



Axial Spondyloarthritis International Federation

Report and Accounts

31 December 2022

GORDON & CO

Chartered Accountants and Business Advisors
4 Bloomsbury Square
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Axial Spondyloarthritis International Federation

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Year ended 31 December 2022

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Axial Spondyloarthritis International Federation

Reference and Administrative Details

Year ended 31 December 2022

Reference and administrative details

Registered charity name	Axial Spondyloarthritis International Federation	
Charity registration number	1173902	
Registered office	27 Old Gloucester Street London WC1N 3AX	
The Trustees	Zhivko Yankov Andri Phoka Thierry Vannier Lillann Wermskog Ruta Grigiene Cassandra Shafer Dr Tuncay Duruoz Raj Mahapatra Aleksi Sitalo Maranda van Dam	President Secretary Treasurer To May 2022 From 31 May 2022
Staff and volunteers	Jo Davies Jo Lowe Joanne de Bry Valeria Tassi Michael Mallinson - volunteer	Assistant director Project manager Communications manager Administration assistant Membership
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 2022

The Trustees present their report and the accounts of the charity for the year ended 31 December 2022.

Axial Spondyloarthritis International Federation ("ASIF") was registered as a charity in England and Wales on 21 July 2017.

Structure, governance and management

Constitution

ASIF is an unincorporated association, 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.

ASIF's constitution, adopted on 8 October 2016 and amended on 16 June 2017, 12 June 2019 and 29 July 2019, 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 constitution requires that there are a minimum of five Trustees and a maximum of ten. Trustees are appointed for a term of four years. Current practice is that a Trustee may serve two terms before stepping down from the Board.

Management

ASIF is overseen by the Trustees, who meet at least six times a year. Working with the staff team, the Trustees determine and implement ASIF policies, decide on the appropriateness and timing of projects, 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.

ASIF has started to expand its staff team. In 2020 a Project Manager and an Administration Assistant joined the team, and in 2021 a Communications Manager was recruited. During 2022 Trustees decided that ASIF would now benefit from the appointment of an Executive Director to lead the newly formulated strategic plan. The recruitment campaign started in September 2022 and a candidate, Mike Mandelbaum, was appointed at the end of the year to start in 2023.

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 to advocate globally to improve the lives of people affected by Axial Spondyloarthritis and related conditions, and to grow, strengthen and empower our community, and to raise awareness around the world.

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Trustees' Annual Report

Year ended 31 December 2022

The Objects of the Charity, as adopted at a Special General Meeting in June 2017, and amended in June 2019, are:

"The relief of sickness and preservation of health by advancing the diagnosis of, and treatment of persons suffering from, Axial Spondyloarthritis and its related conditions throughout the world through promoting awareness of 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 2022 ASIF continued to develop its major projects:

ASIF Council Meeting

2022 saw the very welcome return of the ASIF Council Meeting in Copenhagen from 29 to 31 May. The opportunity to meet face to face was embraced by 40 representatives from 23 member organisations and a further five organisations were represented online. 26 countries were represented at the meeting.

There were sessions on ASIF's projects and on the latest developments in axSpA research. We also provided opportunities for members to present what they are doing and there were workshops on a variety of subjects. This year ASIF funded some members to send one person to the meeting; to qualify for assistance, we asked that their organisation had not been represented at a previous ASIF Council Meeting and they employ no staff. Five members took advantage of this offer.

World AS Day

WAS Day remains our main annual global awareness campaign. In 2022 the social media campaign again reached an incredible 11.5 million people. From that there were over 1.5 million engagements with ASIF's Facebook, Instagram and Twitter pages and over 33,000 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 raising awareness about axSpA rather than a specific issue.

IMAS - the International Map of Axial Spondyloarthritis

IMAS is the largest patient survey in axSpA that has ever been carried out. It brings together patients, patient organisations, medical experts and researchers from around the world to address the questions that matter most to patients about their disease - with the aim of shaping discussions towards improving patients' quality of life.

In 2022, the global element of the survey was completed. In total 5,557 people have completed the

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survey providing a unique insight into how axSpA affects daily life.

The data collected continues to be presented all around the world at rheumatology congresses and it is used by researchers and healthcare professionals worldwide to illustrate a range of issues affecting axSpA patients.

Having looked at the survey results, a campaign called Talk to be Heard was developed. The aim was to change the dialogue between people living with axSpA and their support system; from friends and family, to their rheumatologists and other caregivers.

The campaign was predominantly a social media campaign based around four videos featuring people living with axSpA talking about relationships, mental health, working life and personal goals. To support members running the campaign, ASIF produced fully translated patient organisation toolkits. The campaign was run by 22 national patient organisations and was seen in 19 countries across 6 continents with the content available in 13 languages.

Delay to Diagnosis

2022 saw the development of the next phase of the Delay to Diagnosis project. We sought to identify which of the six barriers identified in the report ASIF should focus on to reduce the diagnostic delay. The newly-formed steering committee met in March and a workshop was held during the Council Meeting in Copenhagen at which members were invited to give their thoughts on the priorities.

The outcome was that the recommended barriers the next programme of work should focus on were:

- Limited awareness among those with symptoms and among the wider population;
- Incorrect diagnosis at the first point of healthcare system contact; and
- Challenges within rheumatology.

The recommended next steps agreed on were the development of delay to diagnosis content for members including 2-3 patient videos, key facts/impact leaflet and social media template resources. The second priority agreed on was the development of a delay to diagnosis best-practice repository.

Work on all these programme areas started towards the end of 2022.

Strategic Planning

In October 2022 Trustees met face to face for an Away Day. The purpose of that meeting was to look at the governance of ASIF and the trustee role and at ASIF's work overall in the context of the new strategic plan.

Plans for future periods

Plans for 2023

It is anticipated that the new Executive Director will lead ASIF into a new phase, working with staff and trustees to grow the organisation and implement the strategic plan.

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Year ended 31 December 2022

World AS Day will continue to develop and grow.

The IMAS global report will be developed and launched in 2023.

The agreed next phases of the Delay to Diagnosis project will continue to be developed. The videos will be launched after World AS Day.

A full suite of member resources will be launched in 2023. These cover both information about axSpA and living with axSpA and also how to run a patient organisation covering topics such as fundraising and social media and how to start a patient organisation.

Financial review

Overview

During the year ASIF's total income was £378,330 (2021 - £352,443) of which £372,183 (2021 - £343,767) was grant income. Grant income includes £190,640 (2021 - £194,565) restricted to specific activities.

ASIF's total expenditure was £394,913 (2021 - £292,666) including £381,675 (2021 - £287,912) spent on charitable activities.

Investment performance

ASIF's funds are held with HSBC. A proportion of these funds are held on deposit.

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 2022 restricted funds carried forward totalled £88,901 (2021 - £95,299) and unrestricted funds carried forward totalled £209,304 (2021 - £218,789). This 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).

Axial Spondyloarthritis International Federation

Trustees' Annual Report

Year ended 31 December 2022

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 22 May 2023 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 2022

I report to the Trustees on my examination of the accounts of Axial Spondyloarthritis International Federation ('the charity') for the year ended 31 December 2022.

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

22 May 2023

Axial Spondyloarthritis International Federation

Statement of Financial Activities

Year ended 31 December 2022

			2022		2021
	Note	Unrestricted funds £	Restricted funds £	Total funds £	Total funds £
Incoming resources					
Donations and subscriptions	4	6,114	–	6,114	8,672
Grants received	5	181,543	190,640	372,183	343,767
Investment income	6	33	–	33	4
Total incoming resources		<u>187,690</u>	<u>190,640</u>	<u>378,330</u>	<u>352,443</u>
Expenditure					
Expenditure on charitable activities		183,937	197,738	381,675	287,912
Governance costs	7	13,238	–	13,238	4,754
Total resources expended		<u>197,175</u>	<u>197,738</u>	<u>394,913</u>	<u>292,666</u>
Net movement in funds	8	<u>(9,485)</u>	<u>(7,098)</u>	<u>(16,583)</u>	<u>59,777</u>
Total funds brought forward		218,789	95,299	314,088	254,311
Total funds carried forward	14	<u>209,304</u>	<u>88,201</u>	<u>297,505</u>	<u>314,088</u>

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 16 form part of these accounts.

Axial Spondyloarthritis International Federation

Statement of Financial Position

31 December 2022

	Note	2022 £	2021 £
Current assets			
Debtors	12	-	67,000
Cash at bank and in hand		379,024	298,242
		<u>379,024</u>	<u>365,242</u>
Net current assets		<u>379,024</u>	<u>365,242</u>
Total assets less current liabilities		<u>379,024</u>	<u>365,242</u>
Creditors: amounts falling due after more than one year	13	<u>81,519</u>	<u>51,154</u>
Net assets		<u><u>297,505</u></u>	<u><u>314,088</u></u>
Funds of the charity			
Restricted funds		88,201	95,299
Unrestricted funds		<u>209,304</u>	<u>218,789</u>
Total charity funds	14	<u><u>297,505</u></u>	<u><u>314,088</u></u>

These accounts were approved by the board of Trustees and authorised for issue on 22 May 2023, and are signed on behalf of the board by:



Zhivko Yankov
Chairman



Andri Phoka
Secretary



Thierry Vannier
Treasurer

The notes on pages 10 to 16 form part of these accounts.

Axial Spondyloarthritis International Federation

Notes to the Accounts

Year ended 31 December 2022

1. General information

The charity is a public benefit entity and a registered charity in England and Wales and is unincorporated. 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 FRS 102, 'The Financial Reporting Standard applicable in the UK and the Republic of Ireland', the Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (Charities SORP (FRS 102)) and 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.

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Notes to the Accounts

Year ended 31 December 2022

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.

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Notes to the Accounts

Year ended 31 December 2022

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. Donations and subscriptions

	Unrestricted Funds £	Total Funds 2022 £	Unrestricted Funds £	Total Funds 2021 £
Donations				
Donations	771	771	8,672	8,672
Council meeting fees	5,343	5,343	-	-
	<u>6,114</u>	<u>6,114</u>	<u>8,672</u>	<u>8,672</u>

The charity no longer charges a subscription fee for membership.

5. Grants received

	Unrestricted Funds £	Restricted Funds £	Total Funds 2022 £
Pharma grants - unrestricted	181,543	-	181,543
Pharma grants - restricted	-	190,640	190,640
	<u>181,543</u>	<u>190,640</u>	<u>372,183</u>

	Unrestricted Funds £	Restricted Funds £	Total Funds 2021 £
Pharma grants - unrestricted	149,202	-	149,202
Pharma grants - restricted	-	194,565	194,565
	<u>149,202</u>	<u>194,565</u>	<u>343,767</u>

Axial Spondyloarthritis International Federation

Notes to the Accounts

Year ended 31 December 2022

6. Investment income

	Unrestricted Funds	Total Funds 2022	Unrestricted Funds	Total Funds 2021
	£	£	£	£
Other interest receivable	33	33	4	4
	<u>33</u>	<u>33</u>	<u>4</u>	<u>4</u>

7. Governance costs

	Unrestricted Funds	Total Funds 2022	Unrestricted Funds	Total Funds 2021
	£	£	£	£
Accountancy fees	2,568	2,568	3,800	3,800
Independent examination fees	1,032	1,032	954	954
Trustee meetings	9,638	9,638	-	-
	<u>13,238</u>	<u>13,238</u>	<u>4,754</u>	<u>4,754</u>

8. Net income

Net income is stated after crediting:

	2022	2021
	£	£
Foreign exchange differences	<u>8,060</u>	<u>142</u>

9. Independent examination fees

	2022	2021
	£	£
Fees payable to the independent examiner for: Independent examination of the accounts	<u>1,032</u>	<u>954</u>

10. Staff costs

ASIF has not employed any staff as yet and does not have a payroll. There are four people involved with ASIF who are contracted on a part-time, self-employed basis.

11. Trustee remuneration and expenses

No remuneration or other benefits from the charity were received by the Trustees.

Axial Spondyloarthritis International Federation

Notes to the Accounts

Year ended 31 December 2022

12. Debtors

	2022 £	2021 £
Prepayments and accrued income	-	-
Other debtors	-	67,000
	<u>-</u>	<u>67,000</u>

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

	2022 £	2021 £
Accruals and deferred income	81,519	51,154
	<u>81,519</u>	<u>51,154</u>

14. Analysis of charitable funds

Unrestricted funds

	At 1 January 2022 £	Income £	Expenditure £	At 31 December 2022 £
General funds	218,789	187,690	(197,175)	209,304

	At 1 January 2021 £	Income £	Expenditure £	At 31 December 2021 £
General funds	149,289	149,475	(79,975)	218,789

Restricted funds

	At 1 January 2022 £	Income £	Expenditure £	At 31 December 2022 £
World AS Day (WAS Day)	11,625	42,000	(53,625)	-
International Map of Axial Spondyloarthritis (IMAS)	59,327	78,261	(52,510)	85,078
Delay to Diagnosis (D2D)	-	42,814	(42,814)	-
Other	24,347	27,565	(48,789)	3,123
	<u>95,299</u>	<u>190,640</u>	<u>(197,738)</u>	<u>88,201</u>

Axial Spondyloarthritis International Federation

Notes to the Accounts

Year ended 31 December 2022

Restricted funds (continued)

	At 1 January 2021 £	Income £	Expenditure £	At 31 December 2021 £
World AS Day (WAS Day)	26,889	34,783	(50,047)	11,625
International Map of Axial Spondyloarthritis (IMAS)	40,166	52,174	(33,013)	59,327
Delay to Diagnosis (D2D)	18,320	59,782	(78,102)	-
Other	19,647	47,826	(43,126)	24,347
	<u>105,022</u>	<u>194,565</u>	<u>(204,288)</u>	<u>95,299</u>

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 that ASIF manages in partnership with Novartis and 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.

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) Member Resources – the creation of a suite of information resources for members about axSpA and about creating and running a patient organisation; and ii) the drafting of a Strategic Plan 2022 – 2028.

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Year ended 31 December 2022

15. Analysis of net assets between funds

	Unrestricted Funds £	Restricted Funds £	Total Funds 2022 £
Current assets	290,823	88,201	379,024
Creditors less than 1 year	(81,519)	–	(81,519)
Net assets	<u>209,304</u>	<u>88,201</u>	<u>297,505</u>

	Unrestricted Funds £	Restricted Funds £	Total Funds 2021 £
Current assets	269,943	95,299	365,242
Creditors less than 1 year	(51,154)	–	(51,154)
Net assets	<u>218,789</u>	<u>95,299</u>	<u>314,088</u>