

Axial Spondyloarthritis International Federation Report and Accounts 31 December 2021

GORDON & CO

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

Accounts

Year ended 31 December 2021

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Trustees' Annual Report (continued)

Year ended 31 December 2021

The Trustees present their report and the accounts of the charity for the year ended 31 December 2021.

Axial Spondyloarthritis International Federation ("ASIF") was registered as a charity in England and Wales on 21 July 2017. In June 2019 ASIF elected to change its name from Ankylosing Spondylitis International Federation to Axial Spondyloarthritis International Federation, in order to reflect developments in recent years in defining the broader medical and scientific terms for the conditions which include Ankylosing Spondylitis. The change of name was recorded by the Charity Commission on 28 June 2019.

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 President

Andri Phoka Secretary
Thierry Vannier Treasurer

Lillann Wermskog Aleksei Sitalo Cassie Shafer Dr Tuncay Duruoz Raj Mahapatra Ruta Grigiene

Yuki Zeniya (Resigned September 2021)

Staff and volunteers Jo Davies Executive to the Board

Jo Lowe Project manager

Joanne de Bry Communications manager Valeria Tassi Administration assistant

Michael Mallinson - volunteer Membership

Advisors and officials Fiona Kerin Accountant

HSBC UK Bank PLC Bankers

Independent examiner John Gordon FCA

Gordon & Co

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London WC1A 2RP

Trustees' Annual Report (continued)

Year ended 31 December 2021

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 and 12 June 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 and are then eligible for appointment for a second term.

Management

ASIF is overseen by the Trustees, who meet at least six times a year. ASIF has appointed an Executive to the Board, to support their endeavours. Working with the Executive to the Board, 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.

Risk assessment

The Trustees have reviewed the risks faced by ASIF and have adopted appropriate policies to mitigate these risks. The principal risks and the policies adopted are as follows:

- i) Risk of loss of funds: Funds are maintained solely as bank balances and as a result there is no investment risk; and
- ii) Risk of loss of through fraud: bank accounts are maintained. The Trustees are seeking to switch bank accounts to one that allows multiple online signatories for payments. This has been delayed due to the Covid-19 pandemic during which time relevant banks ceased to accept new customer applications.

The Trustees believe that ASIF has sufficient resources for the time being to support its activities.

Objectives and activities

ASIF's mission is to increase public awareness of axSpA and related diseases and to disseminate knowledge of these diseases throughout the world. 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."

Trustees' Annual Report (continued)

Year ended 31 December 2021

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

ASIF welcomed the following new members in 2021:

- i) ASWS, Ankylosing Spondylitis Welfare Society, India;
- ii) Al Arthritis, International Foundation for Autoimmune & Autoinflammatory Arthritis;
- iii) Eleana, Hellenic League Against Rheumatism, Greece;
- iv) ANMAR, Associazione Nazionale Malati Reumatici, Italy; and
- v) Arthritis Ireland.

In 2021 ASIF continued to develop its major projects:

World AS Day

WAS Day remains our main annual global awareness campaign. In 2021 the social media campaign reached an incredible 12 million people. We also worked with the SAA (Spondylitis Association of America) on their Global Spondyloarthritis Summit by providing translated sub-titles for their educational videos for showing around the globe. We also continue to work with WalkAsOne on the annual Walk Your AS Off campaign which aims to get the world moving.

<u>IMAS - the International Map of Axial Spondyloarthritis</u>

IMAS is the largest patient survey in axSpA to date, that 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 2021, the survey expanded into seven new countries in 2021, including USA, Argentina, The Philippines, Lithuania and South Africa, making it truly global.

IMAS has now collected data from over 4,300 people around the world. The data collected has been 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. For example, in Norway, Spain and the UK, the data has been presented to policy makers to lobby for access to complementary therapies, to elevate axSpA in the political agenda and to demonstrate the need to shorten the time to diagnosis.

The IMAS team worked closely with members to understand their main challenges and to create a toolkit that can support members and provides messages directly underpinned by IMAS data, to approach a range of audiences. We are delighted that IMAS was recognised as the Overall Winner of the 2021 EFPIA (European Federation of Pharmaceutical Industries and Associations) Connecting Healthcare Awards which recognises collaborative projects that have delivered patient benefit.

Delay to Diagnosis

June 2021 saw the publication of ASIF's Delay to Diagnosis Report which provides expert insights

Trustees' Annual Report (continued)

Year ended 31 December 2021

on, and lived experience of, the impact of axSpA diagnostic delay. The report includes contributions from 26 experts: patients, patient organisations, rheumatologists, researchers and other healthcare professionals. It describes what axSpA is and what impact the delay has, it identifies six barriers to timely diagnosis, five recommendations for change and also showcases four best practices.

The hope is that it will support those working to reduce the delay and be a valuable resource in highlighting the need for change to policymakers and healthcare systems. The aim is to create a future where no-one living with the condition has to wait several years for a diagnosis.

We held two virtual launch events in July at which we saw over 80 attendees, from 25 countries across six continents. We showed three short films telling the personal stories of axSpA patients sharing the impact their own delayed diagnosis had on their lives. We then held live panel discussions which explored what needs to happen next to make progress in reducing the delay. We translated the report into a number of languages and we created a members toolkit which includes social media tools to promote the report. The report featured in articles around the world and was presented at a number of congresses.

Strategic Planning

In 2021 Trustees developed and approved a Strategic Plan 2022-2028. It provides a six year roadmap that outlines ASIF's direction and priorities. It is a tool that will be used to improve ASIF's performance and a guideline to be used when making decisions about the allocation of resources.

Financial review

<u>Overview</u>

During the year ASIF raised funds totalling £344,040 (2020 - £232,759) of which £194,565 (2020 - £190,000) related to the specific activities undertaken in the year.

ASIF incurred costs of £284,263 (2020 - £111,617) on charitable activities during the year.

Investment performance

ASIF's funds are held with HSBC. A proportion of these funds are held on deposit on which interest is earned. Due to the current economic climate, interest rates are very low and income from this source is very limited.

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.

<u>Reserves</u>

ASIF's reserves policy indicates that the reserves (which are calculated from the unrestricted funds) should allow the charity to function for a minimum of six months and a maximum of eighteen months. The total unrestricted funds carried forward are £218,789 (2020 - £149,289). The 2022 budget anticipates a monthly running cost of £12,600 so the reserves are just within eighteen months running costs. Expenditure was slightly lower in 2021 than expected, due to the ongoing

Trustees' Annual Report (continued)

Year ended 31 December 2021

pandemic and consequent restrictions on travel and in person meetings, and some project expenditure slipped into 2022.

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.

In 2021, restricted funds carried over totalled £95,299 (2020 - £105,022). This represents grant and sponsorship income from pharmaceutical partners for on-going projects.

Expenditure overall in 2021 was less than anticipated. Trustees and staff were not able to travel to congress meetings, nor was ASIF able to organise an in-person AGM. There was a small delay in some project activities. However, project funding is not lost because it does not need to be spent within ASIF's financial year; project work continues into 2022. Restricted funds are carried forward to the next financial year.

Plans for future periods

Plans for 2022

Starting with the Strategic Plan as a basis, Trustees and staff will develop a more detailed business plan that will define future resource requirements and inform a fundraising strategy. World AS Day will continue to develop and grow. The IMAS team will launch a campaign called Talk to be Heard which was developed in consultation with patient organisations worldwide. This is a campaign that shows real people talking openly about their experiences of living with axSpA. The hope is that it will encourage others to talk about their disease, either to their doctors or to family and friends.

A new Delay to Diagnosis Steering Committee will be convened and will consult with members to help define and direct a strategic plan for the next phase of the project. The membership subcommittee have plans to develop a suite of resources for members. A range of leaflets and tools that cover aspects of setting up a patient organisation and also provide information about axSpA that members will be able to translate and reproduce. Lastly, we are optimistic that we will be able finally to organise a live, in-person Council Meeting in 2022. Early plans are that it will take place in Copenhagen from 29-31 May.

Statement of Trustees' responsibilties

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;

Trustees' Annual Report (continued)

Year ended 31 December 2021

- 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 31 May 2022 and signed on behalf of the board of Trustees by:

Andri Phoka Secretary

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

Year ended 31 December 2021

I report to the Trustees on my examination of the accounts of Axial Spondyloarthritis International Federation ('the charity') for the year ended 31 December 2021.

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:

- 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

31 May 2022

Statement of Financial Activities

Year ended 31 December 2021

	l	Jnrestricted	2021 Restricted		2020
	Note	funds £	funds £	Total funds £	Total funds £
Income and endowments		_	_	_	_
Donations and subscriptions	4	8,672	_	8,672	306
Grants received	5	149,202	194,565	343,767	232,378
Investment income	6	4	-	4	75
Total income		157,878	194,565	352,443	232,759
Expenditure					
Expenditure on charitable activities		88,378	204,288	292,666	111,617
Total expenditure		88,378	204,288	292,666	111,617
Net income and net movement in					
funds		69,500	(9,723)	59,777 ———	121,142
Reconciliation of funds					
Total funds brought forward		149,289	105,022	254,311	133,169
Total funds carried forward		218,789	95,299	314,088	254,311

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.

Statement of Financial Position

31 December 2021

	Note	2021 £	2020 £
Current assets Debtors	11	67,000	1,250
Cash at bank and in hand	••	298,242	256,025
		365,242	257,275
Net current assets		365,242	257,275
Total assets less current liabilities		365,242	257,275
Creditors: amounts falling due after more than one year	12	51,154	2,964
Net assets		314,088	254,311 ———
Funds of the charity			
Restricted funds		95,299	105,022
Unrestricted funds		218,789	149,289
Total charity funds	13	314,088	254,311

These accounts were approved by the board of Trustees and authorised for issue on 31 May 2022, and are signed on behalf of the board by:

Zhivko Yankov Chairman

Andri Phoka Secretary

Thierry Vannier Treasurer

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

Notes to the Accounts

Year ended 31 December 2021

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 entity.

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

Notes to the Accounts

Year ended 31 December 2021

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.
- 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.
- 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.

Notes to the Accounts (continued)

Year ended 31 December 2021

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	Total Funds	Unrestricted	Total Funds
	Funds	2021	Funds	2020
	£	£	£	£
Donations				
Donations	8,672	8,672	215	215
Subscriptions	-	_	91	91
	8,672	8,672	306	306

The charity no longer charges a subscription fee for membership.

5. Grants received

	Unrestricted Funds £	Restricted Funds £	Total Funds 2021 £
Pharma grants - unrestricted	149,202	_	149,202
Pharma grants - restricted		194,565	194,565
	149,202	194,565	343,767
	Unrestricted	Restricted	Total Funds
	Funds	Funds	2020
			2020
	£	£	£
Pharma grants - unrestricted	£ 42,378		
Pharma grants - unrestricted Pharma grants - restricted	_		£

Notes to the Accounts (continued)

Year ended 31 December 2021

6.	Investment i	income
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	Unrestricted	Total Funds	Unrestricted	Total Funds
	Funds	2021	Funds	2020
	£	£	£	£
Other interest receivable	4	4	75	75

7. Net income

Net income is stated after charging/(crediting):

	2021	2020
	£	£
Foreign exchange differences	(142)	(1,040)

8. Independent examination fees

	2021	2020
	£	£
Fees payable to the independent examiner for:		
Independent examination of the accounts	954	-

9. 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.

10. Trustee remuneration and expenses

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

11. Debtors

12.

	2021 £	2020 £
Prepayments and accrued income	_	1,250
Other debtors	67,000	-
	67,000	1,250
Creditors: amounts falling due after more than one year		

2021 2020 **£** £ Accruals and deferred income 51,154 2,964

Notes to the Accounts (continued)

Year ended 31 December 2021

13. Analysis of charitable funds

Unrestricted fu	ınds
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General funds	At 1 January 2021 £ 149,289	Income £ 149,475 ———	Expenditure £ (79,975) ——	At 31 December 2021 £ 218,789
General funds	At 1 January 2020 £ 133,169	Income £ 42,759	Expenditure £ (26,639)	At 31 December 2020 £ 149,289
Restricted funds				
World AS Day (WAS Day) International Map of Axial Spondyloarthritis (IMAS) Delay to Diagnosis (D2D) Other	At 1 January 2021 £ 26,889 40,166 18,320 19,647 105,022	Income £ 34,783 52,174 59,782 47,826 194,565	Expenditure £ (50,047) (33,013) (78,102) (43,126) (204,288)	At 31 December 2021 £ 11,625 59,327 - 24,347 95,299
World AS Day (WAS Day) International Map of Axial Spondyloarthritis (IMAS) Delay to Diagnosis (D2D) Other	At 1 January 2020 £	Income £ 62,727 54,545 40,910 31,818 190,000	Expenditure £ (35,838) (14,379) (22,590) (12,171) (84,978)	At 31 December 2020 £ 26,889 40,166 18,320 19,647 105,022

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.

Notes to the Accounts (continued)

Year ended 31 December 2021

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.

14. Analysis of net assets between funds

	Unrestricted	Restricted	Total Funds
	Funds	Funds	2021
	£	£	£
Current assets	269,944	95,298	365,242
Creditors less than 1 year	(51,154)		(51,154)
Net assets	218,790	95,298	314,088
	Unrestricted	Restricted	Total Funds
	Funds	Funds	2020
	Funds £	Funds £	2020 £
Current assets			
Current assets Creditors less than 1 year	£	£	£
	£ 152,253	£	£ 257,275