Charity numbers: 1183175 & SC049746



## NATIONAL AXIAL SPONDYLOARTHRITIS SOCIETY

TRUSTEES' REPORT AND FINANCIAL STATEMENTS

FOR THE YEAR ENDED 31 DECEMBER 2022

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# REFERENCE AND ADMINISTRATIVE DETAILS OF THE CHARITY, ITS TRUSTEES AND ADVISERS FOR THE YEAR ENDED 31 DECEMBER 2022

Trustees Rajeevendra Kumar Mahapatra, Chair

Nicholas Reid, Treasurer (elected 25 September 2022)

Dr Antoni Tuck Yin Chan, Trustee

Gillian Eames, Trustee

Nicholas Clarke, Trustee (retired 25 September, 2022) Paul Curry, Trustee (re-elected 25 September 2022)

Poppy Hocken, Trustee Claire Jeffries, Trustee Dr Jacqueline Harris, Trustee Dr Lesley Jane Kay, Trustee

Patricia O-Callaghan, Trustee (retired 28 June, 2022) Danny McFarlane, Trustee (retired 25 September, 2022)

Hannah Elizabeth Murphy, Trustee

Prof Hasan Imam Syed Tahir, Trustee (elected 25 September 2022) Alexia Katherine Dreese Granatt, Trustee (elected 25 September 2022)

Charity registered

**numbers** 1183175 and SC049746

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### TRUSTEES' REPORT FOR THE YEAR ENDED 31 DECEMBER 2022

The Trustees present their annual report together with the audited financial statements of the National Axial Spondyloarthritis Society for the year 1 January 2022 to 31 December 2022.

## Objectives and activities

NASS' vision is as follows:

"The future we want to create is one where every person with axial spondyloarthritis (axial SpA) has timely and effective diagnosis, treatment and care, is empowered to make informed health choices and feels part of a supportive community."

The Charity seeks to do this by:

- providing information to the general public about axial SpA, and advice to people living with the condition, their families, carers, service-providers and employers
- advocating to ensure that every person with axial SpA has timely and effective diagnosis, treatment and care
- funding and disseminating research and analysis to advance scientific understanding of the condition and its effective treatment.

## a. Policies and objectives

In setting objectives and planning for activities, the Trustees have given due consideration to general guidance published by the Charity Commission relating to public benefit, including the guidance 'Public benefit: running a charity (PB2)'. NASS provides public benefit by:

- working with statutory bodies and others that provide for the treatment and welfare of people affected by axial SnA
- educating people affected by axial SpA, as well as healthcare professionals and the public, on the problems related to it
- putting people affected by axial SpA in contact with expert advisers
- promoting research into the management and cure of axial SpA and its causes
- · disseminating the results of research related to axial SpA.

In so doing, NASS improves the lives of those affected by axial SpA, particularly in relation to their ability to contribute positively to the prosperity of their communities and the country as a whole.

## b. Strategies for achieving objectives

In accordance with the provisions set out in its Constitution, the Trustees have adopted the following strategy for the period 2020 – 2024 to meet NASS' principal objects:

To ensure that people with axial SpA receive timely diagnosis, effective treatment and care

- Maintain pressure at national level to ensure effective and widespread implementation of the NICE Guideline and Quality Standard for axial SpA
  - Continue to run an All Party Parliamentary Group for axial spondyloarthritis
  - Undertake Parliamentary work in the devolved nations
  - Develop and publish a Gold Standard time to diagnosis route map
  - Commission research on the economic consequences of a delay to diagnosis
  - Create impactful ways to engage primary care professionals and those in appropriate secondary care services to ensure that they identify and refer patients who may have axial SpA

# TRUSTEES' REPORT (CONTINUED) FOR THE YEAR ENDED 31 DECEMBER 2022

- Form an alliance to protect NHS hydrotherapy services
- Develop a primary care clinical champions programme
- Continue to work in partnership with professional bodies
- Support rheumatology and other services to test approaches to improving diagnosis and treatment and spread the learning across the UK
  - Expand the Aspiring to Excellence healthcare improvement programme
  - Ensure that patient values and needs underpin NHS service delivery
  - Disseminate learning from Aspiring to Excellence
  - Raise awareness among those working in emergency care and NHS 111

## To empower, inform and inspire people affected by axial SpA

- Ensure that everyone affected by axial SpA has access to personalised support and the best information about the condition
  - Extend personalised support through our Helpline service, and reliable and user-friendly information resources for everyone affected by axial SpA
- Promote physical activity, and support and motivate people to exercise
  - Support and develop the NASS branch network to continue to ensure people can access regular group, physiotherapy led exercise sessions
  - Support and motivate people to confidently and safely exercise independently
- Ensure that everyone affected by axial SpA has the skills, confidence and knowledge they need to manage their condition optimally
- Develop a face-to-face self-management pilot programme and roll out if successful
- Consider an online version of a self-management programme for NASS members

## To foster a connected and supportive community, raising axial SpA awareness everyday, everywhere

- Conduct public awareness campaigns using various methods and channels to try and increase knowledge.
   Chiefly this activity will include:
  - Using case studies of people living with axial SpA to generate media coverage
  - Encouraging our members and supporters to become advocates for NASS and campaigners for improvements in axial care
  - Online and social media campaigns to create interest and inform the public
  - Using related national and international awareness days
  - Create an active community of NASS members and supporters who work together
  - Make more use of online tools such as Facebook Live for streaming events, conversations and debates, to encourage participation and engagement
  - Increase our online supporter numbers through social media promotion, listening, and outreach to potential supporters
  - Encourage members and supporters to take up fundraising activity for NASS, whether large-scale challenge events or activity such as raffles and coffee mornings
- Ensure that people know what NASS stands for, the changes that we are seeking to bring about, and how
  we operate
  - Offer thought leadership and op-ed pieces from the CEO, Chair and other key colleagues to professional and trade outlets, and also for mainstream health outlets.
  - Use social media listening techniques to reach out to people talking about axial SpA, making them aware of NASS and its resources
  - Develop annual membership campaigns to increase the number of members and membership revenue
  - Seek opportunities to outreach through external events outside of the sector at which NASS can contribute and have visibility.

# TRUSTEES' REPORT (CONTINUED) FOR THE YEAR ENDED 31 DECEMBER 2022

### c. Activities undertaken to achieve objectives and achievements

#### **Introduction**

2022 was a very successful year for NASS. Our large programmes – reducing diagnostic delay, improving the quality of care, and supporting self-management – made significant progress and extended their reach. Our Helpline and Information service continued to meet very high levels of demand and our national network of branches started to return to some sense of normality following the pandemic. Our profile – within Government, the NHS, the media and social media – was extended.

COVID-19 continued to impact significantly on our work. Although total numbers of enquiries to the helpline and information service dropped from their peak in 2021, demand was still higher than pre-COVID. This situation is likely to continue in the short term, so in 2023 we will seek to maintain our self-management programme as well as our extended helpline opening hours and benefits advice support.

There are chronic workforce shortages in hospital rheumatology departments across the UK. The severe understaffing has led to long waiting times and delays in care. Our helpline regularly speaks to patients who find calls to rheumatology department helplines go unreturned, whose appointments are cancelled after months of waiting and who find referrals to physiotherapy or occupational therapy are never followed up. This puts more pressure on NASS services and makes it even more critical that we work to help inform people about axial SpA and how they can self-manage their condition.

The economic climate has deteriorated, with a cost of living crisis and high inflation. This is likely to impact negatively on our fundraised income, increase our costs and increase the volume of callers to our information and support service. A recent YouGov poll found that 21% of people are donating less than usual to charities because of the economic situation. However, in the same poll, 20% also report that they are more likely to donate their time and 21% said that they are more likely to campaign for a charitable cause. In 2023 we will strengthen our volunteer base wherever possible and tap into the other non-cash assets of our supporters.

We were able to maintain and extend the visibility of our work on improving diagnosis and care at a time when the NHS is under enormous pressures and there is a general sense of fragility in rheumatology services. As a patient organisation we have an important role in holding up a mirror to the NHS. Our challenge is to frame our work in such a way that it will engage rather than alienate healthcare professionals (HCPs).

## Reducing diagnostic delay

It should be possible for every person experiencing symptoms of axial spondyloarthritis (axial SpA) to receive a diagnosis within one year of symptom onset. In 2020, respondents to our national consultation process – HCPs, professional bodies and patients – all agreed that this ambition could be realised, and in June 2021 NASS published a route map to achieve a Gold Standard time of one year.

Starting from a current baseline average of 8.5 years, the achievement of this goal will require transformational change. This includes a significant increase in awareness of the condition among HCPs and the general public, a critical mass of clinical leaders who will drive up health care performance in axial SpA, the widespread use of technology to ensure that axial SpA is higher within clinical reasoning and to support diagnosis, the routine use of pathways to ensure that patients are referred directly to rheumatology for assessment, and consistent use of agreed national protocols for imaging.

Above all, to attain such a dramatic change in time to diagnosis we must win hearts and minds, build a social movement of people who want to work with us to create change, and demonstrate proof of concept for our ideas.

2022 was the first full year of implementation of our route map.

# TRUSTEES' REPORT (CONTINUED) FOR THE YEAR ENDED 31 DECEMBER 2022

### Making the case for change

We have been successful in making the case for change through national inquiries, Freedom of Information (FOI) requests and research studies:

- We commissioned and published the first economic model of the economic costs of delayed diagnosis. It estimated that the cost to the UK economy is £18.7 billion per year, and the total average cumulative cost per person of an 8.5 year wait is £193,512, most of which is borne by the individual.
- We used a FOI request to assess the current provision across the UK in direct internal referrals to rheumatology from the key specialities of Dermatology, Gastroenterology and Ophthalmology, including the methods used, screening tools and the ability of providers to track internal referral volumes and an estimation of current frequency of referrals. We proposed four recommendations aimed at ensuring delays to direct referrals are reduced.
- We undertook an analysis via a FOI of the UK wide use of MRI in the diagnosis of axial SpA, comparing the changes since an initial review in 2017 and the publication of consensus guidance in 2019.
- We collaborated with the British Society of Gastroenterology and Chron's and Colitis UK on a landscape review to help us understand awareness of axial SpA in the speciality, the practise and confidence in referring into rheumatology and the tools in place to help this.
- We partnered with Moorfields Eye Hospital and the Royal College of Ophthalmologists and began work on a landscape review to help us understand the awareness of axial SpA in the speciality, the practise and confidence in referring into rheumatology and the tools in place to help this.

We brought these results to the attention of Government Ministers, other parliamentarians, policymakers and HCPs:

- In June, we shared the economic modelling results with the relevant Minister in the Department of Health and Social Care and discussed the importance of raising public awareness in reducing time to diagnosis.
- We influenced the funder of the National Early Inflammatory Arthritis Audit to include new datapoints on time
  to diagnosis so that, for the first time, we will have comprehensive national audit data to track changes in
  performance in axial SpA.
- We supported the best MSK/GIRFT programme to embed our approach in a new national axial SpA patient pathway.
- We presented our findings on the impact of the programme to the All Party Parliamentary Group for axial SpA.
- We presented our burning platform to British and European health conferences and regional SpA academies.

## Raising public awareness about early diagnosis

Raising public awareness about axial SpA and inflammatory back pain is key to earlier diagnosis. We demonstrated proof of concept in our public awareness campaign which since its launch has reached almost 2,000,000 people through social media. In addition, 1,000,000 people watched our campaign videos. There were 106,000 visits to our bespoke diagnosis website, over 20,000 visited our online symptom checker and 9,000 completed the symptom checker. Key campaign content included:

- A set of campaign videos, including three comedy hero videos to motivate a cold audience aged 40 under who are on social media to find out more about axial SpA. People who watch the videos were retargeted with case study videos and digital ads that feature SPINE acronym.
- A set of digital ads that use the SPINE acronym, to increase recognition of the five key symptoms of axial SpA. The ads drive people to the symptoms checker on <a href="https://www.actonaxialspa.com">www.actonaxialspa.com</a>
- A series of videos telling stories about life with axial SpA.
- Two videos featuring case studies of people who faced financial insecurity, while they waited for a diagnosis, one of which was a finalist in the Charity Film Awards.

# TRUSTEES' REPORT (CONTINUED) FOR THE YEAR ENDED 31 DECEMBER 2022

#### Raising clinical visibility for axial SpA in primary care

The lengthiest part of the delay in diagnosis is in primary care. We sought to address this by creating a cadre of clinical champions in primary care and community services whose work would ensure that axial SpA is higher within the clinical reasoning of primary care professionals, so that patients who present with suspected axial SpA are identified at the first presentation and urgently referred to rheumatology.

We appointed the NHS Transformation Unit as our technical provider to design and deliver *Champions in Primary Care* and, following a competitive process, we offered places to twelve primary care professionals to be Champions. At the end of September our 12 *Champions in Primary Care* started their journey. Over the next two years they will:

- Receive leadership development support, training in the theory and methods of quality improvement and assistance with identifying and implement improvement projects which they will test and refine
- Work together in a national network to foster community-building, the exchange of ideas and good practise and act as catalysts for change
- Co-create a body of knowledge, methods, tools and experience, and work to share their learning with primary and community services.

We also secured an agreement with the University of Nottingham for the *Champions in Primary Care* to act as pilot sites for an axial SpA pop up tool in the medical records system which alerts the GP to suspected axial SpA. A webinar was held in late November to introduce the tool to them and agree how it can be adopted.

At the end of 2022, the All Party Parliamentary Group on axial SpA published the results of a new Inquiry into the implementation of NICE Guideline 65 (NG65).

#### Engaging healthcare professionals (HCPs)

We carried out focus group work with HCPs about the drivers and barriers in relation to the delay to diagnosis, what tools they feel would assist them and how they would like to engage in a peer-to-peer support network. From those discussions, we will develop a campaign that includes rheumatology department visits, the development of a toolkit of resources for HCPs, the creation of a peer to peer network to provide support, and the creation of a Change Maker award to acknowledge the work of those who have demonstrated significant progress in implementing the gold standard time to diagnosis.

## Creating national level data to measure the time to diagnosis

Without large scale UK data on the time to diagnosis we will be unable to monitor with accuracy any changes. England and Wales have the National Early Inflammatory Arthritis Audit, but it contains very little information about axial SpA. However, we were successful in influencing the funder of the audit to contain new data points about diagnostic delay which will be implemented from mid 2023.

In addition, we developed a new audit tool to understand how we are influencing and catalysing change to drive down diagnosis with the 19 departments involved in our *Aspiring to Excellence* programme (see later). A group of participating clinicians worked with us to create the audit tool which went live in October. We will provide a first report in September 2023.

# TRUSTEES' REPORT (CONTINUED) FOR THE YEAR ENDED 31 DECEMBER 2022

### Helping people to live well with axial SpA

### Helpline and information services

The COVID-19 pandemic placed unprecedented stress on the NHS. With many patients unable to access rheumatology services, the demand for our services was greater than ever. Helpline contacts for 2021 (7434) were a third higher than for 2020 (5632), and 50% higher than 2019. In 2022, we supported 6,945 people, a drop of only 9% from the previous year. It demonstrated the continued backlog facing rheumatology coming out of the pandemic. There was also a noticeable number of calls on the NASS helpline relating to people who are having economic difficulties and have turned to NASS for help and advice.

"Honestly thank you so much for all of this information and thank you for understanding. I know it's hard for people without this to quite comprehend what an AS sufferer deals with on a daily basis. I am truly amazed at all the help you guys are giving."

In 2022 we wrote 229 letters in support of disability benefit claims which resulted in approximately £1,000,000 of benefits being awarded.

"I am very relieved to have finally got the award as it's been a stressful time for me. I doubt I would have got that if it wasn't for your letter. Thank you so much. They said the evidence submitted was excellent so that there was no need for an assessment in person."

#### Our national network of NASS branches

As life began to return to normal after COVID-19, our branches returned to normality, providing vital physiotherapy and hydrotherapy support to thousands of people living with axial SpA. By December 2022, 65 branches were active again. The return to physical sessions has represented a great deal of hard work by the volunteers involved in NASS branches. Few have simply been able to return to sessions as they were pre-COVID. Instead, they have had to find new ways of working and, in a number of cases, find new venues. Five branches sadly closed, but three new branches opened. Our new branches cover Cheltenham and Gloucester, Nottingham and Cornwall.

## Helping people to self-manage effectively

Our self-management programme aims to help people build the skills and confidence they need to take control of their axial SpA and their life. On average, someone with axial SpA might spend two hours each year with a healthcare professional discussing their axial SpA. That leaves 8,758 hours where they have to manage their condition on their own.

In 2022 we ran 34 My AS, My Life Facebook Live sessions. There were over 77,500 views of our sessions on Facebook and YouTube. Since April 2020, we have run 102 sessions with over 263,000 views. Evaluation shows that 90% of users feel more connected to other people with the condition, 88% understand more about axial SpA after watching the sessions and 80% feel more confident managing the condition as a consequence.

I want to say a huge thank you. My anti-TNF stopped working, leading to a rather rough year. I can't express how much your videos have helped and been a real comfort.

In addition, we established a regional self-management programme in collaboration with local rheumatology departments. We ran 28 online sessions with 11 rheumatology departments, reaching 649 people with axial SpA. We presented the evaluation results at the British Society of Rheumatology conference and won a prize for best conference poster. We also published an article on the programme in *OT News*, the member magazine for the Royal College of Occupational Therapists.

We acquired funding for an online learning programme (Your SpAce). Over the summer- we ran an online consultation with people living with axial SpA along with rheumatology consultants, physiotherapists, occupational therapists, researchers and nurses. It was agreed that Your SpAce should be aimed at people at

# TRUSTEES' REPORT (CONTINUED) FOR THE YEAR ENDED 31 DECEMBER 2022

any stage of their axial SpA journey, but particularly those at the start of their journey. Additionally, we wanted to bring in people who are less motivated and those feeling isolated.

The consensus was that *Your SpAce* should be bite sized, sharp and easily digestible. It should be active, engaging and upbeat. Most importantly, it should not be linear – people should choose their own route through the resources. In early 2023 we will launch a series of short videos with signposting to longer videos and downloadable resources for those who want to learn more. As part of *Your SpAce* there will be monthly meetups so people can meet others and share experiences.

#### Self-management podcast

NASS was one of six patient organisations invited to be involved in the One Immune Voice podcast series. The focus was on supporting people living with autoimmune and immune-mediated conditions, and their carers.

## Ensuring access to hydrotherapy

Hydrotherapy, also known as aquatic physiotherapy, provides vital support to people with axial SpA, particularly to those unable to tolerate land-based therapy. However, hydrotherapy services are often a target for NHS budget cuts. In 2021 we created the Aquatic Physiotherapy and Hydrotherapy Alliance. Members include the Chartered Society of Physiotherapy, the Aquatic Therapy Association of Chartered Physiotherapists (ATACP), Arthritis Action, Muscular Dystrophy UK, Good Boost, Swim England and Versus Arthritis. In 2022 it:

- Undertook a Freedom of Information (FOI) request to all NHS Trusts and Health Boards in the UK to determine current hydrotherapy in the NHS
- Surveyed all ATACP members to glean their intelligence about the provision of hydrotherapy in the NHS
- Published a report containing a compilation of the current research as well as FOI results
- Created resources to promote and save pools, as well as template letters and press releases
- Made a research application for a qualitative study.

## Supporting healthcare professionals to improve the quality of care

In 2019 we established a quality improvement programme called *Aspiring to Excellence*. Delivered by our partner the NHS Transformation Unit, the programme provides education, team coaching and a national learning network to those participating. In 2022 we welcomed a further eight rheumatology departments – giving a total of 19.

We continued to disseminate learning from the programme. This included the launch of a set of six new CPD accredited podcasts called *Rheum for Improvement*. The podcasts share service improvement innovations from HCPs who work with axial SpA patients. We also launched a series of blogs showing how the teams are using quality improvement methods.

It's important to ensure that rheumatology care is underpinned by a clear patient perspective. To this end, we commissioned Headstrong Thinking Limited to survey more than 900 people living with axial SpA about their values and needs from axial SpA care and launched the report at a Parliamentary reception in November.

We created a service improvement video involving NASS CEO and one of our rheumatologists in a discussion of issues being faced by primary and secondary care in the diagnosis and treatment of axial SpA, and the action NASS is taking to work together with healthcare professionals to change this. This was the most watched video at the British Society of Rheumatology conference in April 2022.

# TRUSTEES' REPORT (CONTINUED) FOR THE YEAR ENDED 31 DECEMBER 2022

## Raising the profile of axial SpA within Government

In 2019 we worked with Parliamentarians to create an All Party Parliamentary Group on axial SpA with the aim of providing national level oversight of the implementation of NICE Guideline 65 concerning the diagnosis and treatment of spondyloarthritis.

The eighth meeting of the APPG was held in May, with a focus on the role of rheumatology physiotherapy and the current work force crisis in rheumatology. The ninth meeting occurred in May and took the form of a landscape review.

The APPG commissioned a second FOI Request to all NHS Trusts and Health Boards regarding the implementation of the NICE Guideline on the diagnosis and management of spondyloarthritis. We published the report at a Parliamentary reception in November.

In June, NASS CEO Dale Webb met with the then Minister for State for Care and Mental Health Gillian Keegan to discuss the possibility of government support for an awareness campaign on axial SpA.

We also worked with the new musculoskeletal clinical leads in the Welsh Government, and continued to support Scotland's Cross Party Group on Arthritis and Musculoskeletal Conditions.

### Women and axial SpA - tackling inequalities

Women and axial SpA has long been an issue that needs to be addressed. Women have a longer time to diagnosis than men (prompted in part by a lack of awareness in primary care). We secured funding to commission research from Headstrong Thinking on gender and gender identity in axial SpA which we will publish in 2023. We are also supporting a research application on pregnancy led by University College London Hospitals.

#### **Ensuring effective switching to biosimilars**

In 2018 Humira lost its patent and biosimilars entered the UK market. Due to the available cost savings, this meant that people taking Humira for a range of conditions were switched across to the new biosimilar medications. During this process NASS was part of an NHS England steering group with other patient organisations including the National Rheumatoid Arthritis Society, Crohn's and Colitis UK and the Psoriasis Association. The four patient associations ran a joint survey asking people for their experience of the switch process. We were particularly keen to learn whether patient consent was obtained before switching. Over 900 people took part, and a paper was published in the *British Medical Journal*.

#### Supporting good emotional wellbeing research

In summer 2019, NASS funded King's College London to carry our research into the emotional impact of living with axial SpA. Over the past three years they have carried out a diary study, depth interviews and focus groups. The researchers produced a narrative report for NASS along with a short animation and gave presentations at scientific conferences.

## Media engagement

We were successful in securing articles in the broadcast and print media about axial SpA:

- The Times (in-print and online) ran a story on our research which shows women wait longer for a diagnosis of axial SpA than men
- Our report about the economic cost of delayed diagnosis received coverage on Sky News Radio and in The Daily Express and The Limbic
- Women magazine published a feature article about the struggles NASS community member Amy Fisher experienced as she waited for a diagnosis
- ITV Tonight featured a story of NASS community member Rowan Lutton. Rowan faced a five-year delay to

# TRUSTEES' REPORT (CONTINUED) FOR THE YEAR ENDED 31 DECEMBER 2022

diagnosis and believes her gender played a part in this

• NASS trustee Gillian Eames was interviewed for the *Grumpy Gits* podcast about her life with axial SpA. It is the world's most listened to podcast on disability issues.

#### Social media

We continued to reach and engage broader audiences on social media, creating a sense of community and sharing stories about people's experiences of life with axial SpA. We grew our followership, with over 42,000 followers across social media:

- 25,158 followers on Facebook
- 3,665 followers on Instagram
- 7,414 followers on Twitter
- 792 followers on Linkedin
- 6,200 subscribers on You Tube.

### Membership

Our members are the lifeblood of the society. In 2022, our membership grew by 2.5% to 4,164. We held another successful Members Day and scheduled in NASS Voices events in Glasgow and Cardiff for early 2023.

#### d. Key performance indicators

Performance against key indicators was as follows:

- Return on Investment (ROI) by fundraising channel. We want to ensure that our income generation activities are optimizing income in an efficient way. We achieved ROI ratios as follows (target ratios are in parenthesis): subscriptions 9:1 (9:1), donations 6:1 (6:1), Trust Fundraising 6:1 (10:1), Community 2:1 (5:1), Events 6:1 (5:1), Trading 8:1 (8:1). In 2023 we will strengthen data segmentation, to understand donor behaviour and be more targeted in our communications. We will also focus on building relationships with people with a higher net worth to increase their engagement in giving and fundraising
- % of expenditure on charitable activities. In 2022 75% of our expenditure was charitable, with a target of 70-80%
- Total annual value of successful benefit applications for our members. We again helped members to secure £1,000,000 of welfare support payments
- Number of people accessing our website information pages: 294,000
- Numbers of people accessing our Facebook Live sessions: 77,500
- Helpine requests processed within two working days: 97% (target is 95%).

## e. Volunteers

NASS is heavily dependent on 250 volunteer members who provide support at branch level. Volunteer members are unpaid and NASS' accounts do not reflect the value to NASS of the many hours work provided free to NASS. The Trustees are fully conscious of this value and recognise that the work of NASS would be considerably curtailed without the support provided by volunteer members.

Our 80 NASS branches offer regular, physiotherapist-led group exercise for anyone living with axial SpA. They Our are sub-committees of NASS and are led by a committee usually comprising a Chair, Treasurer and Secretary. We support our branches with a suite of resources, regular promotion of their activities, online meetings and a named member of staff who is available Monday to Friday to help with any problems or issues.

## TRUSTEES' REPORT (CONTINUED) FOR THE YEAR ENDED 31 DECEMBER 2022

### f. Fundraising activities and income generation

### Raising funds for NASS

Thank you to everyone who supported us in 2022 by donating or fundraising. We don't receive public funding and couldn't do our work without the generosity of our supporters. The money we raise ensures that we're here to transform axial SpA diagnosis and care, and offer practical support and advice to anyone affected by the condition. In 2022 our fundraising activities included:

**Community and events fundraising:** 294 people took part in a fundraising event. Thank you to everyone who took part in Walk Your AS Off, Stretch-tember, took on a challenge event, or organised their own fundraising.

**Donations and individual giving**: Despite a cost-of-living crisis 728 people gave a cash gift. Whether you gave a one-off cash gift, a regular donation, a gift in celebration or gave to our Spring or Winter Appeal, we want to thank you for your generosity.

**Legacy fundraising**: We are extremely grateful to everyone who leaves a gift in their Will. We received income from five legacies in 2022.

#### Trading:

We want to thank everyone who took part in a raffle, made a bid in one of our online auctions or bought one of our Christmas Cards in 2022.

*Trust fundraising*: we would like to thank the following charitable Trusts that supported us in 2022 collectively giving £64,000.

Douglas Heath Eves Charitable Trust

John Coates Charitable Trust

Lord Leverhulme's Charitable Trust

Margaret Jeannie Hindley Trust

Marsh Christian Trust

Miss M E Swinton Paterson's Charitable Trust

Souter Charitable Trust

Stoke-on-Trent and North Staffordshire CCGs Long Term Condition Support Fund

The Bernadette Charitable Trust

The February Foundation

The Forrester Family Trust

The G C Gibson Charitable Trust

The Garfield Weston Foundation

The Hamilton Wallace Trust

The Hospital Saturday Fund

The Mary Homfray Charitable Trust

The Michael Cornish Charitable Trust

The Purey Cust Trust CIO

The Shanly Foundation

The Simon Gibson Charitable Trust

The Walter Guinness Charitable Trust

The William Webster Charitable Trust

# TRUSTEES' REPORT (CONTINUED) FOR THE YEAR ENDED 31 DECEMBER 2022

We would also like to thank the following companies that supported us in 2022:

AbbVie Ltd £30,400
Biogen Idec Ltd £30,000
Eli Lilly and Company £30,000
Innovate UK £11,145
Janssen-Claig Limited £6,320
Novartis Pharmaceuticals UK Ltd £115,688
UCB Pharma Ltd £265,789

Any relationship NASS has with a pharmaceutical company is underpinned by the following principles:

- Independence The independence of NASS must not be compromised by the relationship with an external organisation or by the agreed working arrangements. The financial benefit must be made available for the support of our charitable activities without restriction. We will not allow funders to influence our campaigning, policymaking, research or fundraising for their own purposes. We will ensure our editorial independence is maintained and all information produced by NASS will be based on the latest evidence, informed by our Medical Advisory Board
- **Transparency** Any relationship with an external organisation is not an endorsement of their product or organisation and will be made transparent to our members, supporters, staff and the general public including in our annual Report and Accounts. All partnerships will be governed by a written agreement which will detail requirements and expectations from each party
- Benefit for those living with axial SpA Any relationship formed with an external organisation must be positive for NASS members and people living with axial SpA and in furtherance of our charitable aims
- Regulation and good practice All funders must comply with all relevant laws and regulations, as well as good practice. This includes full compliance with the Association of the British Pharmaceutical Industry's Code of Practice
- Use of NASS logo our logo may only be used following written approval from NASS. We may use a funder's mark where relevant to the relationship including in webinars, event banners, on our website or on press releases where appropriate. The use of a funder's trademark will have no impact on the independence of the charity
- **Sharing expertise and knowledge** We will work with funders to share non-product expertise and knowledge. This may include participation in networking events and meetings
- **Privacy policy** In line with our privacy policy NASS will not, under any circumstances, share the personal data of any of our service users or supporters with a pharmaceutical company
- Alignment with our strategy and values Any collaboration or cooperation with pharmaceutical companies will be assessed against the ethics, desirability and practicality in relation to the overall plans and work of NASS.

# TRUSTEES' REPORT (CONTINUED) FOR THE YEAR ENDED 31 DECEMBER 2022

## **Fundraising responsibly**

We rely on the generosity of our donors and fundraisers to do our life changing work and have processes and policies in place to ensure we fundraise responsibly.

- We are a member of the Fundraising Regulator and pay an annual levy
- We are transparent about our fundraising and treat donors and fundraisers respectfully and fairly
- We provide personal stewardship to anyone who is taking part in a fundraising activity for us; this includes
  ensuring people are aware of the risks of taking part in activities
- We explain how to opt out of communications and people are easily able to unsubscribe from emails
- We adhere to data-protection legislation and provide information on our website about our data-privacy policy, and how to opt-out of communications
- We take all reasonable steps to opt-people out of communications if they request to no longer hear from us
- We respond quickly and efficiently to any complaints about fundraising. We received no official complaints in 2022
- We mitigate against the risk of not reaching our fundraising targets by reviewing our management accounts monthly to monitor income levels, reforecasting and taking appropriate actions if fundraising income is below the levels we forecast. We have also introduced a quarterly analysis of our fundraising income by ROI
- We are registered with Hammersmith and Fulham Council as a Small Society Lottery under Paragraph 42 of Part 5 of Schedule 11 to the Gambling Act 2005
- Our Summer Raffle in 2022 raised, £5,445. 57.6% of the proceeds were retained as unrestricted income to fund our work, the remaining income covered prizes and the administrative cost of running the lottery
- Our Winter Raffle in 2022 raised £4,225. 57% of the proceeds were retained an unrestricted income and
  used to fund our work, the remaining income covered prizes and the administrative cost of running the lottery.
  A £50 prize was donated back to NASS as a cash gift.

#### g. Investment policy and performance

To minimise the risk of potential loss of funds and maintain financial security, a portion of our funds is held in cash within a reputable bank.

Additionally, the charity has made strategic investments in two properties we own which provide a consistent and reliable source of income for our charitable initiatives.

NASS' investments also include one statuette gifted by Dame Elisabeth Frink. All investments are carried at market value.

# TRUSTEES' REPORT (CONTINUED) FOR THE YEAR ENDED 31 DECEMBER 2022

## Financial review

### a. Going concern

After making appropriate enquiries, the Trustees have a reasonable expectation that the Charity has adequate resources to continue in operational existence for the foreseeable future. For this reason, they continue to adopt the going concern basis in preparing the financial statements. Further details regarding the adoption of the going concern basis can be found in the accounting policies.

Trustees closely monitored the charity's reserves as a consequence of the deteriorating economic environment. The Board of Trustees approved in principle taking out a loan against the properties that NASS owns should reserves deteriorate further. Trustees approved a plan for cost reductions measures proposed by the CEO.

### b. Reserves policy

Free reserves, defined as the balance of unrestricted funds less fixed assets, at the end of reporting period amount to £93,145 (2021 - £342,843).

The remaining funds are comprised of two properties (valued at £650,000) from which NASS derives rental income, other tangible assets of £332, branch funds of £265,269, other restricted grants totalling £143,707, and one statue gifted by Dame Elisabeth Frink valued at £27,000.

Unrestricted cash reserves represent 1.3 months operating costs.

At present NASS does not have an endowment fund and therefore income must be raised each year from voluntary sources and total income is likely to fluctuate from year to year.

We aim to hold 6-9 months' free reserves. This working capital protects the continuity of our core work, that is, work not funded through restricted income. Core work includes our information and support service, awareness raising, campaigning and policy influencing, and the work of our branches across the UK. We have chosen a reserves level of 6-9 months' having considered the level of predictability/unreliability in our income sources and the extent to which our cost base is flexible or committed. Our largest income sources (legacies and grant funding from pharmaceutical companies) come at irregular intervals, and the majority of our costs are committed, principally in the form of the staff who deliver our charitable objectives.

In 2022 our unrestricted cash reserves fell below our policy target. This was a consequence of two factors: the impact of the COVID pandemic on community and events fundraising and a lower than average legacy income. We will continue to monitor this in 2023 and take action if necessary. To ensure continued delivery of our charitable objectives, the Board decided to use some of the reserves below the reserves policy level. We remain committed to ensuring the long-term sustainability of our organisation and its mission.

## c. Material investments policy

The Charity holds two properties that are rented out to private tenants. Properties were chosen as a reliable source of income for the Charity and the expected income is set at £28,000 per annum given both properties are fully let.

# TRUSTEES' REPORT (CONTINUED) FOR THE YEAR ENDED 31 DECEMBER 2022

### d. Principal risks and uncertainties

The Trustees have adopted appropriate policies necessary to limit or mitigate the risks faced by NASS. The principal risks are:

- Loss of income: NASS seeks to broaden and expand its income from all sources. Nevertheless, NASS is
  dependent upon voluntary income, both at branch level and at national level, and aims to increase its
  membership locally and nationally
- Loss of reputation: NASS seeks at all times to maintain its independent viewpoint. Grants from pharmaceutical companies are strictly controlled so as to ensure that our independence is not compromised
- Loss of staff: NASS has a reward strategy to ensure that the charity is able to recruit and retain high quality staff. It also has a set of HR policies to provide the appropriate framing for all HR matters.

NASS has a safeguarding policy and set of procedures applicable to beneficiaries, staff, trustees and volunteers. Staff are trained in safeguarding and NASS branches have a training resource. The safeguarding policy and procedures are reviewed on an annual basis.

### e. Financial risk management objectives and policies

Effective management of financial risk is a high priority. Given the importance of accurate financial projections and reporting, we have taken a comprehensive approach to ensure that we consistently maintain a high standard in all aspects of financial management. It includes implementing robust budgeting and costing methods, adhering to donor-imposed restrictions, maintaining strong financial systems and controls, regular reporting and ensuring adequate reserves and cash flow management. We also conduct regular audits and financial reviews to maintain transparency and accountability. We have a range of policies and procedures to achieve these objectives. We employ processes and controls to guarantee accurate financial forecasting and reporting. We follow a well-defined procedure for expenditure approval, ensuring that any spending is fully authorised, and documented accordingly. Furthermore, we take great care to keep detailed records of all restricted funds, which helps to ensure complete transparency and accountability in their utilisation.

Collaborative budgeting methods are also used to ensure our financial management practices are practical and efficient. These policies and practices reflect our commitment to sound financial management, compliance, transparency, and accountability.

## f. Principal funding

45% of our funding in 2022 came from grants from pharmaceutical companies for specific projects (restricted) and a contribution to general running costs.

Other income was as follows:

Membership subscriptions: 18% (being 10% at branch level and 8% at national level)

Donations: 16%Legacies: 7%Fundraising: 11%Investments: 3%

# TRUSTEES' REPORT (CONTINUED) FOR THE YEAR ENDED 31 DECEMBER 2022

## Structure, governance and management

#### a. Constitution

The charity is a Charitable Incorporated Organisation and was registered with the Charity Commission in April 2019. The rules and regulations of the CIO are set out in its Constitution, adopted by the Board of Trustees on 14 September 2019.

## b. Methods of appointment or election of Trustees

The governing body of NASS is a Board of Trustees consisting of elected Trustees. Only members of NASS may be appointed as Trustees and the maximum number is twelve.

At every annual general meeting of the members of NASS, one third of the charity trustees shall retire from office. The charity trustees to retire by rotation shall be those who have been longest in office since their last appointment or reappointment. If any trustees were last appointed or reappointed on the same day those to retire shall (unless they otherwise agree among themselves) be determined by lot. The vacancies so arising may be filled by the decision of the members at the annual general meeting; any vacancies not filled at the annual general meeting may be filled by the charity trustees. Such persons shall retire at the conclusion of the next annual general meeting after the date of their appointment, and shall not be counted for the purpose of determining which of the charity trustees is to retire by rotation at that meeting.

The members or the charity trustees may at any time decide to appoint a new charity trustee, whether in place of a charity trustee who has retired or been removed in accordance with clause 15 (Retirement and removal of charity trustees), or as an additional charity trustee, provided that the limit specified on the number of charity trustees would not as a result be exceeded.

The Chair and Treasurer are approved by the Board and selected from among the trustee group. Their term of office as Chair and Treasurer is consistent with their term of office as a trustee. In advance of each AGM members of NASS are widely encouraged to nominate a fellow member as Trustee.

On appointment, new trustees are asked to spend a half day in the NASS central office for a briefing with the Chief Executive and staff to understand how the society works. Formal training is provided when required.

#### c. Organisational structure and decision-making policies

The Trustees meet quarterly to review matters of policy and to make appropriate judgements, directions and decisions on CIO issues. Trustees delegate authority on some matters to a Finance and General Purposes Committee consisting of the Chair, the Treasurer, up to three appointed Trustees and the Chief Executive and Finance and Administration Manager. This Committee meets four times per year. NASS also has a Medical Advisory Board which acts in advisory capacity only. Day to day management of NASS is undertaken by the Chief Executive and their staff. The trustees consider the Chief Executive and management team as comprising the key management personnel of the charity in charge of directing and running and operating the charity on a day to day basis.

## d. Policies adopted for the induction and training of Trustees

All new trustees receive an induction programme which includes the organisation's structure, scheme of delegation, NASS constitution, strategic plan, business plan and budget, trustee code of conduct and CC3, *The Essential Trustee*. Periodic training is provided (e.g. how to read management accounts).

# TRUSTEES' REPORT (CONTINUED) FOR THE YEAR ENDED 31 DECEMBER 2022

## e. Pay policy for key management personnel

Every three years we commission Croner HR to undertake independent benchmarking of all roles. The last review was in November 2022. Our medium term aim is to pay at the midpoint. The pay of the Chief Executive is reviewed annually by the trustees.

### f. Related party relationships

There are no related party relationships. NASS is a member of various umbrella groups, including the Arthritis and Musculoskeletal Alliance, The Axial SpA International Federation, National Voices, the National Council for Voluntary Organisations and The Disability Benefits Consortium. Our membership of these bodies does not impact on the operating policies adopted by the charity.

## g. Financial risk management

Further to the risks identified above, in 2023 trustees will be asked to approve a revised risk management strategy.

#### h. Trustees' indemnities

NASS holds Trustee Indemnity insurance through Markel UK, providing cover with a limit of 1 million pounds against any wrongful act claim made against a Trustee.

# TRUSTEES' REPORT (CONTINUED) FOR THE YEAR ENDED 31 DECEMBER 2022

## Plans for future periods

Our priority areas for 2023 are:

## Reducing diagnostic delay

- Embed Champions in Primary Care
- Publish landscaping reviews on axial SpA in dermatology, gastroenterology, ophthalmology and radiology and develop educational tools for these specialities
- Publish reports on the work of the 19 Aspiring to Excellence sites in reducing time to diagnosis
- Promote an endorsement campaign to encourage NHS organisations to support the implementation of Act on Axial SpA
- Continue to implement the Act on Axial SpA public awareness raising campaign across online media and PR including the use of out of home advertising
- Embed a new audit tool on time to diagnosis and publish our first report

### Supporting the NHS to improve axial SpA care

- Support the three cohorts of Aspiring to Excellence
- Begin work to develop a gold standard approach to treatment, long-term care and self-management
- Continue to capacitate rheumatology departments to provide supported self-management through co-designed sessions and an e-library of resources
- Make preparations to hold the first national quality improvement conference in axial Spa in 2024
- Publish a set of patient quality standards

## Supporting people affected by axial SpA (including self-management)

- Seek to maintain our information and support our services at the current level
- Continue developing free-to-access self-management resources
- Launch the first phase of an E-learning programme
- Publish new research into issues faced in relation to sex, gender and gender identity
- Continue to support our branch network and promote their services.

# TRUSTEES' REPORT (CONTINUED) FOR THE YEAR ENDED 31 DECEMBER 2022

### Statement of Trustees' responsibilities

The Trustees are responsible for preparing the Trustees' report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

The law applicable to charities in England & Wales and Scotland requires the Trustees to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the Charity and of its incoming resources and application of resources, including its income and expenditure, for that period. In preparing these financial statements, the Trustees are required to:

- select suitable accounting policies and then apply them consistently
- observe the methods and principles of the Charities SORP (FRS 102)
- make judgements and accounting estimates that are reasonable and prudent
- state whether applicable UK Accounting Standards (FRS 102) 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 business.

The Trustees are responsible for keeping adequate accounting records that are sufficient to show and explain the Charity's transactions and disclose with reasonable accuracy at any time the financial position of the Charity and enable them to ensure that the financial statements comply with the Charities Act 2011, the Charity (Accounts and Reports) Regulations 2008, the Charities and Trustee Investment (Scotland) Act 2005, the Charities Accounts (Scotland) Regulations 2006 (as amended) and the provisions of the Memorandum of Association. They are also responsible for safeguarding the assets of the Charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

#### Disclosure of information to auditors

Each of the persons who are Trustees at the time when this Trustees' report is approved has confirmed that:

- so far as that Trustee is aware, there is no relevant audit information of which the charity's auditors are unaware, and
- that Trustee has taken all the steps that ought to have been taken as a Trustee in order to be aware of any relevant audit information and to establish that the charity's auditors are aware of that information.

#### **Auditors**

The auditors, BKL Audit LLP, have indicated their willingness to continue in office. The designated Trustees will propose a motion reappointing the auditors at a meeting of the Trustees.

Approved by order of the members of the board of Trustees and signed on their behalf by:

Rajeevendra Kumar Mahapatra

Date: 07/08/2023

## INDEPENDENT AUDITORS' REPORT TO THE MEMBERS OF NATIONAL AXIAL SPONDYLOARTHRITIS SOCIETY

### **Opinion**

We have audited the financial statements of National Axial Spondyloarthritis Society (the 'Charity') for the year ended 31 December 2022 which comprise the Statement of financial activities, the Balance sheet, the Statement of cash flows and the related notes, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland' (United Kingdom Generally Accepted Accounting Practice).

In our opinion the financial statements:

- give a true and fair view of the state of the Charity's affairs as at 31 December 2022 and of its incoming resources and application of resources, including its income and expenditure for the year then ended
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice, and
- have been prepared in accordance with Accounting and Reporting by Charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) and in other respects the requirements of the Charities Act 2011.

#### **Basis for opinion**

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the Auditors' responsibilities for the audit of the financial statements section of our report. We are independent of the Charity in accordance with the ethical requirements that are relevant to our audit of the financial statements in the United Kingdom, including the Financial Reporting Council's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

## Conclusions relating to going concern

In auditing the financial statements, we have concluded that the Trustees' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the charity's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the Trustees with respect to going concern are described in the relevant sections of this report.

# INDEPENDENT AUDITORS' REPORT TO THE MEMBERS OF NATIONAL AXIAL SPONDYLOARTHRITIS SOCIETY (CONTINUED)

#### Other information

The other information comprises the information included in the Annual report other than the financial statements and our Auditors' report thereon. The Trustees are responsible for the other information contained within the Annual report. Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon. Our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the course of the audit, or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether this gives rise to a material misstatement in the financial statements themselves. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact.

We have nothing to report in this regard.

## Opinion on other matters prescribed by the Companies Act 2006

In our opinion, based on the work undertaken in the course of the audit:

- the information given in the Trustees' Report for the financial year for which the financial statements are prepared is consistent with the financial statements
- the Trustees' Report has been prepared in accordance with applicable legal requirements.

## Matters on which we are required to report by exception

In the light of our knowledge and understanding of the Charity and its environment obtained in the course of the audit, we have not identified material misstatements in the Trustees' Report.

We have nothing to report in respect of the following matters in relation to which Companies Act 2006 and the Charities Accounts (Scotland) Regulations 2006 (as amended) require us to report to you if, in our opinion:

- adequate accounting records have not been kept, or returns adequate for our audit have not been received from branches not visited by us, or
- the financial statements are not in agreement with the accounting records and returns, or
- certain disclosures of Trustees' remuneration specified by law are not made, or
- we have not received all the information and explanations we require for our audit, or
- the Trustees were not entitled to prepare the financial statements in accordance with the small companies
  regime and take advantage of the small companies' exemptions in preparing the Trustees' Report and
  from the requirement to prepare a Strategic Report.

# INDEPENDENT AUDITORS' REPORT TO THE MEMBERS OF NATIONAL AXIAL SPONDYLOARTHRITIS SOCIETY (CONTINUED)

### Responsibilities of trustees

As explained more fully in the Trustees' responsibilities statement, the Trustees (who are also the directors of the charitable company for the purposes of company law) are responsible for the preparation of the financial statements and for such internal control as the Trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the Trustees are responsible for assessing the Charity's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the Trustees either intend to liquidate the Charity or to cease operations, or have no realistic alternative but to do so.

#### Auditors' responsibilities for the audit of the financial statements

We have been appointed as auditor under section 44(1)(c) of the Charities and Trustee Investment (Scotland) Act 2005 and under the Companies Act 2006 and report in accordance with the Act and relevant regulations made or having effect thereunder.

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an Auditors' report that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above, to detect material misstatements in respect of irregularities, including fraud. The extent to which our procedures are capable of detecting irregularities, including fraud is detailed below:

- Enquiring of management around actual and potential litigation and claims
- Reviewing board meeting minutes of meetings of those charged with governance
- Reviewing financial statement disclosures and testing to supporting documentation to assess compliance with applicable laws and regulations
- Performing audit work over the risk of management override of controls, including testing of journal entries
  and other adjustments for appropriateness, evaluating the business rationale of significant transactions
  outside the normal course of business and reviewing accounting estimates for bias.

As part of an audit in accordance with ISAs (UK), we exercise professional judgement and maintain professional scepticism throughout the audit. We also:

- Identify and assess the risks of material misstatement of the financial statements, whether due to fraud or
  error, design and perform audit procedures responsive to those risks, and obtain audit evidence that is
  sufficient and appropriate to provide a basis for our opinion. The risk of not detecting a material
  misstatement resulting from fraud is higher than for one resulting from error, as fraud may involve collusion,
  forgery, intentional omissions, misrepresentations, or the override of internal control
- Obtain an understanding of internal control relevant to the audit in order to design audit procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion of the effectiveness of the charity's internal control
- Evaluate the appropriateness of accounting policies used and the reasonableness of accounting estimates and related disclosures made by the Trustees
- Conclude on the appropriateness of the Trustees' use of the going concern basis of accounting and, based on the audit evidence obtained, whether a material uncertainty exists related to events or conditions that

# INDEPENDENT AUDITORS' REPORT TO THE MEMBERS OF NATIONAL AXIAL SPONDYLOARTHRITIS SOCIETY (CONTINUED)

may cast significant doubt on the charity's ability to continue as a going concern. If we conclude that a material uncertainty exists, we are required to draw attention in our Auditors' Report to the related disclosures in the financial statements or, if such disclosures are inadequate, to modify our opinion. Our conclusions are based on the audit evidence obtained up to the date of our Auditors' Report. However, future events or conditions may cause the charity to cease to continue as a going concern.

• Evaluate the overall presentation, structure and content of the financial statements, including the disclosures, and whether the financial statements represent the underlying transactions and events in a manner that achieves fair presentation

We communicate with those charged with governance regarding, among other matters, the planned scope and timing of the audit and significant audit findings, including any significant deficiencies in internal control that we identify during our audit.

A further description of our responsibilities for the audit of the financial statements is located on the Financial Reporting Council's website at: www.frc.org.uk/auditorsresponsibilities. This description forms part of our Auditors' report.

## Use of our report

This report is made solely to the Charity's trustees, as a body, in accordance with Chapter 3 of Part 16 of the Companies Act 2006, and to the Charity's shareholders, as a body, in accordance with regulation 10 of the Charities Accounts (Scotland) Regulations 2006. Our audit work has been undertaken so that we might state to the Charity's trustees those matters we are required to state to them in an Auditors' report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the Charity and its trustees, as a body, for our audit work, for this report, or for the opinions we have formed.

# INDEPENDENT AUDITORS' REPORT TO THE MEMBERS OF NATIONAL AXIAL SPONDYLOARTHRITIS SOCIETY (CONTINUED)

BKL Audit LLP

**BKL Audit LLP** 

35 Ballards Lane

London

N3 1XW

Date: 08/08/2023

BKL Audit LLP are eligible to act as auditors in terms of section 1212 of the Companies Act 2006.

# STATEMENT OF FINANCIAL ACTIVITIES FOR THE YEAR ENDED 31 DECEMBER 2022

	Note	Restricted funds - Branches 2022 £	Restricted funds - All other 2022 £	Unrestricted funds 2022 £	Total funds 2022 £	Total funds 2021 £
Income from:						
Donations and						
legacies	3	109,721	450,824	319,120	879,665	1,030,334
Other trading activities	4	5,296	221	106,996	112,513	116,088
Investments	5	:-	-	29,116	29,116	25,029
Other income	6	3,082	1.50	2,148	5,230	11,017
Total income	-	118,099	451,045	457,380	1,026,524	1,182,468
Expenditure on:	5	3)	<del></del>		7	
Raising funds	7	355	5	197,057	197,412	128,771
Charitable activities	9	126,688	633,731	560,915	1,321,334	1,009,331
Total expenditure	9	127,043	633,731	757,972	1,518,746	1,138,102
Net (expenditure)/incom e before net (losses)/gains on investments		(8,944)	(182,686)	(300,592)	(492,222)	<i>44</i> ,366
Net (losses)/gains on investments				(50,000)	(50,000)	24,900
Net						
(expenditure)/incom e	-	(8,944)	(182,686)	(350,592)	(542,222)	69,266
Transfers between funds	19	(24,558)	6,951	17,607	-	
Net movement in funds		(33,502)	(175,735)	(332,985)	(542,222)	69,266
lulius	-	(33,302)	(173,733)	(332,303)	(342,222)	
Reconciliation of funds:						
Total funds brought forward		298,771	319,442	1,103,462	1,721,675	1,652,409
Net movement in funds		(33,502)	(175,735)	(332,985)	(542,222)	69,266
Total funds carried forward		265,269	143,707	770,477	1,179,453	1,721,675
	-					

The Statement of Financial Activities includes all gains and losses recognised in the year.

The notes on pages 28 to 50 form part of these financial statements.

# BALANCE SHEET AS AT 31 DECEMBER 2022

	Note		2022 £		2021 £
Fixed assets			_		~
Tangible assets	14		332		6,619
Investments	16		27,000		54,000
Investment property	15		650,000		700,000
			677,332	•	760,619
Current assets					
Debtors	17	42,464		115,061	
Cash at bank and in hand		656,510		894,766	
	1	698,974		1,009,827	
Creditors: amounts falling due within one year	18	(196,853)		(48,771)	
Net current assets		-	502,121	<u>.                                      </u>	961,056
Total assets less current liabilities		30	1,179,453	•	1,721,675
Total net assets		ă ă	1,179,453		1,721,675
Charity funds					
Restricted funds - Branches	19		265,269		298,771
Restricted funds - All other	19		143,707		319,442
Unrestricted funds	19		770,477		1,103,462
Total funds		į	1,179,453		1,721,675

The financial statements were approved and authorised for issue by the Trustees on 8 August 2023 and signed on their behalf by:

Rajeevendra Kumar Mahapatra

(Chair of Trustees)

The notes on pages 28 to 50 form part of these financial statements.

## STATEMENT OF CASH FLOWS FOR THE YEAR ENDED 31 DECEMBER 2022

	2022	2021
Cash flows from operating activities	£	£
Net cash used in operating activities	(267,350)	(117,374)
Cash flows from investing activities		
Dividends, interests and rents from investments	28,209	25,029
Proceeds from the sale of tangible fixed assets	885	-
Purchase of tangible fixed assets	-	(1,318)
Net cash provided by investing activities	29,094	23,711
Change in cash and cash equivalents in the year	(238,256)	(93,663)
Cash and cash equivalents at the beginning of the year	894,766	988,429
Cash and cash equivalents at the end of the year	656,510	894,766

The notes on pages 28 to 50 form part of these financial statements

### NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2022

#### 1. General information

The National Axial Spondyloarthritis Society is a CIO incorporated under articles of association dated 29th April 2019 in England & Wales with charity registration number 1183175. It was subsequently registered with the Scottish Charity Regulator on 19th November 2019 with Scottish charity registration number SC049746.

## 2. Accounting policies

## 2.1 Basis of preparation of financial statements

The financial statements have been prepared in accordance with the Charities SORP (FRS 102) - Accounting and Reporting by Charities: 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) (effective 1 January 2019), the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) and the Charities Act 2011, the Charities and Trustee Investment (Scotland) Act 2005 and the Charities Accounts (Scotland) Regulations 2006 (as amended).

National Axial Spondyloarthritis Society meets the definition of a public benefit entity under FRS 102. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy.

## 2.2 Income

All income is recognised once the Charity has entitlement to the income, it is probable that the income will be received and the amount of income receivable can be measured reliably.

The recognition of income from legacies is dependent on establishing entitlement, the probability of receipt and the ability to estimate with sufficient accuracy the amount receivable. Evidence of entitlement to a legacy exists when the Charity has sufficient evidence that a gift has been left to them (through knowledge of the existence of a valid will and the death of the benefactor) and the executor is satisfied that the property in question will not be required to satisfy claims in the estate. Receipt of a legacy must be recognised when it is probable that it will be received and the fair value of the amount receivable, which will generally be the expected cash amount to be distributed to the Charity, can be reliably measured.

Grants are included in the Statement of financial activities on a receivable basis. The balance of income received for specific purposes but not expended during the period is shown in the relevant funds on the Balance sheet. Where income is received in advance of entitlement of receipt, its recognition is deferred and included in creditors as deferred income. Where entitlement occurs before income is received, the income is accrued.

Income tax recoverable in relation to investment income is recognised at the time the investment income is receivable.

Other income is recognised in the period in which it is receivable and to the extent the goods have been provided or on completion of the service.

### NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2022

### 2. Accounting policies (continued)

#### 2.3 Expenditure

Expenditure is recognised once there is a legal or constructive obligation to transfer economic benefit to a third party, it is probable that a transfer of economic benefits will be required in settlement and the amount of the obligation can be measured reliably. Expenditure is classified by activity. The costs of each activity are made up of the total of direct costs and shared costs, including support costs involved in undertaking each activity. Direct costs attributable to a single activity are allocated directly to that activity. Shared costs which contribute to more than one activity and support costs which are not attributable to a single activity are apportioned between those activities on a basis consistent with the use of resources. Central staff costs are allocated on the basis of time spent, and depreciation charges allocated on the portion of the asset's use.

Expenditure on raising funds includes all expenditure incurred by the Charity to raise funds for its charitable purposes and includes costs of all fundraising activities events and non-charitable trading.

Expenditure on charitable activities is incurred on directly undertaking the activities which further the Charity's objectives, as well as any associated support costs.

Grants payable are charged in the year when the offer is made except in those cases where the offer is conditional, such grants being recognised as expenditure when the conditions attaching are fulfilled. Grants offered subject to conditions which have not been met at the year end are noted as a commitment, but not accrued as expenditure.

All expenditure is inclusive of irrecoverable VAT.

## 2.4 Government grants

Government grants relating to tangible fixed assets are treated as deferred income and released to the Statement of financial activities over the expected useful lives of the assets concerned. Other grants are credited to the Statement of financial activities as the related expenditure is incurred.

### 2.5 Interest receivable

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 institution with whom the funds are deposited.

## 2.6 Tangible fixed assets and depreciation

Tangible fixed assets costing £1,000 or more are capitalised and recognised when future economic benefits are probable and the cost or value of the asset can be measured reliably.

Tangible fixed assets are initially recognised at cost. After recognition, under the cost model, tangible fixed assets are measured at cost less accumulated depreciation and any accumulated impairment losses. All costs incurred to bring a tangible fixed asset into its intended working condition should be included in the measurement of cost.

### NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2022

### 2. Accounting policies (continued)

#### 2.6 Tangible fixed assets and depreciation (continued)

Depreciation is charged so as to allocate the cost of tangible fixed assets less their residual value over their estimated useful lives, using the straight-line method.

Depreciation is provided on the following basis:

Office equipment - 25% Straight Line

#### 2.7 Investments

Fixed asset investments are a form of financial instrument and are initially recognised at their transaction cost and subsequently measured at fair value at the Balance sheet date, unless the value cannot be measured reliably in which case it is measured at cost less impairment. Investment gains and losses, whether realised or unrealised, are combined and presented as 'Gains/(Losses) on investments' in the Statement of financial activities.

Investments held as fixed assets are shown at cost less provision for impairment.

#### 2.8 Debtors

Trade and other debtors are recognised at the settlement amount after any trade discount offered. Prepayments are valued at the amount prepaid net of any trade discounts due.

#### 2.9 Cash at bank and in hand

Cash at bank and in hand includes cash and short-term highly liquid investments with a short maturity of three months or less from the date of acquisition or opening of the deposit or similar account.

#### 2.10 Liabilities and provisions

Liabilities are recognised when there is an obligation at the Balance sheet date as a result of a past event, it is probable that a transfer of economic benefit will be required in settlement, and the amount of the settlement can be estimated reliably.

Liabilities are recognised at the amount that the Charity anticipates it will pay to settle the debt or the amount it has received as advanced payments for the goods or services it must provide.

Provisions are measured at the best estimate of the amounts required to settle the obligation. Where the effect of the time value of money is material, the provision is based on the present value of those amounts, discounted at the pre-tax discount rate that reflects the risks specific to the liability. The unwinding of the discount is recognised in the Statement of financial activities as a finance cost.

#### 2.11 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 amortised cost using the effective interest method.

## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2022

## 2. Accounting policies (continued)

### 2.12 Fund accounting

General funds are unrestricted funds which are available for use at the discretion of the Trustees in furtherance of the general objectives of the Charity and which have not been designated for other purposes.

Restricted funds are funds which are to be used in accordance with specific restrictions imposed by donors or which have been raised by the Charity for particular purposes. The costs of raising and administering such funds are charged against the specific fund. The aim and use of each restricted fund is set out in the notes to the financial statements. Due to the significant nature of branches on the accounts, the Restricted branch fund is displayed separately throughout the accounts.

Investment income, gains and losses are allocated to the appropriate fund.

## 3. Income from donations and legacies

Restricted Funds - Branches 2022 £	Restricted funds - All other 2022 £	Unrestricted funds 2022 £	Total funds 2022 £
6,822	37,241	112,084	156,147
-	-	72,657	72,657
-	413,583	54,346	467,929
102,899	-	80,033	182,932
109,721	450,824	319,120	879,665
Restricted Funds - Branches 2021 £	Restricted funds - All other 2021 £	Unrestricted funds 2021 £	Total funds 2021 £
2,887			226,495
· -	-	154,563	154,563
-	424,381	65,950	490,331
74,860	-	84,085	158,945
77,747	475,455	477,132	1,030,334
	Funds - Branches 2022 £  6,822 - 102,899  109,721  Restricted Funds - Branches 2021 £ 2,887 - 74,860	Funds - Branches 2022 £ £ 2022 £ £ 6,822 37,241 413,583 102,899 450,824	Funds - Branches         funds - All other funds           2022         2022         2022           £         £         £           6,822         37,241         112,084           -         -         72,657           -         413,583         54,346           102,899         -         80,033           109,721         450,824         319,120           Restricted Funds - All other funds - All other funds           2021         2021         2021           £         £         £           2,887         51,074         172,534           -         154,563           -         424,381         65,950           74,860         -         84,085

Charity grants includes Pharmaceutical Industry grants of £466,536 (2021: £485,331) and other grants of £1,393 (2021: £5,000).

# NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2022

## 4. Income from other trading activities

## Income from fundraising events

	Restricted Funds - Branches 2022 £	Restricted funds 2022 £	Unrestricted funds 2022 £	Total funds 2022 £
Fundraising events	5,296	221	106,996	112,513
		Restricted Funds - Branches 2021 £	Unrestricted funds 2021 £	Total funds 2021 £
Fundraising events		2,876	113,212	116,088

## 5. Investment income

	Unrestricted funds 2022 £	Total funds 2022 £
Rental income	28,023	28,023
Bank Interest	186	186
Profit on disposal of fixed assets	907	907
	<u> </u>	<del></del>
	29,116	29,116
	Unrestricted funds 2021 £	Total funds 2021 £
	~	~
Rental income	24,793	24,793
Bank Interest	236	236
	25,029 ====================================	25,029

## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2022

## 6. Other incoming resources

	Restricted Funds - Branches 2022 £	Unrestricted funds 2022 £	Total funds 2022 £
Other Income	3,082	2,148	5,230
	Restricted Funds - Branches 2021 £	Unrestricted funds 2021 £	Total funds 2021 £
Other Income	2,884	8,133	11,017

## 7. Expenditure on raising funds

## Fundraising trading expenses

	Restricted funds - Branches 2022 £	Unrestricted funds 2022 £	Total funds 2022 £
Expenditure on raising donations and legacies	-	15,292	15,292
Staging fundraising events	355	7,936	8,291
Fundraising for membership	-	1,529	1,529
Staff remuneration	-	118,368	118,368
General fundraising expenditure	-	26,442	26,442
Allocated centrally incurred fundraising and governance costs	-	27,490	27,490
	355	197,057	197,412

# NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2022

## 7. Expenditure on raising funds (continued)

Fundraising trading expenses (continued)

	Unrestricted funds 2021 £	Total funds 2021 £
Expenditure on raising donations and legacies	8,571	8,571
Staging fundraising events	7,567	7,567
Fundraising for membership	2,164	2,164
Staff remuneration	71,372	71,372
General fundraising expenditure	16,682	16,682
Allocated centrally incurred fundraising and governance costs	22,415	22,415
	128,771	128,771

## 8. Analysis of grants

In	Grants to estitutions 2022 £	Total funds 2022 £
	Grants to Institutions 2021 £	Total funds 2021 £
Grants, Every Patient Every Time Grants, A Connected and Supportive Community	45,358 250	45,358 250
	45,608	45,608

### NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2022

## 9. Analysis of expenditure on charitable activities

## Summary by fund type

Restricted funds - Branches 2022 £	Restricted funds - All other 2022 £	Unrestricted funds 2022 £	Total 2022 £
-	492,734	180,078	672,812
126,688	87,018	209,034	422,740
-	53,979	171,803	225,782
126,688	633,731	560,915	1,321,334
Restricted Funds - Branches 2021 £	Restricted funds - All other 2021 £	Unrestricted funds 2021 £	Total 2021 £
-	282,658	187,465	470,123
67,052	49,069	163,430	279,551
-	10,406	249,251	259,657
67,052	342,133	600,146	1,009,331
	runds - Branches 2022 £  - 126,688 - 126,688  Restricted Funds - Branches 2021 £  - 67,052	funds - Branches 2022 £ £ 2022 £ £	funds - Branches         funds - All other other other funds         funds funds funds           2022         £         £         £           -         492,734         180,078         126,688         87,018         209,034           -         53,979         171,803           126,688         633,731         560,915           Restricted Funds - All Branches         61,015         00,015           10,021         2021         2021           2021         £         £           -         282,658         187,465           67,052         49,069         163,430           -         10,406         249,251

## 10. Analysis of expenditure by activities

Activities undertaken directly 2022 £	Support costs 2022 £	Total funds 2022 £
603,911	68,901	672,812
362,638	60,102	422,740
166,683	59,099	225,782
1,133,232	188,102	1,321,334
	undertaken directly 2022 £ 603,911 362,638 166,683	undertaken directly 2022 £ £ Support costs 2022 £ £ £ 603,911 68,901 362,638 60,102 166,683 59,099

## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2022

## 10. Analysis of expenditure by activities (continued)

2021 £
470,123
279,551
259,657
1,009,331
_

## Analysis of direct costs

Every Patient Every Time 2022 £	A Connected and Supportive Community 2022	Empower, Inform and Inspire 2022 £	Total funds 2022 £
212,784	162,848	135,682	511,314
5,301	1,000	268	6,569
928	4,123	1,389	6,440
36,750	25,432	16,073	78,255
8,855	21,472	2,364	32,691
62,057	21,075	-	83,132
247,874	-	10,907	258,781
29,362	-	-	29,362
-	126,688	-	126,688
603,911	362,638	166,683	1,133,232
	Patient Every Time 2022 £  212,784 5,301 928 36,750 8,855 62,057 247,874 29,362 -	Every Patient Every Time 2022 £ £ 212,784 162,848 5,301 1,000 928 4,123 36,750 25,432 8,855 21,472 62,057 247,874 - 29,362 - 126,688	Every Patient Patient Every Time 2022         Supportive Community 2022         Empower, Inform and Inspire 2022           212,784         162,848         135,682           5,301         1,000         268           928         4,123         1,389           36,750         25,432         16,073           8,855         21,472         2,364           62,057         21,075         -           247,874         -         10,907           29,362         -         -           -         126,688         -

### NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2022

## 10. Analysis of expenditure by activities (continued)

## Analysis of direct costs (continued)

		A Connected		
	Every	and	Empower,	
	Patient	Supportive	Inform and	Total
	Every Time	Community	Inspire	funds
	2021	2021	2021	2021
	£	£	£	£
Staff remuneration	249,721	137,553	123,638	510,912
Travel Expenses	5,696	104	1,057	6,857
Office costs	339	897	931	2,167
Courier & distribution of materials	92	477	15	584
Literature, brochures & information	36,605	1,703	39,498	77,806
Hire of venues & facilities	22,838	35	15,377	38,250
Third party technical providers	53,754	3,483	18,499	75,736
Branches	-	67,052	-	67,052
	369,045	211,304	199,015	779,364

## Analysis of support costs

Supportive Community 2022 £	Empower, Inform and Inspire 2022 £	Total funds 2022 £
19,484	26,398	62,852
1,405	1,188	4,430
1,091	924	3,443
16,791	14,207	52,954
450	379	1,415
7,357	4,562	20,361
2,058	1,740	6,488
504	427	1,591
6,763	5,723	21,330
113	94	353
232	196	731
3,854	3,261	12,154
60,102	59,099	188,102
	Supportive Community 2022 £ 19,484 1,405 1,091 16,791 450 7,357 2,058 504 6,763 113 232 3,854	Community 2022 £ £ 19,484 26,398 1,405 1,188 1,091 924 16,791 14,207 450 379 7,357 4,562 2,058 1,740 504 427 6,763 5,723 113 94 232 196 3,854 3,261

## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2022

#### 10. Analysis of expenditure by activities (continued)

Analysis of support costs (continued)

		A Connected		
	Every	and	Empower,	
	Patient	Supportive	Inform and	Total
	Every Time	Community	Inspire	funds
	2021	2021	2021	2021
	£	£	£	£
Staff costs	5,825	5,825	7,489	19,139
Depreciation	1,905	1,429	1,389	4,723
Other staff costs	12,122	9,092	8,839	30,053
Premises costs	21,483	16,201	15,751	<i>53,435</i>
Travel expenses	767	575	559	1,901
IT and communications	8,320	6,241	6,068	20,629
Office costs	2,568	1,926	1,872	6,366
Conference costs	(3,754)	1,801	1,751	(202)
Accountancy	1,820	1,365	1,327	4,512
Insurance, legal & professional	1,501	3,378	3,284	8,163
Other support costs	-	13,858	-	13,858
Bank charges	388	291	283	962
Governance costs	2,775	6,015	12,030	20,820
	55,720	67,997	60,642	184,359
Auditors' remuneration				

## 11.

	2022 £	2021 £
Fees payable to the Charity's auditor for the audit of the Charity's annual accounts	9,000	7,200
Fees payable to the Charity's auditor in respect of: All non-audit services not included above	3,000	2,400

### NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2022

#### 12. Staff costs

	2022 £	2021 £
Wages and salaries	462,676	401,585
Social security costs	46,171	39,451
Contribution to defined contribution pension schemes	65,319	95,673
	574,166	536,709
The average number of persons employed by the Charity during the year wa	s as follows:	

	2022 No.	2021 No.
Employees	13	13

The number of employees whose employee benefits (excluding employer pension costs) exceeded £60,000 was:

	2022	2021
	No.	No.
In the band £100,001 - £110,000	1	1

Key management personnel consists of the CEO, Head of Communications and Fundraising, Head of Information and Support Services, Head of Policy and Health Services and the Finance and Administration Manager. The total employee remuneration and benefits of the key management personnel of the Charity were £332,882 (2021: £290,325).

#### 13. Trustees' remuneration and expenses

During the year, no Trustees received any remuneration or other benefits (2021 - £NIL).

During the year ended 31 December 2022, expenses totalling £67.50 were reimbursed or paid directly to 2 Trustees (2021 - £353 to 3 Trustees). These expenses were in relation to travel expenses.

## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2022

## 14. Tangible fixed assets

15.

	Office equipment £
Cost or valuation	
At 1 January 2022	21,609
Disposals	(3,536)
At 31 December 2022	18,073
Depreciation	
At 1 January 2022	14,990
Charge for the year	5,402
On disposals	(2,651)
At 31 December 2022	17,741
Net book value	
At 31 December 2022	
At 31 December 2021	<u>6,619</u>
Investment property	
	Freehold investment property £
Valuation	
At 1 January 2022	700,000
Gain / (loss) on revaluation	(50,000)
At 31 December 2022	650,000
	<del></del>

Investment property comprises residential flats let. The fair value of the investment property has been arrived at by reference to market evidence of transaction prices for similar properties and informal valuations by a number of local estate agents. A formal valuation was made post the year end on an open market value basis.

# NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2022

16.	Fixed	asset	investments

			Other fixed asset investments £
	Cost or valuation		
	At 1 January 2022		54,000
	Disposals		(27,000)
	At 31 December 2022	;	27,000
	Net book value		
	At 31 December 2022		27,000
	At 31 December 2021	;	54,000
17.	Debtors		
	20	)22 £	2021 £
	Due within one year		
	Trade debtors 8,8	40	23,622
	Other debtors 24,6		85,361
	Prepayments and accrued income 8,9		6,078
	42,4	64	115,061
18.	Creditors: Amounts falling due within one year		
	20	)22 £	2021 £
	Trade creditors 116,4	34	12,985
	Other taxation and social security 6,1		18,510
	Other creditors 26,4	75	1,249
	Accruals and deferred income 47,7	63	16,027
	196,8	53	48,771

## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2022

### 19. Statement of funds

Statement of funds - current year

	Balance at 1 January 2022 £	Income £	Expenditure £	Transfers in/out £	Gains/ (Losses) £	Balance at 31 December 2022 £
Unrestricted funds						
General Funds - all funds	1,103,462	457,380	(757,972)	17,607	(50,000)	770,477
Restricted Funds - Branches						
Branches	298,771	118,099	(127,043)	(24,558)		265,269

## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2022

## 19. Statement of funds (continued)

	Balance at 1 January 2022 £	Income £	Expenditure £	Transfers in/out £	Gains/ (Losses) £	Balance at 31 December 2022 £
Restricted funds - All other						
Branch Development Fund	4,592	_	(600)	4,000	-	7,992
Fergus Rogers Fund	2,052	-	-	-	-	2,052
Aspiring to Excellence	149,638	115,938	(223,342)	-	-	42,234
Cimzia Select Programme Ophthalmology	150	-	-	-	-	150
Gastroenterolo gy project Self	9,205	-	(8,350)	-	-	855
Management Programme	15,241	49,972	(44,146)	-	-	21,067
COVID-19 Gold Standard Delay to	-	-	-	-	-	-
Diagnosis	120,584	200,838	(286,106)	-	-	35,316
Good Boost	165	9,752	(9,917)	-	-	-
APPG	3,922	27,600	(31,005)	-	-	517
NASS Voices	1,993	2,000	(500)	-	-	3,493
Round Table	11,900	-	-	-	-	11,900
Health Inequalities Members Day	- -	18,459 26,486	(328) (29,437)	- 2,951	-	18,131 -
	319,442	451,045	(633,731)	6,951		143,707
Total of funds	1,721,675	1,026,524	(1,518,746)	-	(50,000)	1,179,453

#### NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2022

#### 19. Statement of funds (continued)

#### **Branch Network Funds**

The Branch Network Funds support the local activities of NASS Branches, which offer regular physiotherapy or hydrotherapy sessions led by qualified instructors. Each Branch raises its funds and decides how to utilise them for specific activities.

#### Branch Development Fund

The Branch Development Fund is created through donations from local NASS Branches. It aims to ensure the establishment and promotion of all Branches, and it provides start-up grants to new Branches and funds for ordering promotional materials such as posters and leaflets.

### Fergus Rogers Fund

The Fergus Rogers Fund was established in memory of Fergus Rogers to assist people with axial SpA in purchasing specific items that can improve their quality of life. It is used to provide support for those in financial need to obtain essential items recommended by their healthcare professionals.

#### Aspiring to Excellence Fund

The Aspiring to Excellence Fund supports a multi-year quality improvement program to transform healthcare for people with axial SpA. The fund facilitates strategic partnerships between NASS, BRITSpA, and the NHS transformation unit, bringing together rheumatology teams and service improvement experts. It is utilised for various activities, including recruitment to the program, learning sessions, online coaching, podcasts, and the development of an audit tool to track the time to diagnosis.

#### Ophthalmology / Gastroenterology Project Fund

The Ophthalmology/Gastroenterology Project Fund supports the Gold Standard time to diagnosis program and its efforts to improve the identification and referral of suspected axial SpA in Ophthalmology and Gastroenterology. It finances the involvement of clinical associates from both specialities in gathering intelligence and understanding the current landscape. Additionally, the fund covers the development of educational materials, audits, posters, surveys, and policy reports.

## The Self-Management Programme

The Self-Management Fund covers the costs of NASS's Supported Self-Management Program, which equips people with axial SpA with the skills and tools to manage their symptoms confidently. It supports various aspects of the program, including online resources, self-management sessions, and regional events held in conjunction with local NHS rheumatology departments.

#### Delay to Diagnosis - Gold Standard Fund

The Delay to Diagnosis - Gold Standard Fund is utilised to implement The Gold Standard Time to Diagnosis program for axial SpA. It supports various activities such as producing campaign impact reports, conducting economic analysis, delivering landscape reports, reviewing the use of MRI in diagnosis, and running public awareness campaigns.

#### NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2022

#### 19. Statement of funds (continued)

### **Good Boost Fund**

The Good Boost Fund was received from Innovate UK for the project 'Transforming older adult disability through virtual, peer-led community rehabilitation.' It finances the development of an online community for older adults with axial SpA. It covers staff salaries, platform development, and volunteer recruitment to lead virtual groups.

## APPG (All Party Parliamentary Group) for Axial Spondyloarthritis Fund

The APPG Fund is established to oversee the implementation of the National Institute for Health and Care Excellence (NICE) guidelines for Spondyloarthritis and its Quality Standard. It supports the functioning of the parliamentary group. It is used to conduct meetings, national inquiries, and parliamentary receptions to engage with MPs on axial SpA NHS services.

### **NASS Voices**

The NASS Voices Fund supports regional events to facilitate interactions between local people with axial SpA and their rheumatology healthcare professionals. It helps cover the costs of venue payments and other expenses for organising these events.

#### Round Table

The Round Table Fund supports wider policy work and national discussions on axial SpA in the UK. Although there was no activity in 2022, the fund is carried forward to continue its purpose in 2023.

### Health Inequalities Fund

The Health Inequalities Fund finances a qualitative study focusing on people's experiences with axial SpA through the lens of sex, gender, and gender identity. It covers expenses related to recruitment for focus groups and data collection.

#### Members Day Fund

The Members Day Fund facilitates the annual Members Day and AGM events held in different towns/cities across the UK. It covers the costs of organising these events, including venue arrangements, speaker fees, workshops, and other activities for attendees.

## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2022

## 19. Statement of funds (continued)

Statement of funds - prior year

	Balance at					Balance at 31
	1 January 2021 £	Income £	Expenditure £	Transfers in/out £	Gains/ (Losses) £	December 2021 £
Unrestricted funds						
General Funds - all funds	1,172,015	623,506	(725,272)	8,313	24,900	1,103,462
Restricted Funds - Branches						
Branches	304,487	83,507	(80,910)	(8,313)		298,771

## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2022

## 19. Statement of funds (continued)

	Dolongo et					Balance at 31
	Balance at 1 January 2021 £	Income £	Expenditure £	Transfers in/out £	Gains/ (Losses) £	December 2021 £
Restricted funds - All other						
Branch Development Fund	5,127	_	(535)	_	_	4,592
Fergus Rogers Fund	2,052	-	_	-	-	2,052
Aspiring to Excellence	123,620	134,531	(108,513)	-	-	149,638
Cimzia Select Programme Ophthalmology	150	-	-	-	-	150
Gastroenterolo gy project Self	9,205	-	-	-	-	9,205
Management Programme	13,962	32,240	(30,961)	-	_	15,241
COVID-19	3,541	-	(3,541)	-	-	-
Gold Standard Delay to						
Diagnosis	1,458	251,722	(132,596)	-	-	120,584
Good Boost	11,755	4,662	(16,252)	-	-	165
APPG	-	28,000	(24,078)	-	-	3,922
NASS Voices	-	12,400	(10,407)	-	-	1,993
Round Table	-	11,900	-	-	-	11,900
Health Inequalities			_	_	_	_
Members Day	<del>-</del>	-	-	-	-	-
	170,870	475,455	(326,883)		-	319,442
Total of funds	1,647,372	1,182,468	(1,133,065)	<u>-</u>	24,900	1,721,675

## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2022

## 20. Summary of funds

Summary of funds - current year

	Balance at 1					Balance at 31
	January 2022 £	Income £	Expenditure £	Transfers in/out £	Gains/ (Losses) £	December 2022 £
General funds Restricted funds -	1,103,462	457,380	(757,972)	17,607	(50,000)	770,477
Branches Restricted	298,771	118,099	(127,043)	(24,558)	-	265,269
funds - All other	319,442	451,045	(633,731)	6,951	-	143,707
	1,721,675	1,026,524	(1,518,746)		(50,000)	1,179,453
Summary of fur	nds - prior year					
	Balance at 1 January 2021 £	Income £	Expenditure £	Transfers in/out £	Gains/ (Losses) £	Balance at 31 December 2021 £
General funds Restricted	1,172,015	623,506	(725,272)	8,313	24,900	1,103,462
funds - Branches Restricted	304,487	83,507	(80,910)	(8,313)	-	298,771
funds - All other	170,870	475,455	(326,883)	-	-	319,442
	1,647,372	1,182,468	(1,133,065)		24,900	1,721,675

## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2022

#### 21. Analysis of net assets between funds

## Analysis of net assets between funds - current year

	Restricted Funds - Branches 2022 £	Restricted funds - All other 2022 £	Unrestricted funds 2022 £	Total funds 2022 £
Tangible fixed assets	-	_	332	332
Fixed asset investments	-	-	27,000	27,000
Investment property	-	-	650,000	650,000
Current assets	265,269	143,707	289,998	698,974
Creditors due within one year	-	-	(196,853)	(196,853)
Total	265,269	143,707	770,477	1,179,453
Analysis of net assets between fund	s - prior year			
	Postriotod	Postriotod		

	Restricted	Restricted		
	funds -	funds - All	Unrestricted	Total
	Branches	other	funds	funds
	2021	2021	2021	2021
	£	£	£	£
Tangible fixed assets	-	-	6,619	6,619
Fixed asset investments	-	-	54,000	54,000
Investment property	-	-	700,000	700,000
Current assets	298,771	319,442	391,614	1,009,827
Creditors due within one year	-	-	(48,771)	(48,771)
Total	298,771	319,442	1,103,462	1,721,675

## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2022

## 22. Reconciliation of net movement in funds to net cash flow from operating activities

	2022 £	2021 £
Net income/expenditure for the year (as per Statement of Financial Activities)	(542,222)	69,266
Adjustments for:		
Depreciation charges	5,402	5,402
(Gains)/losses on investments	77,000	(24,900)
Dividends, interests and rents from investments	(28,209)	(25,029)
Decrease in debtors	72,597	13,018
Increase/(decrease) in creditors	148,082	(155,131)
Net cash used in operating activities	(267,350)	(117,374)

## 23. Analysis of cash and cash equivalents

	2022 £	2021 £
Cash in hand	656,510	894,766
Total cash and cash equivalents	656,510	894,766

## 24. Analysis of changes in net debt

	At 1 January 2022	Cash flows	At 31 December 2022
Cash at bank and in hand	£ 894,766	£ (238,256)	£ 656,510
	894,766 ————	(238,256)	656,510

## 25. Subsequent Events

Subsequent to the Financial Year End the Charity took out a £300,000 mortgage from Charity Bank secured on the investment properties owned by the charity. The loan has a term of 25 years.