CHARITY REGISTRATION NUMBER: 1205000

Axial Spondyloarthritis International Federation

Report and Accounts

31 December 2024

GORDON & CO
Chartered Accountants and Business Advisors
4 Bloomsbury Square
London
WC1A 2RP

Axial Spondyloarthritis International Federation

Contents

Year ended 31 December 2024

	Page
Reference and administrative details	**1**
Trustees' annual report	**2**
Independent examiner’s report to the Trustees	**7**
Statement of financial activities	**8**
Statement of financial position	**9**
Notes to the accounts	**10**

Axial Spondyloarthritis International Federation

Reference and Administrative Details

Year ended 31 December 2024

Reference and administrative details

Registered charity name	Axial Spondyloarthritis International Federation	
Charity registration number	1205000	
Registered office	27 Old Gloucester Street London WC1N 3AX	
The trustees	Zhivko Yankov - Chair	(from 2 October 2023)
	Lillann Wermskog – Vice-Chair	(from 2 October 2023)
	Andri Phoka - Secretary	(from 2 October 2023)
	Susan Davies – Treasurer	(to 20 November 2024)
	Dr Tuncay Duruöz	(from 2 October 2023)
	Raj Mahapatra	(to 25 September 2024)
	Cassie Shafer	(from 2 October 2023)
	Maranda van Dam	(to 25 September 2024)
	Prachee Bhosle	(from 25 November 2024)
	Nadia Malliou	(from 25 November 2024)
	Julieth Buitrago	(from 25 November 2024)
	René Bräm	(from 1 February 2025)
Staff and volunteers	Mike Mandelbaum	Executive Director (to 15 November 2024)
	Jo Davies	Assistant Director
	Jo Lowe	Project Manager
	Joanne de Bry	Communications Manager
Advisor	Fiona Kerin	Accountant
Banker	HSBC UK Bank PLC 15 Wellington Street Woolwich London SE18 6PH	
Independent examiner	John Gordon FCA Gordon & Co 4 Bloomsbury Square London WC1A 2RP	

Axial Spondyloarthritis International Federation

Trustees' Annual Report

Year ended 31 December 2024

The Trustees present their report and the accounts of the charity for the year ended 31 December 2024.

Axial Spondyloarthritis International Federation ("ASIF") has been in existence as a charity since 1988. Following approval from the members at an AGM in 2022, the charity was registered as a Charitable Incorporated Organisation (CIO) on 2 October 2023.

Structure, governance and management

Constitution

ASIF is a charitable incorporated organisation (CIO), formed in 1988, comprising a world network of societies and associations representing patients suffering from Axial Spondyloarthritis ("axSpA"). These societies and associations are members of ASIF.

At an Annual General Meeting of the 'old' charity 1173902 held on 28 June 2023, member organisations gave in principle approval for the incorporation of the charity as a Charitable Incorporated Organisation (CIO). A CIO was subsequently established under a constitution dated 2 October 2023 and registered with the Charity Commission for England and Wales as charity number 1205000. The assets and activities of ASIF were transferred to the CIO with effect from 1 January 2024.

ASIF's constitution includes the requirement that a general meeting of all members of ASIF must be held annually, at which Trustees are elected to manage the affairs of the association.

The CIO constitution allows that Trustees can be either a nominated representative of a member organisation or other persons who are elected on the basis of relevant skills and experience that they will bring to the charity trustee board.

The constitution requires that there are a minimum of five Trustees and a maximum of twelve Trustees. Trustees are normally appointed for a term of three years and a maximum of three terms. At the first AGM held on 19 October 2024, the following Trustees were re-appointed for the following terms.

Tuncay Duruöz – 3 years
Cassie Shafer – 2 years
Lillann Wermskog – 2 years
Zhivko Yankov – 1 year
Andri Phoka – 1 year

At a meeting of the Trustees on 25 November 2024, Prachee Bhosle, Nadia Malliou and Julieth Buitrago were co-opted to the trustee board. Co-opted Trustees shall retire at the next AGM (October 2025) and can be nominated to stand for election.

Management

ASIF is overseen by the Trustees, who meet at least six times a year. Working with the staff team, the Trustees determine ASIF policies, decide on the strategic direction of ASIF and review existing

funds and set budgets for future expenditure. Decisions are made by a simple majority vote.

Trustees are entitled to claim reimbursement of expenses.

All staff transferred employment from the old charity to the new charity. ASIF underwent a TUPE (Transfer of Undertakings, Protection of Employment) process and carried out consultations as required.

Risk assessment

The Trustees have reviewed the risks faced by ASIF and have adopted appropriate policies to mitigate these risks. These risks are reviewed periodically by the Trustees. The Trustees believe that ASIF has sufficient resources for the time being to support its activities.

Objectives and activities

ASIF's mission is *A world where everyone affected by axSpA lives their best life.*

The Object of the Charity is:

"The relief of sickness and preservation of health by advancing the diagnosis and treatment of persons suffering from, Axial Spondyloarthritis and its related conditions throughout the world through promoting awareness and funding and encouraging research into, the causes, diagnosis and effective treatments of Axial Spondyloarthritis and its related conditions throughout the world and disseminating the results of such research worldwide."

ASIF seeks to achieve this objective through organising conferences for member organisations, running global projects and disseminating information to members and the public, and through making presentations to and working with affiliated groups including representatives of the pharmaceutical industry.

Achievements and performance

In 2024 ASIF continued to develop its major projects:

ASIF Council Meeting

In October 2024 the ASIF Council Meeting was held in Bogotá, Colombia. A hugely successful event attended by member representatives from over 25 countries, many members attending for the first time.

The programme included sessions by eminent rheumatologists, other stakeholders and by members themselves. The sessions were a mix of presentations and workshops. All present welcomed the opportunity to meet face to face and recognised the importance of building a global network to drive change.

As the meeting was in Colombia, the opportunity was taken to hold a one-day meeting, the day before the main Council Meeting, for ASIF Latin American members and other representatives

from the region. This meeting was organised in collaboration with ASOPAN, a network of patient organisations in Latin America. ASIF and ASOPAN signed a memorandum of understanding to enhance their collaboration.

World AS Day

WAS Day remains our main annual global awareness campaign. In 2024 the social media campaign reached an incredible 9.45 million people and over 67,000 visits to ASIF's website pages. The campaign tools were made available, ready to use, to our members, with the ability for them easily to translate the language and add their own organisational branding.

This year's theme focused on signs and symptoms of axSpA. Six £500 grants for social media boosting were offered to members for the first time. And support to learn about social media boosting and how to measure impact was offered to all members.

Many members and industry partners held events including webinars. The Spondylitis Association of America ran the annual Global Spondyloarthritis Summit which provides insightful presentations for people affected by axSpA.

IMAS - the International Map of Axial Spondyloarthritis

In January 2024, the Global IMAS report was published, highlighting the key messages from the IMAS findings. We had six IMAS posters at the Spondyloarthritidies congress in Ghent, plus a poster at ACR and three at EULAR.

As of 2 January 2024 IMAS ownership was transferred from Novartis to ASIF. ASIF was started at the University of Seville by Prof Marco Garrido-Cumbrera and ASIF signed a new services agreement with University of Seville, where we will continue to work with Marco and his team on data analysis and dissemination.

In June we held a *Spotlight on IMAS* event in Vienna which brought together people living with axSpA, representatives from patient organisations, rheumatologists, researchers and some of our industry partners. We provided an overview of IMAS, explored the IMAS findings and their real-life impact. The keynote speech was given by Victoria Navarro-Compan, who was president elect of ASAS (Assessment of Spondyloarthritis International Society).

Delay to Diagnosis

We continued to disseminate the assets that were created at the end of 2023. At the heart of the campaign were three short films, all raising awareness of the disease. These films were part of a toolkit of materials, including social media posts, messages, quote cards and infographics. The films are now available in ten languages. This campaign is not time-limited, and can continued to be used by ASIF and its members as long as it is relevant.

Plans for future periods

Plans for 2025
ASIF's plans for 2025 include:

- Continue to build a regional focus;
- Develop ASIF's research partnership potential;
- Create an Expert Advisory Committee;
- Decide on the strategic direction and next steps for IMAS;
- Continue the development of the Delay to Diagnosis programme with a particular focus on addressing the barrier relating to HCP awareness and education;
- Develop a psychosocial support network; and
- Continue to grow and develop the membership.

Financial review

Overview
During the year ASIF's total income was £329,517 of which £314,350 was grant income. Grant income includes £92,701 restricted to specific activities.

ASIF's total expenditure was £419,477 including £415,517 spent on charitable activities.

Investment performance
ASIF's funds are held with HSBC. A proportion of these funds are held on deposit. Trustees have approved the opening of a bank account at the Charities Aid Foundation (CAF Bank) during 2025.

Fundraising
ASIF does not seek to raise funds direct from the public; instead it solicits support from the pharmaceutical industry and from associated institutions and charitable organisations.

Reserves
At the end of 2024 restricted funds carried forward totalled £17,050 and unrestricted funds carried forward totalled £229,994 represents grant and sponsorship income from pharmaceutical partners for on-going projects.

The restricted funds are those amounts set aside to fund specific projects for which grants from pharmaceutical companies and other interested institutions are solicited. The unrestricted funds represent accumulated surplus income and unrestricted sponsorship funding and can be expended in accordance with ASIF's objectives without further restriction.

Statement of Trustees' responsibilities

The Trustees are responsible for preparing a Trustees' Annual Report and accounts in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

Trustees are required to prepare accounts for each financial year which give a true and fair view of the state of affairs of ASIF and of the incoming resources and application of funds for that year. In preparing those accounts, the Trustees are required to:

- select suitable accounting policies and then apply them consistently;
- observe the methods and principles in the applicable accounting standards;
- make judgements and accounting estimates that are reasonable and prudent;
- state whether applicable accounting standards have been followed, subject to any material departures disclosed and explained in the accounts; and
- prepare the accounts on a going concern basis unless it is inappropriate to presume that ASIF will continue in operation.

The Trustees are responsible for keeping proper accounting records that are sufficient to show and explain the transactions undertaken and to disclose with reasonable accuracy at any time the financial position of ASIF and to enable them to ensure that the accounts comply with relevant regulations and the provisions of the Constitution. They are also responsible for safeguarding the assets of ASIF and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

The Trustees are responsible for the maintenance and integrity of the financial information included on ASIF's website. Legislation in the United Kingdom governing the preparation and dissemination of accounts may differ from legislation in other jurisdictions.

Independent examiner

John Gordon FCA is the charity's independent examiner.

The Trustees' Annual Report was approved on 26 May 2025 and signed on behalf of the board of Trustees by:

Andri Phoka
Secretary

Axial Spondyloarthritis International Federation

Independent Examiner's Report to the Trustees of Axial Spondyloarthritis International Federation

Year ended 31 December 2024

I report to the Trustees on my examination of the accounts of Axial Spondyloarthritis International Federation ('the charity') for the year ended 31 December 2024.

Responsibilities and basis of report

As the Trustees of the charity 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 charity's accounts carried out under section 145 of the 2011 Act and in carrying out my examination I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

Independent examiner's statement

Since the charity's gross income exceeded £250,000 your examiner must be a member of a body listed in section 145 of the 2011 Act. I confirm that I am qualified to undertake the examination because I am a member of the Institute of Chartered Accountants in England and Wales (ICAEW), which is one of the listed bodies.

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 charity 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.

John Gordon FCA
Independent Examiner

4 Bloomsbury Square
London
WC1A 2RP

26 May 2025

Axial Spondyloarthritis International Federation

Statement of Financial Activities

Year ended 31 December 2024

	Note	2024 Unrestricted funds £	2024 Restricted funds £	2024 Total funds £
Incoming resources				
Donations and subscriptions	**5**	5,018	–	5,018
Grants received	**6**	221,649	92,701	314,350
Investment income	**7**	10,149	–	10,149
Total incoming resources		236,816	92,701	329,517
Expenditure				
Expenditure on charitable activities		303,844	111,673	415,517
Governance costs	**8**	3,960	–	3,960
Total resources expended		307,804	111,673	419,477
Net movement in funds	**9**	(70,988)	(18,972)	(89,960)
Funds transferred on 1 January 2024	**4**	283,932	36,022	319,954
Total funds carried forward	**15**	212,944	17,050	229,994

The statement of financial activities includes all gains and losses recognised in the year.
All income and expenditure derive from continuing activities.

The notes on pages 10 to 15 form part of these accounts.

Axial Spondyloarthritis International Federation

Statement of Financial Position

31 December 2024

	Note	2024 £
Current assets		
Debtors	**13**	17,050
Cash at bank and in hand		223,442
		240,492
Creditors: amounts falling due within one year		10,498
Total assets less current liabilities		229,994
Net assets		229,994
Funds of the charity		
Restricted funds		17,050
Unrestricted funds		212,944
Total charity funds	**16**	229,994

These accounts were approved by the board of Trustees and authorised for issue on 26 May 2025, and are signed on behalf of the board by:

Zhivko Yankov
Chair

Andri Phoka
Secretary

The notes on pages 10 to 15 form part of these accounts.

1. General information

The charity is a public benefit entity and a registered charitable incorporated organisation (CIO) in England and Wales and is. The address of the registered office is 27 Old Gloucester Street, London, WC1N 3AX.

2. Statement of compliance

These accounts have been prepared in compliance with the Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Charities Act 2011.

3. Accounting policies

Basis of preparation

The accounts have been prepared on the historical cost basis, as modified by the revaluation of certain financial assets and liabilities and investment properties measured at fair value through income or expenditure.

The accounts are prepared in Sterling, which is the functional currency of the charity. Monetary amounts in these accounts are rounded to the nearest £1.

Going concern

There are no material uncertainties about the charity's ability to continue.

Judgements and key sources of estimation uncertainty

The preparation of the accounts requires management to make judgements, estimates and assumptions that affect the amounts reported. These estimates and judgements are continually reviewed and are based on experience and other factors, including expectations of future events that are believed to be reasonable under the circumstances.

Foreign currencies

Foreign currency transactions are initially recorded in the functional currency, by applying the spot exchange rate as at the date of the transaction. Monetary assets and liabilities denominated in foreign currencies are translated at the exchange rate ruling at the reporting date, with any gains or losses being taken to the statement of financial activities.

Fund accounting

Restricted funds are maintained where the funds raised are to be used for specific purposes. Accumulated surplus income, which forms the Fund's reserves, is retained in unrestricted funds. Reserves are maintained to meet the Fund's continuing obligations and to cater for future needs and contingencies. Unrestricted funds comprise those funds which the Trustees are free to use for any purposes in furtherance of the charitable objects.

Incoming resources

All incoming resources are included in the statement of financial activities when entitlement has passed to the charity; it is probable that the economic benefits associated with the transaction will flow to the charity and the amount can be reliably measured. The following specific policies are applied to particular categories of income:

- grants received from pharmaceutical companies towards shared costs are included in the Statement of Financial Activities when received or deferred to the extent that they relate to future accounting periods;

- income from donations is recognised when there is evidence of entitlement to the gift, receipt is probable and its amount can be measured reliably; and

- donated facilities and services are recognised in the accounts when received if the value can be reliably measured. No amounts are included for the contribution of general volunteers.

Resources expended

Expenditure is recognised on an accruals basis as a liability is incurred. Expenditure includes any VAT which cannot be fully recovered, and is classified under headings of the statement of financial activities to which it relates:

- expenditure on charitable activities includes all costs incurred by a 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; and

- other expenditure includes all expenditure that is neither related to raising funds for the charity nor part of its expenditure on charitable activities.

All costs are allocated to expenditure categories reflecting the use of the resource. Direct costs attributable to a single activity are allocated directly to that activity. Shared costs are apportioned between the activities they contribute to on a reasonable, justifiable and consistent basis.

Financial instruments

A financial asset or a financial liability is recognised only when the entity becomes a party to the contractual provisions of the instrument.

Basic financial instruments are initially recognised at the amount receivable or payable including any related transaction costs, unless the arrangement constitutes a financing transaction, where it is recognised at the present value of the future payments discounted at a market rate of interest for a similar debt instrument.

Current assets and current liabilities are subsequently measured at the cash or other consideration expected to be paid or received and not discounted.

Debt instruments are subsequently measured at amortised cost.

4. Transfer of funds

On 1 January 2024 the unrestricted and restricted funds from Axial Spondyloarthritis International Federation (charity number 1173902) were transferred into the charity.

5. Donations and subscriptions

	Unrestricted Funds £	Total Funds 2024 £
Donations		
Donations	1,219	1,219
Council meeting fees	3,799	3,799
	5,018	5,018

6. Grants received

	Unrestricted Funds £	Restricted Funds £	**Total Funds 2024 £**
Pharma grants - unrestricted	221,649	–	221,649
Pharma grants - restricted	–	92,701	92,701
	221,649	92,701	314,350

7. Investment income

	Unrestricted Funds £	**Total Funds 2024 £**
Other interest receivable	10,149	10,149

8. Governance costs

	Unrestricted Funds	Total Funds 2024
	£	£
Accountancy fees	2,400	2,400
Independent examination fees	1,560	1,560
	3,960	3,960

9. Net income

Net income is stated after charging:

	2024
	£
Foreign exchange differences	5,730

10. Independent examination fees

	2024
	£
Fees payable to the independent examiner for:	
Independent examination of the accounts	1,560

11. Staff costs

The average monthly number of employees (excluding trustees) during the year was:

	2024
Administration and organisation	4

	Unrestricted Funds	Total Funds 2024
	£	£
Wages and salaries	224,582	224,582
Social security costs	13,235	13,235
Other pension costs	10,145	10,145
	247,961	247,961

The number of employees whose employee benefits for the reporting period fell within the band £100,001-£110,000 was one. No other employees received employee benefits of more than £60,000.

12. Trustee remuneration and expenses

In the reporting period, six Trustees were reimbursed a total of £13, 922.97, for expenses incurred for travel, accommodation and subsistence, whilst on charity business.

13. Debtors

	2024
	£
Other debtors	17,050
	17,050

14. Creditors: amounts falling due after more than one year

	2024
	£
Accruals and deferred income	10,498

15. Analysis of charitable funds

Unrestricted funds

	At 1 January 2024	Income	Expenditure	Transfer (to) / from restricted funds	**At 31 December 2024**
	£	£	£	£	£
General funds	283,932	236,816	(143,599)	(164,205)	212,944

General funds of £283,932 were transferred from charity 1173902 on 1 January 2024.

Restricted funds

	At 1 January 2024	Income	Expenditure	Transfer (to) / from unrestricted funds	**At 31 December 2024**
	£	£	£	£	£
World AS Day (WAS Day)	-	-	(53,781)	53,781	-
International Map of Axial Spondyloarthritis (IMAS)	36,022	29,954	(94,249)	28,273	-
Delay to Diagnosis (D2D)	-	12,913	(28,798)	15,885	-
Other	-	49,834	(99,050)	66,266	17,050
	36,022	92,701	(275,878)	164,205	17,050

Restricted funds of £36,022 were transferred from charity 1173902 on 1 January 2024.

Analysis of charitable funds (continued)

World AS Day (WAS Day)
This is an annual global world health day used to raise awareness of axSpA worldwide through a social media campaign and global online events.

International Map of Axial Spondyloarthritis (IMAS)
This is a project managed by ASIF in partnership the University of Seville. IMAS is a global survey which generates and disseminates evidence about how people with axSpA experience their disease physically, psychologically and socially.

As of 2 January 2024, the International Map of axSpA is owned solely by the Axial Spondyloarthritis International Federation following an in-kind donation of the project by Novartis Pharma AG.

The value of the assets received by ASIF cannot be reliably measured and therefore no value is assigned to them in these accounts.

Delay to Diagnosis (D2D)
The objectives of this project are to significantly reduce the average time to diagnosis internationally; and to globally raise awareness about the disease and the detrimental effects of the delay, physically, psychologically and economically. In 2021 we produced a Global Burden Statement and built awareness and advocacy tools for our members.

Other
This includes: i) The ASIF Council meeting that happens every two years and ii) support of the AbbVie research project into the ASAS Quality Standards in axSpA.

16. Analysis of net assets between funds

	Unrestricted Funds	Restricted Funds	**Total Funds 2024**
	£	£	**£**
Current assets	223,442	17,050	240,492
Creditors less than 1 year	(10,498)	–	(10,498)
Net assets	212,944	17,050	229,994