



Axial SpA
works silently.
We don't.

Improving Care, Transforming Diagnosis and Influencing Change.

Our Impact in 2021



Our story

Axial SpA is an inflammatory disease of the spine and joints. Inflammation, where muscles attach to the bones, causes extreme pain. If left untreated, it can permanently fuse bones together.

www.nass.co.uk

Axial SpA works silently. We don't.

We are the National Axial Spondyloarthritis Society (NASS) and we transform the diagnosis and care of people living with axial SpA.

It's an invisible and misdiagnosed condition, often leaving people feeling powerless, in increasing pain and extreme exhaustion. So, we campaign policy makers for early diagnosis, treatment and better services.

We work with the NHS to get axial SpA identified and diagnosed quickly, and are determined that everyone receives effective care.

We make sure people with axial SpA can access the latest information and the support they need to tackle living with this condition. And we build active communities, online and through our local branches across the UK. We're with you all the way.

Join us. Help us raise our voices and raise funds. Axial SpA works silently. We don't.



Raising our voices, changing lives

The COVID19 pandemic continued to cast a shadow over us all in 2021 and we began to face a new challenge, a cost-of-living crisis.

The NHS remained under pressure and people found getting access to their rheumatology team increasingly challenging.

We were determined to ensure that people received the support they needed to understand how to live well with axial spondyloarthritis. We were also determined to lead change to end the unacceptable 8.5 year delay to diagnosis and drive improvements in care.

With demand for support from our Helpline remaining at unprecedented levels, we provided clarity in a confusing world and ensured that people got timely and accurate information about the vaccine roll-out.

We innovated, piloting our first supported self-management programme in partnership with rheumatology teams. We showed that online patient education sessions give people the skills and knowledge they need to live with the daily challenges of axial SpA. We will continue to develop the programme and are confident that we'll get funding to launch in full during the coming year.

We also launched our ground-breaking *Act on Axial SpA* programme in June 2021, aiming to establish a Gold Standard time to diagnosis of just one year. Our public awareness campaign reached people with unexplained back pain and encouraged them to take steps towards a diagnosis. Our priority over the next few years is to continue to work with health care professionals to ensure that the right patient pathways, diagnostic support and education is in place to ensure early diagnosis.

Our campaigning work continued to gain momentum. We are particularly grateful to the All-Party Parliamentary Group (APPG) on Axial Spondyloarthritis for shining a light on the importance of mental health support and the role of primary care in the diagnosis of axial SpA.

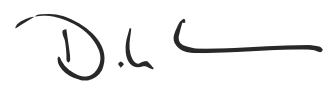
We successfully lobbied to ensure that time to diagnosis of axial spondyloarthritis has a much stronger focus in the National Early Inflammatory Arthritis Audit. This will give us invaluable data and a deeper understanding of the causes of diagnostic delay.

We're proud of our achievements in 2021 but we couldn't have done it without our committed networks of branches volunteers, healthcare professionals, donors and funders, Parliamentarians and policy-makers, who were unfailing in their support.

We want to thank everyone for helping us to deliver more than ever for people with axial SpA during an unprecedented time.



Raj Mahapatra
Chair

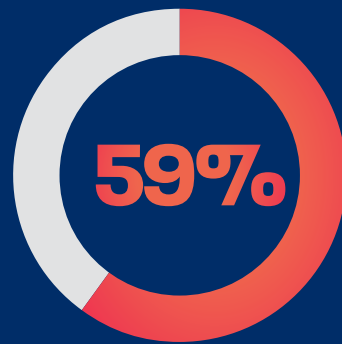


Dr Dale Webb
CEO

Life with axial spondyloarthritis



1 in 200
people live
with axial
SpA in
the UK



of people suffer
with depression

Average number of years
to diagnosis of axial SpA



8.5



The average age of onset

26

Our impact



7,524

Responses to requests
for advice and support



Estimated value
of disability
benefits we
helped
people claim



349m

Total reach of our
media coverage

Total number
of axial SpA
online symptom
checker
completions

2,249



82,000+
views of My AS
My Life, Facebook
Live sessions



Number of
NASS members
4,089

Our influence



Launched a ground-breaking campaign to end the 8.5 year delay to diagnosis



Called for improvements in mental health support for people with axial SpA



Built political pressure for improved diagnosis in primary care



Ensured axial SpA is a larger part of the National Early Inflammatory Arthritis Audit



Campaigned to get hydrotherapy the attention it deserves



Continued to deliver the largest UK programme to improve the quality of care for axial SpA patients

By your side in 2021

The COVID19 pandemic continued to overshadow us in 2021 and the need for our support was greater than ever. When lockdowns ended, people remained concerned about stepping outside. And with the NHS under increasing pressure, many people experienced longer waiting times for vital healthcare appointments.

"I get loads of support both emotionally and physically from NASS, I don't know what I would do without it. Instead of scrolling through social media in the long lockdown evenings, I have been watching live sessions (or recordings) on so many AS bits and pieces, Yoga, self-care, relaxation, AS and psoriasis (biggie for me!)"

NASS Supporter

Providing clarity in a changing world

As the COVID19 vaccine was rolled out and the UK was under lockdown for the early part of the year, we provided up-to-date information when people needed it most.

We worked hard to understand the impact of the virus, the vaccines and the treatments for people living with axial SpA. We ensured our website was kept up-to-date and provided vital information at a time when official information could be confusing.

The COVID19 vaccine pages of our website were visited 27,542 times.

We also continued to provide our guides to rheumatology departments and to individuals with more than 16,000 guides being sent out over the year.

Our Helpline providing a lifeline

Our Helpline team are here to listen, understand and provide advice and practical support to anyone affected by axial SpA. With people struggling to get in contact with their rheumatology department and the COVID19 pandemic still causing disruption, people needed our help and support more than ever.

Calls to our Helpline rose to an all-time high and we responded to over 7,500 requests for advice and support, a third more than in 2020. To do so, we sustained the extended Helpline opening hours that we established in 2020. Along with information and advice on COVID19, we worked to support people who had questions about how to best manage their axial SpA.

As more people started to experience greater financial pressure because of the pandemic, we were there helping them get the benefits they are entitled to.

We wrote over 200 letters in support of disability benefits claims, resulting in benefits awards totalling more than an estimated £1,000,000. We also wrote letters to employers, to housing departments and to support Blue Badge parking applications.

Helping people live well with axial SpA, wherever they are

In 2021, we continued our innovative *My AS, My Life* programme which empowers people to overcome the challenges of living with axial SpA. We ran 33 sessions through Facebook Live, which were designed to help people understand how to live well and self-manage their condition. These sessions were viewed over 82,000 times.

Our *My AS, My Life* website pages continued to be popular, with 10,376 visitors using resources including videos, blogs and exercise sheets.

Enabling people to overcome daily challenges

We're determined to enable people to thrive with axial SpA and developed an online supported self-management programme to help people develop the skills and knowledge they need to manage daily challenges.

We piloted the programme during the first five months of 2021. Thanks to a grant from the Postcode Neighbourhood Trust, we ran 10 online sessions and established a case for running a full programme in the future.

The results from the pilot showed the programme gives people with axial SpA the information and support they need to manage their condition, helps them build connections in their local area and feel less isolated. It also helps rheumatology departments provide more patient education for people who are struggling to access routine appointments.

We will continue to develop the programme in 2022.

“Thank you so much! It was a really enjoyable session. I haven't been prioritising my health recently and it has spurred me on to get back on track with exercising.”

Session participant,
November 2021



Campaigning to transform care and diagnosis

With people finding it harder to access NHS services and the pandemic causing significant disruption, we did more than ever to ensure that parliamentarians and policy makers heard the voice of people with axial SpA.

Calling for improvements in mental health services

Axial SpA has a significant impact on people's mental health, as well as physical health. Indeed, up to 59% of people with the condition report having poor mental health.

We were acutely aware that the pandemic and lockdown had put more pressure on people's mental health and in April, the All-Party Parliamentary Group (APPG) on Axial Spondyloarthritis met to look at the issue.

We were grateful to NASS Trustee, Paul Curry, for sharing a very emotional and personal story about the impact living with axial SpA has on his own mental health.

The meeting shone a light on research that shows the emotional impact of living with axial SpA, steps that have been taken in Newcastle to ensure people have access to mental health services and approaches to improving the management of long-term conditions. Sue Brown from the Arthritis and Musculoskeletal Alliance shared its view on how mental health services could be improved for people with MSK conditions.

Improving diagnosis and referral in primary care

Lack of awareness of axial SpA in primary care is one barrier to the faster diagnosis of the condition. The seventh meeting of the APPG explored this area and highlighted the main challenges faced by GPs and secondary care professionals in recognising and diagnosing axial SpA, the role of first contact practitioners and the NHS England Best MSK Health programme and how it's supporting improved outcomes for those affected by axial SpA.

Dr Dale Webb, our CEO, also talked about the *Act on the Axial SpA* campaign and our programme to introduce a Gold Standard time to diagnosis of just one year.

Ensuring hydrotherapy gets the recognition it deserves

We are determined that hydrotherapy is recognised as a vital treatment for people with axial SpA. In 2021, we established a new alliance to promote aquatic physiotherapy and hydrotherapy for a range of conditions.

Standing together gives us a strong voice. The group includes professional bodies for physiotherapy and aquatic therapy, Swim England, as well as our fellow patient organisations.

Campaigning for hydrotherapy services to re-open

Too many people are missing out on vital hydrotherapy because pools in some parts of the country have remained closed.

To help keep up the pressure for pools to reopen following the COVID19 pandemic, Tom Randall MP asked a question in the House of Commons. This led to Dale Webb meeting with Health Minister Ed Agar and the Department of Health to discuss the issue in more detail.

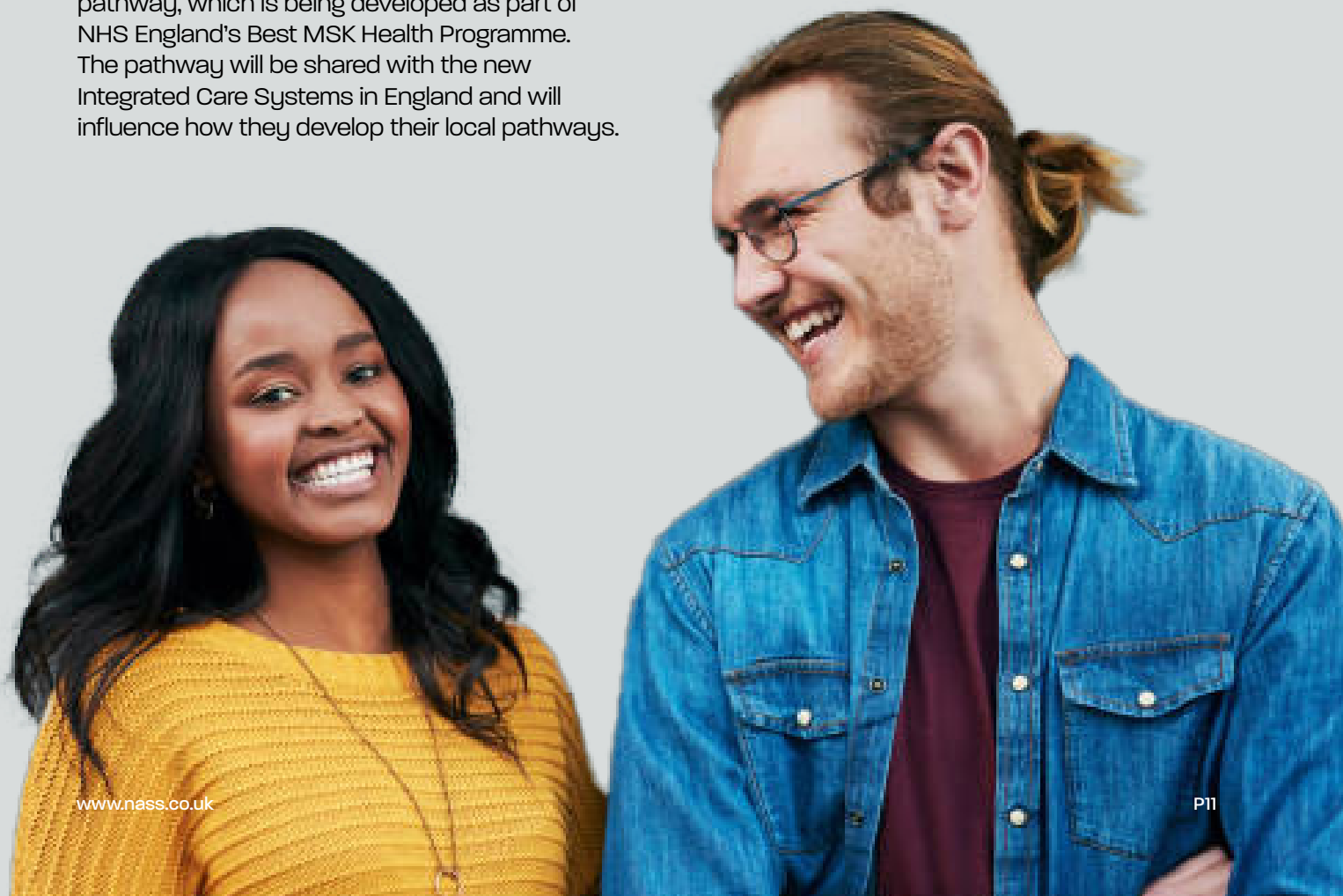
Influencing change

We worked hard to influence policy to ensure that axial SpA gets the attention it deserves.

We helped shape the new axial SpA patient pathway, which is being developed as part of NHS England's Best MSK Health Programme. The pathway will be shared with the new Integrated Care Systems in England and will influence how they develop their local pathways.

Our work with the National Early Inflammatory Arthritis Audit ensured that axial spondyloarthritis has a stronger focus in the audit. Data will be collected on people's journey to diagnosis, giving us invaluable evidence on the causes of diagnostic delays that will influence our *Act on Axial SpA campaign*.

We helped improve treatment options for people with axial SpA by providing evidence for two National Institute for Health and Care Excellence (NICE) technology appraisals which led to two new treatments being approved for non-radiographic axial SpA and ankylosing spondylitis.



Ending the delay to diagnosis

In June 2021 we launched our ground-breaking *Act on Axial SpA programme* to tackle the unacceptable 8.5 year delay to diagnosis of axial spondyloarthritis and introduce the world's first Gold Standard time to diagnosis of one year.

Building consensus

Over the next four years, we will work closely with people living with axial SpA, primary and community care, secondary care, professional bodies, commissioners, Parliamentarians and policy-makers, to reduce the time to diagnosis.

Our first step was to build strong foundations for the programme by developing it in consultation with people with axial SpA and healthcare professionals. We used the insights we gathered to refine the campaign strategy and develop a new language and visual identity for the campaign.

Increasing public awareness

Lack of public awareness of axial SpA and its symptoms contributes to the delay to diagnosis. According to our research, 91% of people say they haven't heard of the condition and eight out of 10 people are unable to identify the three main symptoms.

Our first step was to launch a public awareness campaign and a new website, www.actonaxialspa.com. It provides the most comprehensive hub of information for healthcare professionals and people who think they may have the condition, and hosts an easy-to-use symptom checker.

The campaign targets people aged 40 and under who are experiencing lower-back pain. In the first year, we showed that by telling emotionally compelling and relatable stories about axial SpA, we can motivate people to find out more about the condition and use our online symptoms checker.

Making progress in 2021

Our focus for the first year was testing the public awareness campaign. By the end of the year, social media content had touched people 1.2m times, we secured 14 pieces of media coverage, 16,000 people visited our campaign website and 2,249 people had completed the symptom checker.

Stepping into 2022

During 2022 we will work closely with primary and secondary care professionals, including launching a *Champions in Primary Care* programme and developing a local pilot to test data-led innovative approaches to driving up referrals to rheumatology.


We will also launch ground-breaking research on the full economic cost of the 8.5 year delay to diagnosis, to support our influencing work.

We are grateful to UCB for fully funding the programme and to Norfolk & Norwich NHS Foundation Trust and Royal United Hospital Bath NHS Foundation Trust for their support.



www.actonaxialspa.com

The most comprehensive hub
of information and hosts an
symptom checker



“More than eight years is too long to wait for a diagnosis but we can only tackle this delay by working together. NASS is not only increasing public awareness but leading a community of healthcare professionals who are committed to this movement for change. A movement that will make a life changing difference to thousands of people.”

Raj Sengupta

Consultant Rheumatologist

Improving axial SpA care

We're determined to improve axial SpA care. Established in 2019, *Aspiring to Excellence* encourages and recognises service improvement in axial SpA care. The programme is a strategic partnership between NASS, BRITSpA, the NHS Transformation Unit, and sponsors AbbVie, Biogen, Lilly, Novartis and UCB.

Driving improvement

The programme provides tailored support that helps rheumatology teams drive improvements in their departments. Teams from across the UK are taking part and exploring novel approaches to care to inform, encourage and support national changes in axial SpA services.

Six rheumatology departments joined the programme in 2019 and five more in 2021.

Resilience in the face of Covid19

Against a backdrop of increasing pressures on the NHS, the teams demonstrated an impressive ability to stay engaged and implement many of their planned improvement initiatives.

They have shown significant adaptability, resilience and teamwork and, turned adversity into opportunity – harnessing digital solutions and innovative new ways of working – in rapid response to the pandemic.

- The Newcastle rheumatology team trained community-based physiotherapists, leading to improved rheumatology referrals in order to reduce the time to diagnosis.
- The Southampton team implemented an inflammatory back pain (IBP) pathway from primary care in order to reduce time to presentation in rheumatology. They also introduced an MRI spine inflammatory back pain protocol to reduce variation in imaging.

- The Leeds team established a tertiary referral service which has significantly improved time to diagnosis.
- The Berkshire team implemented mental health interventions for patients which have reduced the percentage of patients with abnormal Hospital Anxiety and Depression Scale scores.
- The Fife team established a pathway for physiotherapy self-referral and reduced physiotherapy 'Did Not Attend' rates.
- The Sheffield team used audit data to make the business case for an extended scope practitioner.

“The Aspiring to Excellence programme has given us structure and focus to build on our work to achieve the best standard of care in axial SpA. We have embedded new practices into our axial SpA patient pathway that have both spread and are sustainable. This will ensure there is continuous improvement in our service long after we have completed the programme for the benefit of our patients.”

Dr Antoni Chan

Consultant Rheumatologist

Building a community

People tell us that living with axial SpA can be isolating, so through branches and NASS membership we build connected communities that help people feel less alone.

Branches are our lifeblood

During 2021, there were 85 NASS branches run entirely by volunteers. Against a backdrop of Covid lockdowns, many continued to meet online, giving hundreds of people a much needed opportunity to take part in essential physiotherapy-led exercise and connect with friends.

As things started to open up, our branches worked tirelessly to get back to in-person sessions. We are grateful for the resilience they showed during an unprecedented time.

Connecting through membership

Our members tell us that by joining NASS they feel less alone and isolated with axial SpA, and part of a community that understands life with the condition.

We have seen a steady growth in the number of NASS members, and by the end of 2021 we had 4089 members.

We also held our first hybrid Members' Day, which was attended by 60 people in person and 200 online. Attendees spent a day diving into sessions on the latest treatments for axial SpA and also new ideas on how to manage the condition at home.

“NASS has been invaluable and enabled me to connect with other people with axial SpA.”

Richard Shire

NASS Member

NASS Voices

[It was] a very informative day with lots of new information on issues I need to address. Great venue. It was lovely to meet new people.”

In 2021, over eighty people attended events in Chester and Newcastle to learn more about axial SpA from NASS, rheumatologists, physiotherapists and occupational therapists, and to meet others affected by the condition.

Over 90% of attendees came away from NASS Voices events, feeling more confident about managing their condition.

NASS Voices Newcastle was funded by the National Lottery Community Fund, which is funded by National Lottery players while NASS Voices Chester was funded by The Ursula Keyes Trust.

Raising funds, raising voices

We want to say a special thank you to everyone who helped us raise vital funds and stepped forward to tell their story to increase awareness of axial SpA. You helped us raise our voices and change lives.

Raising essential funds in a tough year

We receive no statutory funding and rely on the generosity of our fundraisers to do our amazing work.

Thank you to everyone who donated or took part in fundraising, despite the pandemic. Thanks to you, we continued to run our helpline, support people with benefits applications, provide free resources such as guides and videos and run Facebook Live sessions. You helped power us through the pandemic and we couldn't have made a life changing difference to so many people without your help.

"I decided that I wanted to combine my love of swimming to raise awareness about axial SpA, and raise money to support NASS, who have been such amazing support for me over the years."

Darren Fletcher swam 10 miles
and raised £1,459 for NASS.



Raising our voices in the media

We are doing more work than ever to ensure axial SpA gets the attention it deserves and to tell the story of life with the condition in the media and on social media

During 2021, our media relations work led to nearly 349 million opportunities to see or hear our campaign messages. Coverage included BBC Radio 2 Jeremy Vine Show, The Dundee Courier, The Daily Express, The Daily Mirror, The Daily Mail, Men's Fitness Magazine, The Sun Online, Chat Magazine and Irish News.

We have also changed our approach to social media and seen a significant growth in the number of followers. During 2021, the total reach of our Facebook page was 1,148,046, a growth of 469% compared to 2020. Our Facebook followers grew by 59%.

We're grateful to everyone who stepped forward to tell their story, but particularly grateful to Singer-Songwriter, Talia Dean, and DJ and Entrepreneur, Mark Wilkinson.

We would like to thank the Charitable Trusts that supported us in 2021

- The Alice Ellen Cooper Dean Charitable Foundation
- The Baker Charitable Trust
- The David Gibbons Foundation
- The Eveson Charitable Trust
- The Edward Cadbury Charitable Trust
- The Edward Gostling Foundation
- The G C Gibson Charitable Trust
- The Ganzoni Charitable Trust
- The Hospital Saturday Fund
- The Hugh Fraser Foundation
- The Hamilton Wallace Trust
- John Coates Charitable Trust
- The James Weir Foundation
- James Tudor Foundation
- The Khayami Foundation
- Lord Leverhulme's Charitable Trust
- Lottery Awards for All
- The Mary Homfray Charitable Trust
- Masonic Charitable Foundation
- The Norman Family Charitable Trust
- Northern Pharmacies Limited Trust Fund
- Summers & May Charitable Settlement
- Sir Jules Thorn Charitable Trust
- The Simon Gibson Charitable Trust
- The Thousandth Man-Richard Burns Charitable Trust
- The Ursula Keyes Trust
- The Weinstock Fund
- Postcode Neighbourhood Trust

We would like to thank the companies that supported us in 2021

abbvie

 Biogen

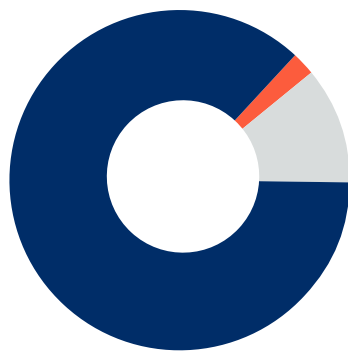
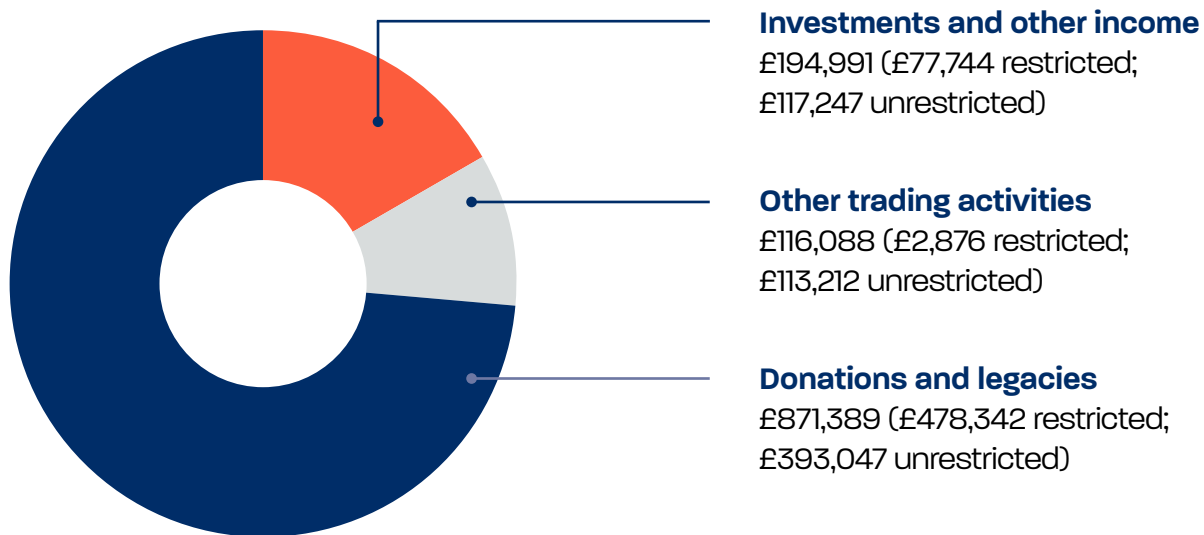
Lilly

janssen 

 NOVARTIS

 Inspired by patients.
Driven by science.

Our year in numbers



Our expenditure

Cost of raising funds £126,457 (£106,356 Direct costs; £20,101 allocation of overheads)

Governance £23,134

Charitable activities £988,511 (£412,830 restricted; £575,681 unrestricted)



A breakdown of how every £1 was spent in 2021

■ 87% was on charitable activities

■ 11% was on raising funds

■ 2% was on governance

**Axial SpA
works silently.
We don't.**



**National Axial
Spondyloarthritis
Society**

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Facebook: **@NationalAxialSpondyloarthritisSociety**

Instagram: **@NASS_exercise**

NASS is a registered charity in England and Wales (1183175) and Scotland (SC049746)