current Assets			
Debtors & Prepayments	7	15,400	-
Cash at Bank		167,584	152,272
		182,985	152,272
Creditors:			
Amounts falling due within one year	8	19,404	17,940
Net Current Assets		163,581	134,332
Accumulated Funds			
Restricted Funds	10	-	13,402
Unrestricted Funds:			
General Fund		163,581	120,930
	9	163,581	134,332

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 2022.

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 10 to 19 were approved by the Board of Directors on 21 November, 2022 and were signed on their behalf by:



David Ali

Honorary Treasurer

Date: November 21, 2022

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 from 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

At 30 June 2022, there was one restricted fund. This is for the support and development of existing and potential member organisations, including grants: either towards the costs of travel and attendance at the Alliance Annual Meetings and International Symposium or to promote partnership and mentoring of member organisations.

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 £0 Grants and £183,199 worth of Sponsorship receivable during the year (2021: £24,691).

2 Income from subscriptions

	2022 £	2021 £
United Kingdom	16,087	18,906
Europe	26,088	19,543
Africa	100	100
Asia	3,579	3,619
North America	40,863	36,035
South America	847	668
Australasia	7,103	2,383
	<u>94,668</u>	<u>81,255</u>

3 Charitable activities

Expenditure on charitable activities includes:

	2022 £	2021 £
Independent Examiner's remuneration	<u>750</u>	<u>550</u>

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. Expenses were paid out of the funds of the charity to one Director for reimbursement of travel and accommodation expenses incurred in the course of their duties.

International Alliance of ALS/MND Associations

5 Total expenditure

Community Expenditure

	Unrestricted Funds £	Restricted Funds £	2022 £	2021 £
Membership	19,367	-	19,367	11,263
PALS & CALS	10,960	-	10,960	6,718
SAC	8,463	-	8,463	5,542
Other	19,135	-	19,135	11,986
	57,924	-	57,924	35,510

Capability Expenditure

	Unrestricted Funds £	Restricted Funds £	2022 £	2021 £
Advocacy	4,239	-	4,239	3,035
Annual Meeting	145,466	-	145,466	72,707
Education & Awareness	32,509	-	32,509	35,069
Other	19,135	-	19,135	9,771
	195,815	-	195,815	120,582

International Alliance of ALS/MND Associations

Capacity Expenditure

	Unrestricted Funds £	Restricted Funds £	2022 £	2021 £
Administration	40,617	13,402	54,019	54,954
Governance	37,334	-	37,334	16,148
Other	473	-	473	945
	<u>78,423</u>	<u>13,402</u>	<u>91,825</u>	<u>72,047</u>
Total Expenditure	<u>332.163</u>	<u>13.402</u>	<u>345.565</u>	<u>228.139</u>

6 Employee and trustee information

The average number of persons (FTE) employed by the charity during the year was 1.25. (2021 : 1.25) Employment costs for the year were:

	Unrestricted Funds £	Restricted Funds £	2022 £	2021 £
Gross wages and salaries	47,770	13,402	61,172	50,101
Statutory payments and health insurance	<u>30,576</u>	<u>-</u>	<u>30,576</u>	<u>26,511</u>
	<u>78,345</u>	<u>13,402</u>	<u>91,747</u>	<u>78,612</u>

International Alliance of ALS/MND Associations

7 Debtors & prepayments

	2022 £	2021 £
Prepayments	7,112	-
Accrued Income	8,288	-
Accrued Bank interest	-	-
	15,400	-

8 Creditors: Amounts falling due within one year

	2022 £	2021 £
Accruals	19,404	17,940
Salary costs	-	-
Deferred income	-	-
	19,404	17,940

9 Movements of funds

	General Fund £	Restricted Funds (Note 10) £	2022 £	2021 £
As at 1 July 2021	120,930	13,402	134,332	198,269
Net income / (expenditure)	42,651	(13,402)	29,249	(63,937)
As at 30 June 2022	163,581	-	163,581	134,332

International Alliance of ALS/MND Associations

10 Restricted funds

The income funds of the charity include restricted funds comprising the following unexpended balances of donations and grants held on trust to be applied for the specific purposes stated:

	Balance at 1 July 2021	Income	Expenditure	Balance at 30 June 2022
	£	£	£	£
City Swim	13,402	-	(13,402)	-
	<u>13,402</u>	<u>-</u>	<u>(13,402)</u>	<u>-</u>

Description of restricted funds

The Amsterdam City Swim donates 1% of their annual proceeds to the Alliance and 75% of all City Swim Foundation funds are restricted for partnership, support grants, website maintenance and marketing of programs. The other 25 % covers indirect costs such as personnel, printing etc to support these programs.

11 Analysis of net assets - movement in funds

	2021 Bfwd £	Restricted £	Unrestricted £	2022 Total £
Current Assets	152,271	(13,402)	44,115	182,985
Net Current Liabilities	(17,940)	-	(1,464)	(19,404)
Total Net Assets	<u>134,332</u>	<u>(13,402)</u>	<u>42,651</u>	<u>163,581</u>
Bfwd funds 1 st July 2021		13,402	120,930	134,332
Cfwd funds 30 th June 2022		<u>-</u>	<u>163,581</u>	

International Alliance of ALS/MND Associations

12 Covid 19

At the date on which the financial statements were approved, the full financial implications resulting from the Coronavirus (Covid-19) outbreak which has affected the world in 2020 and 2021 were uncertain. Based on an expected change in the charity's operational activities in the short term and, having assessed the possible impact of Covid-19 on the charity's projected income, expenditure and its assets, the Directors believe that the charity's assets are not materially impaired.

International Alliance of ALS/MND Associations
Statement of Financial Activities (incorporating an Income and Expenditure Account)
For the Year Ended 30 June 2021

	Notes	Unrestricted Funds £	Restricted Funds £	Total Funds 2021	Total Funds 2020
Income and Expenditure					
Income					
Donations and legacies:					
Donations and gifts		662	-	662	20,676
Grants and Sponsorships	1	24,691	-	24,691	17,353
Subscriptions	2	81,255	-	81,255	78,351
Investment Income:					
Interest Receivable		44	-	44	1,511
Charitable activities:					
Conference income		57,549	-	57,549	62,018
Total income		<u>164,202</u>	<u>-</u>	<u>164,202</u>	<u>179,908</u>
Expenditure					
Charitable activities:					
Awareness raising and publicity	3 & 4	223,863	-	223,863	207,549
Total expenditure	5 & 6	<u>223,863</u>	<u>-</u>	<u>223,863</u>	<u>207,549</u>
Net income / (expenditure) & net movement in funds		(59,661)	-	(59,661)	(27,641)
Reconciliation of funds					
Fund balance brought forward at 1 July		<u>180,591</u>	<u>13,402</u>	<u>193,993</u>	<u>232,521</u>
Fund balance carried forward at 30 June	9	<u>120,930</u>	<u>13,402</u>	<u>134,332</u>	<u>204,881</u>

THE INTERNATIONAL ALLIANCE OF ALS / MND ASSOCIATIONS

England & Wales - Charity number 1079504

Accounts

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 2021

International Alliance of ALS/MND Associations

Reference and Administrative details

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

Craig Stockton (resigned 11th Feb 21)

David Ali

Tammy Moore

Kiki Qu (resigned 19th Nov 20)

Marcela Santos (appointed 19th Nov 20)

Gudjon Sigurdsson

Evy Reviere

Gorrit Jan Blonk

Pablo Aquino

Nick Goldup

Andrea Pauls Bachman

Principal and Registered Office

Francis Crick House

6 Summerhouse Road

Moulton Park

Northampton

NN3 6BJ

Professional Advisers

Independent Examiner	Andrew Luke AWL Accounts 32 Woodland Avenue Paisley PA2 8BH
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Solicitor	Bates Wells Brathwaite
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Bankers	Lloyds Bank plc Public & Community Sector 3rd Floor 25 Gresham Street London EC2V 7HN
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International Alliance of ALS/MND Associations

Directors' Report For the Year Ended 30 June 2021

The Directors present their report together with the financial statements for the year ended 30 June 2021.

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. Individuals with a strong interest in the Alliance and ALS/MND are admitted to Associate Membership on the same terms and conditions as organisational Associate Members.

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. The International Alliance aspires to:

Build Community

Build a global community. Identify, promote, and support meaningful and timely in person and virtual connections between Members. Prioritize building membership in countries and regions which do not yet have membership representation. Be the gateway for relevant external stakeholders. Coordinate the global voice of PALS & CALS.

Build Capability

Build capability in member associations by soliciting feedback to ensure we focus on issues that deliver impactful value. Encourage Member exchange of knowledge and facilitate discourse on issues. 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. Facilitate member peer-to-peer support. Be a gateway for external stakeholders to the network of domestic associations.

Achievements

This financial year was unprecedented due to the advent and impacts of COVID-19 and the Alliance pivoted quickly introducing roundtables and webinars to support members through this difficult time.

International Alliance of ALS/MND Associations

Directors' Report

For the Year Ended 30 June 2021

- **Pandemic Response**
 - As the world went into lockdown in early 2020 the International Alliance very much adopted the motto “ALS /MND doesn't stop so neither will we!” The Alliance commenced holding webinars, roundtables and member meetings to discuss strategies to cope with the evolving situation and continue to deliver quality services to our community. As the pandemic continued through 2020 - 2021 the Alliance continued to meet virtually to continue to provide member value including the Allied Professionals Forum and the Alliance Meeting.
- **Increasing awareness of ALS/MND**
 - The Alliance has worked to raise awareness and engagement globally through the use of Facebook, Twitter, LinkedIn, Instagram and YouTube.
 - The Alliance's website (www.als-mnd.org) was completely overhauled to take a person centred approach.
- **Exchange and disseminate information**
 - In December 2020, the Annual Meeting of the Alliance was held virtually. The Annual Meeting plays a key and enduring role in facilitating the exchange of information. The meeting was attended by 181 delegates representing organisational and individual members, as well as sponsors, observers and stakeholders.
 - In the 2020 – 2021 fiscal year a webinar stream and member roundtables were introduced. The webinars included: Sharing Success: Fireside Chat with 2020 Alliance Award Winner; Q&A with the Alliance's Scientific Advisory Council; Telemedicine Best Practices in Care & Research; Biomarkers in ALS/MND. The roundtables were Genetics in ALS/MND and Innovation and Technology: Spectrum of Possibilities.
- **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.
 - At the virtual meeting, 16 reports describing new or different care and support initiatives were presented, exposing the audience to practical care initiatives from around the world.
- **Stimulate and support research**
 - The Allied Professionals' Forum (APF) is a one-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 Dr Ammar Al Chalabi an outstanding candidate whose contributions to research, literature, and patient care are unparalleled not only the local level but also at the global level. Ammar leads the team at King's MND Care and Research Centre in London, England.
 - The 2019 Humanitarian Award was presented to Carol Birks. Carol is a consummate professional who has dedicated over 20 years to ensuring quality care and support is provided to individuals living with MND not only in Australia and the Asia Pacific Region, but around the globe.
 - The Allied Health Professional Award was awarded to John Costello of Boston Children's Hospital. John's commitment to providing people living with ALS/MND with a voice is demonstrated in his many years of exceptional care and insatiable quest for knowledge. He is dedicated to educating both himself and others on the newest information and technology available.

International Alliance of ALS/MND Associations

Directors' Report

For the Year Ended 30 June 2021

Our goals for the year included

- Increase the number of ALS/MND Association worldwide.
- The Annual International Alliance Meetings provide a unique opportunity for well-established member organisations to develop partnerships and collaborations with individuals interested in establishing an ALS/MND association in their own country or region.

Our achievements for the year included:

- Increasing membership by 3 associations.
- Delivery of the Alliance Meeting virtually, in December 2020.
- Delivery of the Allied Professionals Forum virtually in December 2020.
- Ongoing growth and development of social media networks.
- 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
- Delivering 4 stakeholder roundtables.
- Delivering a minimum of 6 webinars.
- Defining how the Alliance can assist with local advocacy.
- Scoping the increase in Global Advocacy with the WHO and the United Nations.
- Delivering statements/programs regularly from our Scientific Advisory Council, PALS & CALS Advisory Council and Innovation and Technology Council.

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 2021 are set out in the Statement of Financial Activities, as shown on page 10.

There were net outgoing resources of £59,661 (2020 – net outgoing resources £27,640). 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:

All monies that have been put into the Restricted Fund are as a result of the expressed wishes of the donors/grantors. Unrestricted funds comprise the General Fund. Sufficient funds are to be held in Unrestricted Funds to allow the payment of any staff related costs for one full year together with three months average other expenditure. Based on this year's accounts the required level of reserves is estimated to be £74,000. As at 30 June 2021 the charity held total reserves of £134,332, of which £120,930 were unrestricted.

In the event that the total assets as reported on the balance sheet fall, or are projected to fall within three months, to a level of 110% of the amount needed to meet the expenditure commitments of the Reserves Policy the Directors will immediately review all expenditure programs including staffing levels. It should be noted this will be the last year of using this calculation given the Alliance will be phasing in a more sustainable Reserves Policy from 2021-22.

International Alliance of ALS/MND Associations

Directors' Report

For the Year Ended 30 June 2021

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 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, especially due to the pandemic
- Incapacity or loss of key Staff
- Loss of key Directors
- Loss of IT infrastructure and support
- Breaches of governance and compliance requirements
- Breach of privacy.

The Directors are pleased to report that systems have been established 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 £120,930 and restricted funds of £13,402.

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 and are appointed at the Annual General Meeting. The maximum number of Directors is eleven and the minimum number is five. At each Annual General Meeting one third of Directors retire by rotation subject to the length of term in office.

Induction and training for Directors is provided through internal resources and advice and guidance from existing Directors. An orientation session was held in January 2021 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 2021

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 2021 was 62. Members have no beneficial interest in the charitable company.

Appointment of Independent Examiner

A resolution to reappoint the examiner, Andrew Luke, will be proposed at the Annual General Meeting.



Calaneet Balas
Chair

Date: February 7, 2022

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 2021, 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 Act

have 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.



Date: 5/11/2021

ANDREW LUKE
AWL Accounts

International Alliance of ALS/MND Associations

Statement of Financial Activities (incorporating an Income and Expenditure Account) For the Year Ended 30 June 2021

	Notes	Unrestricted Funds £	Restrict ed Funds £	Total Funds 2021	Total Funds 2020
Income and Expenditure					
Income					
Donations and legacies:					
Donations and gifts		662	-	662	15,676
Grants and Sponsorships	1	24,691	-	24,691	14,000
Subscriptions	2	81,255	-	81,255	78,351
Investment Income:					
Interest Receivable		44	-	44	1,458
Charitable activities:					
Conference income		57,549	-	57,549	62,018
Total income		164,202	-	164,202	171,504
Expenditure					
Charitable activities:					
Awareness raising and publicity	3 & 4	223,286	4,853	228,139	205,756
Total expenditure	5 & 6	223,286	4,853	228,139	205,756
Net income / (expenditure) & net movement in funds		(59,084)	(4,853)	(63,937)	(34,252)
Reconciliation of funds					
Fund balance brought forward at 1 July		180,014	18,255	198,269	232,521
Fund balance carried forward at 30 June	9	120,930	13,402	134,332	198,269

The statement of financial activities includes all gains and losses recognised in the year. All incoming resources and resources expended derive from continuing activities.

International Alliance of ALS/MND Associations

Balance Sheet

As at 30 June 2021

	Notes	2021 £	2020 £
Current Assets			
Debtors & Prepayments	7	-	8,405
Cash at Bank		152,272	194,234
		152,272	202,639
Creditors:			
Amounts falling due within one year	8	17,940	4,370
Net Current Assets		134,332	198,269
Accumulated Funds			
Restricted Funds	10	13,402	18,255
Unrestricted Funds:			
General Fund		120,930	180,014
	9	134,332	198,269

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 2021.

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 10 to 19 were approved by the Board of Directors on 23rd September 2021 and were signed on their behalf by:

David Ali
Honorary Treasurer
Date: February 7, 2022

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 2015), 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 accrual's 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

At 30 June 2021, there was one restricted fund. This is for the support and development of existing and potential member organisations, including grants: either towards the costs of travel and attendance at the Alliance Annual Meetings and International Symposium or to promote partnership and mentoring of member organisations.

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

Notes to the Financial Statements

For the Year Ended 30 June 2021

1 Grants and sponsorships receivable

There were £0 Grants and £24,691 worth of Sponsorship receivable during the year (2020: £17,353).

2 Income from subscriptions

	2021 £	2020 £
United Kingdom	18,906	18,838
Europe	19,543	19,689
Africa	100	100
Asia	3,619	2,717
North America	36,035	34,063
South America	668	932
Australasia	2,383	2,012
	81,255	78,351

3 Charitable activities

Expenditure on charitable activities includes:

	2021 £	2020 £
Independent Examiner's remuneration	550	550

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. Expenses were paid out of the funds of the charity to one Director for reimbursement of travel and accommodation expenses incurred in the course of their duties.

International Alliance of ALS/MND Associations

Notes to the Financial Statements

For the Year Ended 30 June 2021

5 Total expenditure

Community Expenditure

	Unrestricted Funds £	Restricted Funds £	2021 £	2020 £
Membership	11,263	-	11,263	3,541
PALS & CALS	6,718	-	6,718	927
SAC	5,542	-	5,542	919
Other	11,986	-	11,986	250
	35,510	-	35,510	5,637

Capability Expenditure

	Unrestricted Funds £	Restricted Funds £	2021 £	2020 £
Advocacy	3,035	-	3,035	335
Annual Meeting	72,707	-	72,707	74,524
Education & Awareness	35,069	-	35,069	64,506
Other	9,771	-	9,771	5,224
	120,582	-	120,582	144,589

International Alliance of ALS/MND Associations

Notes to the Financial Statements

For the Year Ended 30 June 2021

Capacity Expenditure

	Unrestricted Funds £	Restricted Funds £	2021 £	2020 £
Administration	50,101	4,853	54,954	49,014
Governance	16,148	-	16,148	6,516
Other	945	-	945	-
	<u>67,194</u>	<u>4,853</u>	<u>72,047</u>	<u>55,530</u>
Total Expenditure	<u>223,286</u>	<u>4,853</u>	<u>228,139</u>	<u>205,756</u>

6 Employee and trustee information

The average number of persons (FTE) employed by the charity during the year was 1.25.
Employment costs for the year were:

	Unrestricted Funds £	Restricted Funds £	2020 £	2019 £
Gross wages and salaries	45,248	4,853	50,101	35,474
Statutory payments and health insurance	<u>26,511</u>	<u>-</u>	<u>26,511</u>	<u>13,104</u>
	<u>73,759</u>	<u>4,853</u>	<u>78,612</u>	<u>48,578</u>

International Alliance of ALS/MND Associations

Notes to the Financial Statements

For the Year Ended 30 June 2021

7 Debtors & prepayments

	2021 £	2020 £
Prepayments	-	-
Accrued bank interest	-	53
Accrued income - BioGen & AKO	-	8,353
Accrued income - City Swim	-	-
	<u>-</u>	<u>8,405</u>

8 Creditors: Amounts falling due within one year

	2020 £	2019 £
Accruals	17,940	3,370
Salary costs	-	-
Deferred income	-	-
	<u>17,940</u>	<u>3,370</u>

9 Movements of funds

	General Fund £	Restricted Funds (Note 10) £	2021 £	2020 £
As at 1 July 2020	180,014	18,255	198,269	232,521
Net income / (expenditure)	(59,084)	(4,853)	(63,937)	(34,252)
As at 30 June 2021	<u>120,930</u>	<u>13,402</u>	<u>134,332</u>	<u>198,269</u>

International Alliance of ALS/MND Associations

Notes to the Financial Statements

For the Year Ended 30 June 2021

10 Restricted funds

The income funds of the charity include restricted funds comprising the following unexpended balances of donations and grants held on trust to be applied for the specific purposes stated:

	Balance at 1 July 2020	Income	Expenditure	Balance at 30 June 2021
	£	£	£	£
City Swim	18,255	-	(4,853)	13,402
	<u>18,255</u>	<u>-</u>	<u>(4,853)</u>	<u>13,402</u>

Description of restricted funds

The Amsterdam City Swim donates 1% of their annual proceeds to the Alliance and 75% of all City Swim Foundation funds are restricted for partnership, support grants, website maintenance and marketing of programs. The other 25 % covers indirect costs such as personnel, printing etc to support these programs.

11 Analysis of net assets between funds

	Restricted Funds £	Unrestricted Funds £	Total Funds £
Fund balances at 30 June 2021 are represented by:			
Current assets	13,402	138,870	152,272
Other net current liabilities	-	17,940	17,940
Total net assets	<u>13,402</u>	<u>120,930</u>	<u>134,332</u>

International Alliance of ALS/MND Associations

Notes to the Financial Statements

For the Year Ended 30 June 2021

12 Covid 19

At the date on which the financial statements were approved, the full financial implications resulting from the Coronavirus (Covid-19) outbreak which has affected the world in 2020 and 2021 were uncertain. Based on an expected change in the charity's operational activities in the short term and, having assessed the possible impact of Covid-19 on the charity's projected income, expenditure and its assets, the Directors believe that the charity's assets are not materially impaired.