



FOR EVERYONE AFFECTED BY  
AXIAL SPONDYLOARTHRITIS

# 2019 IMPACT REVIEW



[nass.co.uk](http://nass.co.uk)



## **2019 was a year of significant progress for NASS and we are proud to present this summary of our achievements to you.**

We wanted to ensure that axial SpA (AS) gets the attention it deserves among Parliamentarians and policy makers. So we created the first ever Parliamentary committee on axial SpA (AS) and got off to a great start. Already, it has built political pressure for improvements in care, commissioning the first national inquiry into axial SpA services across England, as well as highlighting examples of best practice.

The launch of the *Aspiring to Excellence* programme was particularly exciting for all of us because of the opportunities it presents to improve and shape the future of axial SpA (AS) treatment for many years into the future, with the aim of finally breaking the 8½ year deadlock in the delay to diagnosis that has persisted for so long.

Alongside these significant developments we maintained our important core activity supporting people living with axial SpA (AS) through our helpline and national network of branches. During the year the helpline supported more than 5,000 people with some incredible results you'll read about later.

During 2019 we also changed our name to the National Axial Spondyloarthritis Society to reflect the language more commonly used by healthcare professionals, researchers and policy makers, and we were pleased to have the overwhelming support of our members in bringing about this change, ensuring that NASS continues to be relevant for many years to come. We also changed our legal status, becoming a Charitable Incorporated Organisation (CIO).

**Read  
more about  
our advocacy  
and campaigning  
activity including  
a new focus in  
parliament**

**Page 4-5**

**Read more  
about how we  
are improving the  
future for all axial  
SpA (AS) patients**

**Page 6-7**

**Read about the  
results of NASS's  
advice and support  
services**

**Page 8-9**

We also refreshed and revised our guides and launched new exercise videos all of which were well received by our members and supporters. More than 1,500 people attended a NASS event in 2019, and through regular consultation and engagement at these events and on our social media channels we continue to listen to our members' and supporters' feedback and use this to plan our future guides, videos and other activities.

We must end by extending our thanks to the hundreds of volunteers who've supported our work over the last year, to our small but incredibly dedicated and hard-working staff team, as well as our trustees and our thousands of members. Collectively these people make NASS and enable us to achieve so much.



**Raj Mahapatra**  
Chair of Trustees



**Dr Dale Webb**  
Chief Executive



**Read  
how our  
branches and  
events have kept  
our members at  
the heart of what  
we do.**

**Page 10**

**Read  
about some  
of our amazing  
fundraisers and  
more about our  
finances.**

**Page 11-12**

NB: This Impact Review reports on our work throughout all twelve months of 2019, in other words, during our time as the Society and then subsequent period as the CIO.



# Advocacy and campaigning

While we continued to support people living with axial SpA (AS), in 2019 we shifted up a gear in our advocacy and campaigning activity including with a new focus in parliament.

Axial SpA (AS) affects one in 200 people in the UK making it more common than MS and Parkinson's combined, and yet public awareness remains low and there are multiple challenges in treatment – not least the average 8½ year delay to diagnosis.

Recognising these challenges and with determination to change the life chances of people diagnosed with axial SpA (AS), in March a group of MPs and Peers came together with NASS to launch the first ever **All Party Parliamentary Group** (APPG) on Axial Spondyloarthritis.

Chaired by Lord Campbell-Savours - who has axial SpA (AS) - and Derek Thomas MP, the APPG aims to explore ways in which treatment can be improved whilst monitoring the implementation and success of existing standards – including the NICE Guideline and Quality Standard.

The APPG met twice during 2019 and commissioned NASS to undertake a national inquiry, producing a report under the Freedom of Information Act, to establish how NHS Trusts are meeting the requirements set out by the regulator NICE. Initial results were presented in Parliament in July. The Chief Executive presented the results of the national inquiry in Scotland at the Cross Party Group for Arthritis and Musculoskeletal Conditions in the Scottish Parliament.

We also engaged in campaigns around the country, including launching a petition to save the **hydrotherapy pool** at Bedford Hospital and campaigning to keep the pool at Charring Cross Hospital. We remain concerned that these pools are facing budget cuts nationally.

NASS also published responses to the **NHS Long-Term Plan**, and a response to the **Prevention Green Paper**.

## Key findings from the Freedom of Information inquiry



Only **21%** of Clinical Commissioning Groups (CCGs) have a specific inflammatory back pain pathway in place



Only **15%** of CCGs have specific programmes in place for educating Primary Care practitioners about axial SpA (AS)



**17%** of rheumatology services do not routinely offer full spinal MRI



Just one **quarter** of rheumatology services offer direct access to psychological services via secondary care to those who require it



**One fifth** of rheumatology services do not have access to a specialist rheumatology physiotherapist

**This page**  
Dr Antoni Chan at the  
APPG meeting in July.



# Every Patient, Every Time

We know that not everyone in the UK gets the same standard of care for their axial SpA (AS) and that's why we launched our *Every Patient, Every Time* campaign in Parliament in December 2018 to help us drive improvements for all axial SpA (AS) patients.

At the British Society for Rheumatology conference we launched ***Aspiring to Excellence***, an ambitious five-year programme designed to encourage and recognise service improvement in axial SpA (AS) care. The programme is a partnership between NASS and BRITSpA and sponsoring companies AbbVie, Biogen, Novartis and UCB.

We partnered with the NHS Transformation Unit as our quality improvement delivery team, and after a process that saw applications from rheumatology departments across Britain, we made six initial awards which we announced at the *NASS Voices* conference in London. Participants from the six teams joined the first learning session shortly afterwards.

**ASPIRING TO  
EXCELLENCE**





**Left**  
Map of current  
*Aspiring to Excellence*  
services

**Below**  
*Aspiring To Excellence*  
programme teams at  
NASS voices London

The **NASS Allies programme** aims to reduce the delay to diagnosis – currently averaging 8½ years – by improving the knowledge of health professionals including osteopaths and chiropractors.

During 2019 we developed a template to assist osteopaths and chiropractors in making referrals to rheumatology departments, and we were delighted when the template was approved by the Royal College of General Practitioners, the Chartered Society of Physiotherapy, the Institute of Osteopathy and the Royal College of Chiropractors. It was launched at the Primary Care & Public Health conference where we interacted with more than 1,000 clinicians.

At other **conferences and events** we met with more than 200 visitors to our stand at the British Society for Rheumatology conference, 600 at the Primary Care & Public Health conference where we distributed more than 250 information packs, and 200 visitors to our stand at the BRITSpA conference.

We **published research** in the *Advances in Rheumatology* journal and also featured in a number of other magazines and websites for healthcare professionals, including *Arthritis Digest*.



# Advice and Support services

NASS has supported people living with axial SpA (AS) for more than forty years, and 2019 was no different: thousands of people across the UK benefited from NASS advice and support.

Our **Helpline** is open for three hours every weekday and in 2019 we handled more than 5,000 emails and calls for assistance. A significant change in treatment for axial SpA (AS) led to a large number of enquiries about the introduction of the biosimilar adalimumab, on which we worked closely with NHS England to keep people informed.

We also helped 128 people with **claims for Personal Independence Payment** and as a result £539,054 was paid in back-payment to people who contacted us. Similarly we helped 16 people challenge **work capability assessments** to claim £161,657. In total we helped people living with axial SpA (AS) claim almost £700,000 that was owed to them.

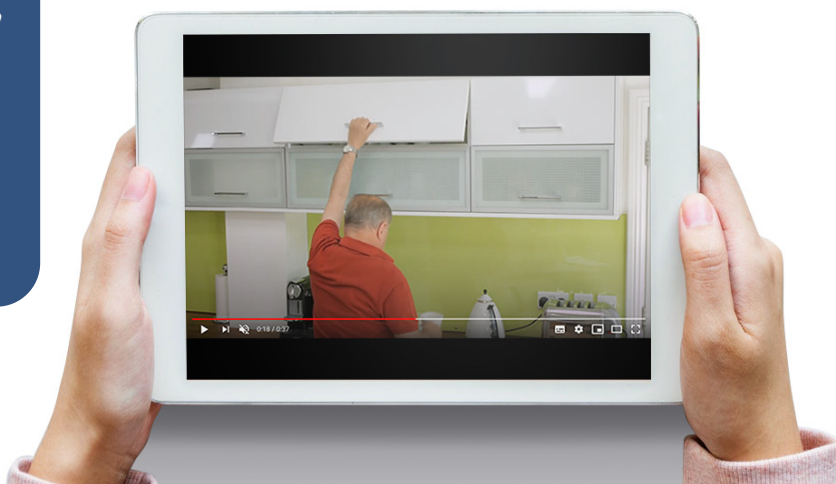
Enquiries relating to 'blue badge' parking permits, housing applications and medical retirement claims were also handled by our Helpline team.

In October we launched a series of **exercise videos** as part of our collaboration with *AStretch* physiotherapists. Designed to show exercise that people living with axial SpA (AS) can enjoy at home, the videos were shot in a home environment rather than an exercise studio, and everyone who featured in the video lives with axial SpA (AS) themselves.

Eleven videos were published in the lead up to World Arthritis Day, and in the three months after launch they had been viewed more than 20,000 times.

"Thank you for taking the time to amend my [PIP] letter prior to submission, I have no doubt that this has contributed significantly to the decision to award."

"[The videos are] really appropriate and realistic. I was able to imagine myself doing them all."





**Left**  
Screenshot of  
exercise video

**Below**  
New guides to living  
with axial SpA (AS)

Seven rewritten **guides to living with axial SpA (AS)** were published, all featuring a fresh new design and with each cover featuring a NASS member. Within two months of their launch, they had been viewed more than 12,500 times and downloaded by more than 8,000 people.

“[The guides] were really informative and easy to read. Great to have the personal insights.”



# Branches and events

People living with axial SpA (AS) are at the very heart of what NASS does. Our work to create and sustain connected and supportive communities of members and supporters continued in 2019.

Across the UK, **NASS branches** have provided support and a sense of community to axial SpA (AS) patients for 35 years. We now have 92 branches all led by volunteers who give up their time and energy to help others living with axial SpA (AS).

People attending NASS branches benefit from improved mobility and flexibility and a reduction in stiffness as a result of accessing regular physiotherapy. During 2019 branches provided 7,000 hours of guided physiotherapy to more than 1,000 patients, saving the NHS more than £2.4m.

Each year we hold engagement events around the country to connect with members, supporters and others living with axial SpA (AS). These are an important opportunity for people to come together, learn new techniques in exercise and the latest treatments, and to find out about NASS' work.

During 2019 our **NASS voices events** took place in Cardiff, Southampton, Sheffield and London, and our Members Day and AGM was held in Birmingham.

The events are welcomed by our community. Of those attending NASS Voices in London, all gave the event a score of eight or nine out of ten. A quarter of those attending Members' Day were new to NASS, and almost a third said their primary reason for attending was to meet other people.



**ASone**, our online community for young people living with axial SpA (AS), welcomed a number of new contributors who blogged on a range of topics and whose content led to a significant increase in engagement towards the end of the year.



The community elements of our **social media** continued to strengthen and grow. Many times throughout the year we asked our followers for their feedback on various topics and subjects including exercise, relaxation, diet and experiences with healthcare professionals. Our online community remains highly engaged and eager to contribute their inspiring ideas and views.



# Fundraising

Our work is only possible thanks to our wonderful donors and the intrepid, inspirational and inventive activities undertaken by supporters who raised funds on our behalf.

During 2019, 235 fundraisers collectively raised £94,894 for NASS through a variety of activities including sponsored sporting feats, social events such as parties and craft sales, and asking for donations to NASS in lieu of birthday and anniversary gifts.

We gratefully acknowledge the legacies and in memoriam donations we received during 2019, totalling £278,999. Our work reflects the lasting legacy of these people – without them we would not be able to continue with so much of our work.



Sandra Bull has axial SpA (AS) and completed a sponsored bike ride and walk, and held a barbeque and raised £800!



Physiotherapist Chris Martey completed the Snowdon Trail Marathon in north Wales and raised £756!

**With sincere thanks to the following charitable trusts:** Bernadette Charitable Trust, Charles Fairweather Charitable Trust, GC Gibson Charitable Trust, Hamilton Wallace Trust, John Coates Charitable Trust, Lord Leverhulme's Charitable Trust, Mary Homfray Charitable Trust and the Simon Gibson Charitable Trust.

**We are grateful to the following corporate partners:** AbbVie Ltd.

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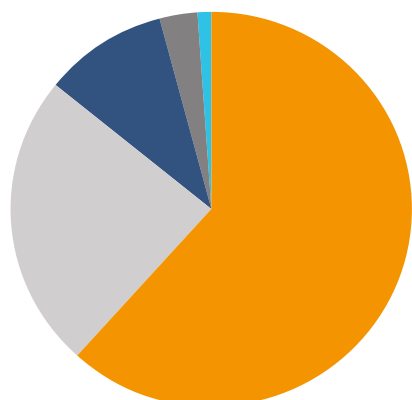
NOVARTIS

ucb Inspired by patients.  
Driven by science.

The financial support from these companies does not influence our work in any way, and complies with the ABPI code of practice.

Our full Annual Report & Accounts can be found at [nass.co.uk](http://nass.co.uk).

The following information is provided as a summary.



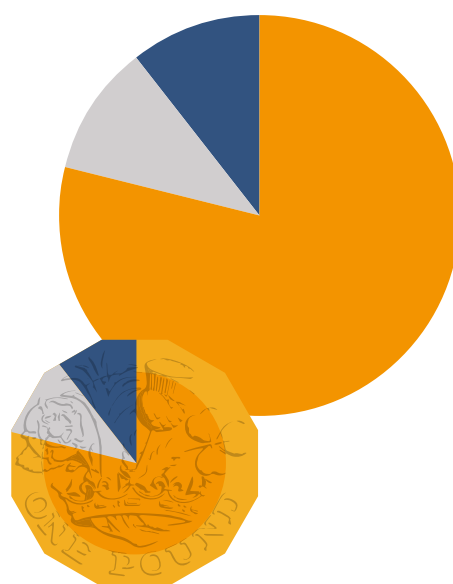
### Income

Donations and legacies	£619,462
Charitable activities	£243,052
Other trading activities	£100,707
Investments	£29,427
Other income	£10,598

### Expenditure

Charitable activities	£948,503
Governance	£127,751
Cost of raising funds	£125,020

Of every £1 we spent in 2019, 79% was spent on charitable activities, 11% was for governance and 10% was spent on raising our funds. Governance costs were higher in 2019 due to the legal, accounting, auditing and administration costs associated with the change in our name and legal status.



### Legal and contact information

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