NATIONAL
ANKYLOSING
SPONDYLITIS
SOCIETY

NASS UK

# Report and Accounts
# For the year ended
# 31 December 2016

Registered Charity Number 272258 Scottish Charity Registration Number 041347

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# Chair's Report

Writing this annual report always gives me a welcome opportunity to look over the year and celebrate everything that we have achieved. It is a moment for reflection and celebration, and for looking back as well as forwards. This year my reflections have perhaps taken a longer view as we have been celebrating our charity's 40th birthday.

Being the Chair of such a long-standing and impressive body as NASS, I am always aware that I am just one in a long line of people on whose shoulders I now stand. In this, our anniversary year, I have been delighted to meet some of the founders and early supporters, and have been struck over and over again that NASS today clearly remains so true to their founding principles; that there should be a community of support and advice available to anyone living with AS no matter where they are in the UK. And it is this word 'community' that I have carried with me throughout this year and is, I believe, what makes our organisation such a privilege to be part of.

Debbie will tell you all about the wonderful events that have taken place up and down the country this year and as I don't want to tread on her toes, I will try not to repeat everything she will say here. I want instead to talk about this idea of community, how I have seen it in action in the past year and what it means to all of us living with AS.

NASS's standing, not just in the UK but in the world, is such that everyone wants to know about what we do here. As NASS Chair, this year alone I have represented our organisation in Russia, Italy, Bulgaria and Switzerland, speaking to people affected by AS and those working professionally in the wider field of the care and research into inflammatory conditions. And I am not alone at NASS in being invited to speak internationally about the things that our members care about. Debbie, Hedley and Sally have also been busy sharing the tremendous work that NASS does on the international stage. One of striking things we learnt through our involvement in the European Patient Innovation Summit in Milan was that as a patient organisation, how we function as a community is recognised as world leading – not just for those with AS in the UK but for many medical conditions, no matter where you are in the world.

But all this international work is just a small part of what NASS has achieved this year. At a national level, NASS's work with NICE on its guidelines for the treatment of AS in this country will impact every person living with the condition from pre-diagnosis onwards. Let me take a moment to let that sink in. NASS's work has reached every single person in the UK whether they know they have AS or not. That is a remarkable achievement and one that we should all be extremely proud of.

Underpinning all of this there are other communities around NASS without whom, our wider work could not continue. Events have taken place across the country this year celebrating the 40th anniversary and I have had the privilege of attending many of them. One of these was a great charity football match held in Newcastle.

Organised by Trustees Gillian Eames and Jean Morton together with Gillian's son Lee and long time NASS supporter Paul Curry (with the assistance of numerous family and friends), players came together to help raise awareness and funds for NASS. Three former Sunderland AFC FA Cup winning legends, Richie Pitt, captain Bobby Kerr and Micky Horswill started the match. Over 150 people turned out to take part and to cheer the teams on. Again, this was the NASS community coming together to raise awareness, raise money and to raise the roof and all this despite the atrocious bank holiday weather! This was quite simply, the NASS community at its finest and it is this that I have seen replicated over and over again at special events this year.

And in the regular branch meetings all across the country, our community is hard at work, week in and week out. In our 40th year we have taken time to recognise the incredible contribution of those who work with our members, providing healthcare, advice and support. It was a great honour to kick off our first ever NASS Patients' Choice Awards for healthcare professionals at the Houses of Parliament. As always at these events, there are never enough prizes for everyone nominated but it was both inspiring and humbling to hear each and every story of how these professionals have touched the lives of so many of our members.

So from the international to the national down to the personal, the community that is NASS shines through. We are not only a group of people who live with a condition and want to talk about it. We are not only a group of people who work in the health care profession who want to make people's lives easier. We are not only a membership organisation who supports just those who have paid their dues. Our community is all these things and at the same time, much more.

As I said at the start of this report, I am only too aware that I stand on the shoulders of those who have gone before me. And in this 40th year, it is clear that I stand on the shoulders of giants.

Raj Mahapatra, NASS Chair

May 2017

# Chief Executive's Report

## NASS – Highlights of 2016

- Back Pain Plus project launched & reaches above industry standard engagement in first phase
- First ever NASS Patients' Choice Awards
- Successful Parliamentary Event
- 5312 Helpline enquiries handled
- Increase in all social media engagement – 11,892 'likes' on Facebook
- You Tube channel on NASS website – 3 new videos produced
- AS & You events in Norwich, Aberdeen, Plymouth and Leeds
- Contribution on NICE Clinical Guideline Group on Spondyloarthritis completed – Guideline published February 2017
- 200 people attend Members' Day in Bath
- Successful year of NASS Fab@40 celebrations

# Campaigning

## Back Pain Plus

This year saw the launch of a brand new campaign by NASS called Back Pain Plus. This is an awareness campaign targeting ophthalmologists, dermatologists and gastroenterologists, aiming to help reduce the current 8.5 year average delay in diagnosis for people with axial spondyloarthritis (including ankylosing spondylitis) (AS).

- 26% of people with AS have uveitis & 40% of people with uveitis have spondyloarthritis
- 9% of people with AS have psoriasis
- 7% of people with AS have inflammatory bowel disease (Crohn’s disease and ulcerative colitis)

Phase 1 of the campaign ran from January to March 2016 and included:

- The creation of three infographics to be used as emails, flyers, posters and banners, describing the project and asking consultants for appropriate referrals to rheumatology
- An email to rheumatologists on the NASS mailing list in advance of the mailing to gastroenterologists, dermatologists and ophthalmologists asking rheumatologists to promote the campaign and giving advance warning that referral numbers would likely increase
- The relevant infographic was emailed to consultants and special interest registrars using lists supplied by a leading healthcare intelligence provider (a total of 2,393 gastroenterologists, dermatologists and ophthalmologists). Recipients were referred to the NASS website to download specific written patient information leaflets about why the referral had been made
- The relevant infographic was posted to consultants and special interest registrars using lists supplied by a leading healthcare intelligence provider (a total of 1,324gastroenterologists, dermatologists and ophthalmologists). Recipients were referred to the NASS website to download specific written patient information leaflets about why the referral had been made
- Distribution of flyers and handouts at the British Society for Rheumatology (BSR) Conference 2016 to further inform and engage rheumatologists.

### Phase 1 results

Website (in first 7 days of the campaign launch)

- 258 page views
- 167 unique page views

Email display rates (over first 7 days of the campaign launch)

- Dermatologists – 10.58% (55) engaged
- Ophthalmologists – 19.55% (184) engaged
- Gastroenterologists – 15.61% (148) engaged
- Industry standard after 7 days is 6% - 8%

250 posters and flyers distributed at the BSR conference, other events and via the office to physiotherapists and rheumatologists to pass to colleagues in the fields of gastroenterology, dermatology and ophthalmology.  Building on this momentum with a view to reducing the delay to diagnosis is essential and so Phases 2 - 5 of this campaign are planned for 2017.

## *AS it is*: Patient Voice & Patient Choice

AS it is...

On 2 November 2016 NASS welcomed 150 supporters to the Houses of Parliament for a reception to promote further our *AS it is* campaign. Many thanks to Ben Howlett, MP for Bath, for hosting the event.

Our 2016 Parliamentary event:

- Encouraged supporters to invite along their MP to discuss how AS affects them
- Saw every MP in the UK invited along to learn more about the NICE Clinical Guideline for Spondyloarthritis and ask for their support for implementation of the Guideline once published in Spring 2017
- Hosted the first ever NASS Patients' Choice Awards for health care professionals

I was honoured to open the event talking about the importance of our main campaign messages. Raj Mahapatra (NASS Chair) introduced the Patients' Choice Awards and Dr Karl Gaffney (Chair of the Medical Advisory Board) announced the award winners after receiving his own award from Raj. A total of 19 MPs attended and a further 22 pledged to support the new Clinical Guideline when published. Special thanks to Lydia Flett, NASS Volunteer and Gillian Eames, NASS Trustee, for the great deal of effort spent in securing the number of MPs attending and engaging, a definte high for a charity of NASS's size and an event of this nature.

In June 2016 we launched our Patients' Choice Awards and asked members to vote online. The submissions were judged by a panel made up of myself and non-medical NASS Trustees. Thank you to everyone who took the time to vote. It was wonderful to be able to recognise the amazing work that has been done by these individuals and teams to help ensure a better quality of life for people with AS.

The winners were:

- Dr Karl Gaffney, Norfolk & Norwich Hospital, Undercover Hero
- Dr Raj Sengupta, Royal National Hospital for Rheumatic Diseases, Bath, Best Care by a Rheumatologist
- Claire Jeffries, Queen Alexandra Hospital, Portsmouth, Best Care by a Physiotherapist
- Clare Longton, Royal Lancaster Infirmary, Best NASS Branch Physiotherapist
- NASS London Harrow group of physiotherapists, Best NASS Branch Physiotherapy Team
- Michelle Rutherford, Freeman Hospital, Newcastle , Best Rheumatology Nurse
- Kelly Hayes-Head, Airedale Hospital, Keighley, Best Rheumatology Nurse (Highly Commended)
- The Queen Alexandra Hospital, Portsmouth, Best AS Clinic
- Dr John Hunter, Glasgow Gartnavel General Hospital, You Changed My Life award*
- Dr Justine Horton, Grove Surgery, Ripley, Derbyshire, Best Care by a GP
- Royal National Hospital for Rheumatic Diseases, Bath, Excellence in AS Care (Team)
- Liz Van Rossen, Kent & Canterbury Hospital, Excellence in AS Care (Individual)

**to be awarded at the Cross Party Group for Musculoskeletal Conditions meeting in the Scottish Parliament on 1 March 2017.*

## World AS Day

World AS Day 2016 fell on 7 May 2016. A Thunderclap focused on NASS's 40th anniversary, asking followers to upload images of how it feels to live with AS which were then made into a collage. Followers were also asked to share a link about AS to further raise awareness of the condition. The total reach via Facebook and Twitter was 153,764 and led to 1,409 views of the NASS website that day (three times more than on an average Saturday).

## World Arthritis Day

World Arthritis Day took place on 12 October 2016. To mark the occasion *AS it is: Patient Voice & Patient Choice* was launched, encouraging supporters to write to their MP and ask them to attend the reception on 2 November. The winners of the Patient Choice Awards were also announced on this day.

## Local healthcare influencing

**England**

Our work with individual clinical commissioning groups (CCGs) continues on an ad-hoc basis dependent on the priorities of each one; all 212 CCGs have different priorities and NASS works with those prioritising musculoskeletal services. NASS is currently working with several of the CCGs on their local services for AS, as well as setting up new branches.

**Wales**

NASS has been working closely with Arthritis Care Wales on an All Wales Alliance calling for a Wales Arthritis Action Plan, meeting with key members of the Welsh Assembly or if unable to attend, submitting information about AS to be presented by Arthritis Care Wales. Many thanks to Hywel Evans of Arthritis Care Wales who has been very supportive of working collaboratively with NASS and has paid particular attention to the delay in diagnosis when meeting with Assembly Members if Jill Hamilton has been unable to attend meetings.

**Scotland**

NASS members in Scotland continue to attend the Musculoskeletal Cross Party Group in the Scottish Parliament. Many thanks to Iain MacDonald and Murray Brown in particular for their support attending these sessions. I will be presenting to the Group in 2017.

## Conferences

NASS had stands at the British Society for Rheumatology conference in April and the European League Against Rheumatism (EULAR) Conference in June, on the latter occasion representing the Ankylosing Spondylitis International Federation (ASIF). These conferences provide an ideal opportunity to speak to a wide ranging and large number of healthcare professionals about the work that the charity is doing and showcase our resources for patients.

# Information and Support

## Helpline

Over the past few years NASS Helpline enquiries have increased year-on-year.

| | Helpline enquiries |
|---|---|
| **2012** | 3,792 |
| **2013** | 4,308 |
| **2014** | 4,950 |
| **2015** | 5,220 |
| **2016** | 5,312 |

During 2016 the Helpline has been run jointly by Sally and Matthew, with Matthew taking benefits and work queries and Sally taking all other queries. Both Sally and Matthew spent around 40% of their time each working week (14 hours) running the Helpline during 2016. Around 60% of medical Helpline contacts during 2016 were via email, 20% were by phone and 20% are via social media, especially our Facebook page.

On the NASS Facebook page (National Ankylosing Spondylitis Society) people can either post publically or send a private message. The public messages sometimes ask for shared experiences and therefore we are able to share questions on our timeline and get a range of helpful replies. On average, we would estimate that we get around 20 comments for each question we post on Facebook and sometimes we can have more than 70 comments. We believe the ‘wisdom of the crowd’ is a great source of help and support for people living with AS.

NASS actioned 612 queries regarding benefits and work in 2016. Requests for support with benefits and work can require more detailed support than other Helpline enquiries. In 2016, we provided 134 letters to support people claiming benefits, appealing benefit decisions, applying for a Blue Badge or requesting more support from their employer.

## Website

Visitors to the NASS website have steadily increased since the site was redeveloped and re-launched in late 2010. However, in 2015 we saw a slight dip in users and sessions. The NASS website was not mobile optimised and we believed this could be key to the reduction in visitors.

| | Sessions | Users |
|---|---|---|
| **2012** | 146,720 | 94,534 |
| **2013** | 223,085 | 148,145 |
| **2014** | 261,408 | 176,626 |
| **2015** | 253,456 | 164,755 |
| **2016** | 257,213 | 175,195 |

We, therefore, asked our web developers to upgrade the NASS website to be mobile optimised. The process of upgrading got started in early 2016, and, due to the size of the NASS website, was not completed until early April 2016. The impact of the new website was, therefore, not seen until the second half of 2016. This means that our figures for sessions and users recovered, but not to the level seen in 2014. The new mobile-optimised website can now be easily browsed on a PC, laptop, tablet or phone. It is now simpler to donate, join NASS and shop online.

## Members' Forum

The Members' Forum continues to be an important outlet for members to share their experiences in confidence, helping others to understand their condition and provide a support network. Our thanks go to the volunteer administrator Mattie Baxter who helps to moderate. We now have 1,688 forum users.

## Facebook

In order to optimise our target audience, NASS has continued to engage with the AS community through social media. The number of followers on our Facebook page (National Ankylosing Spondylitis Society) has shown a steady increase over the past few years.

We try to post at least once a day, every day of the week. 65% of our Facebook followers are female and 35% male. In terms of age, 20% are under 34 and 76% are aged between 35 and 54.

Just under half (44%) of our Facebook followers are actually based in the UK, with a large proportion (31%) based in the USA and smaller numbers from countries all around the world.

As we are a UK charity we would, ideally like to increase our Facebook following in the UK.

| | **Total followers (Likes)** |
|---|---|
| **2013** | 3,000 |
| **2014** | 5,500 |
| **2015** | 8,400 |
| **2016** | 11,892 |

## Social Media - Twitter

We have two Twitter accounts; @NASSchiefexec and @NASSexercise. Followers for both these accounts rose steadily throughout 2016. The @NASSchiefexec account had 3,149 followers at the end of December 2016, a year on year increase of just over 450 followers and @NASSexercise had 3,060 followers, a year on year increase of 810 from 2015.

## YouTube

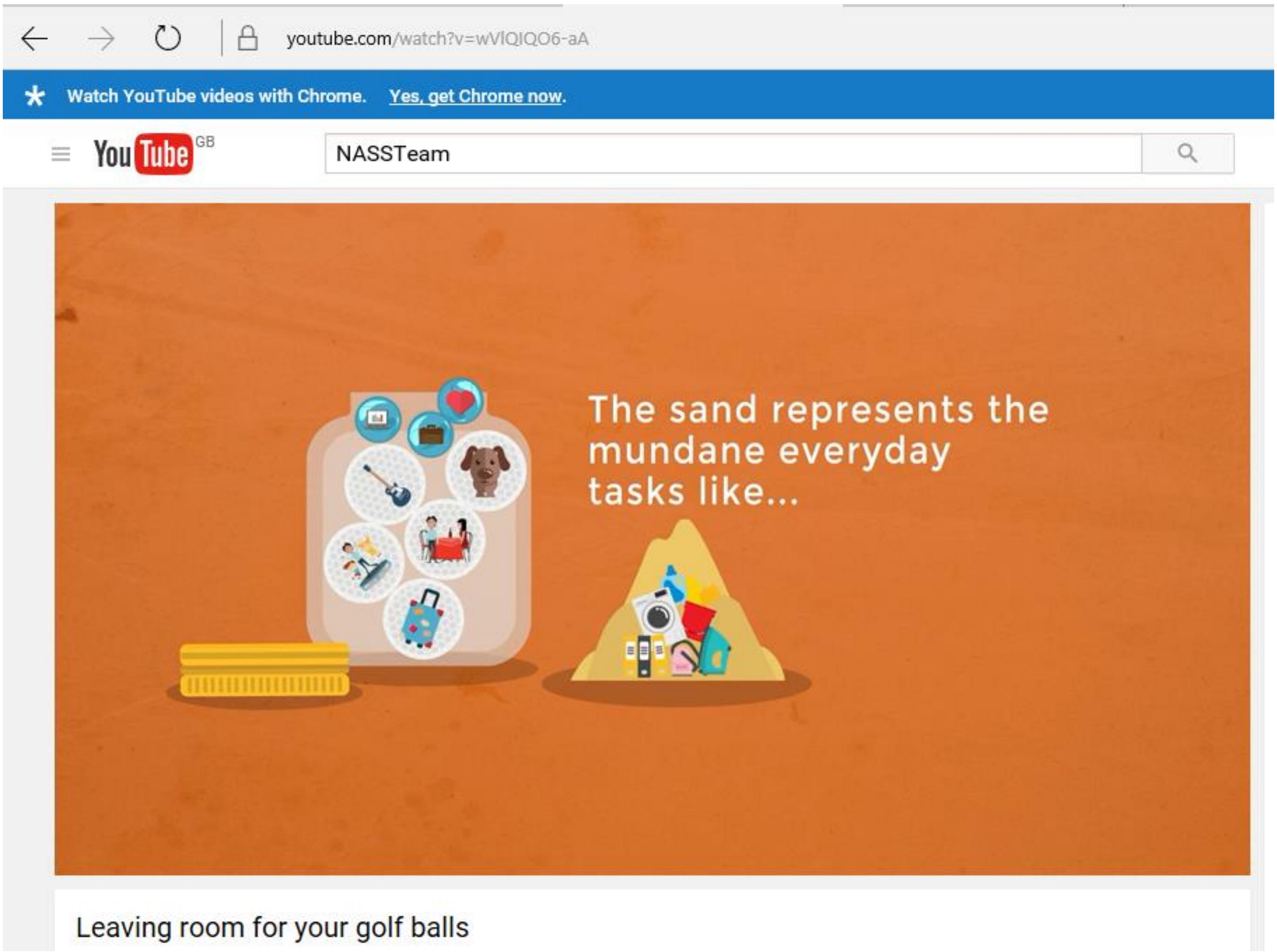
NASS has had a YouTube Channel since 2010 but in 2016 we created a link directly from our website home page to our channel (NASSTeam).

YouTube is an important way of NASS reaching people who are affected by AS. Overall YouTube has over a billion users, almost a third of all people on the internet, and everyday people watch hundreds of millions of hours of YouTube videos. YouTube particularly appeals to the 18-34 age demographic. This is an important demographic as the majority of people diagnosed with AS are within this age group.

We wanted to do more work in this area and subsequently commissioned three new videos in 2016. The first was a very short video showing how to check your posture, the second was top tips for living well with AS and the third covered the importance of prioritising when you have AS. The videos are available both on the NASS website and on our channel.

We are particularly grateful to Clare Clarke, an occupational therapist with Powys Teaching Health Board, who worked hard on helping us develop these videos.

By the end of 2016 we had 219 subscribers to our You Tube channels and our videos have had 60,421 views.  We will be producing further videos in 2017.



## Printed materials

Our new-look printed materials, each of which refer to ‘Ankylosing Spondylitis (Axial Spondyloarthritis) (AS)’, have been available through 2016 and have continued to be very popular.

## Benefits & Work guides

State benefits remain a major issue for many people with AS. NASS has a professional subscription to the Benefits and Work website, which allows us to access to a whole range of practical guides to claiming or appealing benefits. These include guides to claiming and appealing Personal Independence Payment (PIP), Employment and Support Allowance (ESA) and transferring from Disability Living Allowance (DLA) to PIP.  Due to copyright restrictions we cannot put these reports onto the website, but we do email them to any NASS member who contacts us.

In 2016 we downloaded updated guides on claiming and appealing PIP and ESA decisions, which reflected the latest amendments according to government policy.

## Medical Advisory Board (MAB)

The Medical Advisory Board (MAB) is integral to all the information produced by NASS. Dr Karl Gaffney is the Chair of our MAB. The members are:

- Dr Karl Gaffney, Consultant Rheumatologist
- Colin Beevor, Senior Clinical Nurse Specialist for Rheumatology Services
- Dr Alex Bennett, Consultant Rheumatologist
- Clare Clark, Occupational Therapist
- Claire Harris, Senior Physiotherapist
- Dr Andrew Keat, Consultant Rheumatologist
- Dr Helena Marzo-Ortega, Consultant Rheumatologist
- Dr Daniel Murphy, GP
- Dr. Athimalaipet Ramanan, Consultant Paediatric Rheumatologist
- Dr Raj Sengupta, Consultant Rheumatologist
- Dr Stefan Siebert, Consultant Rheumatologist
- Professor Paul Wordsworth, Consultant Rheumatologist

The MAB meets approximately twice a year. Additionally individual members write articles for AS News, assist with key projects, provide guidance for the website, help with the information for guidebooks, factsheets and leaflets and assist with more complex Helpline queries. I would like to thank them all for their hard work and dedication and the valuable contribution they make to NASS.

## Members' Day

Thank you to everyone who came to NASS Members' Day 2016 in Bath. I opened the day's activities with presentation celebrating forty years of NASS. This was followed by a fascinating presentation by rheumatologists, Dr Karl Gaffney and Dr Raj Sengupta, looking at the management of AS, in the past, present and the future.

After a short break, which gave attendees a chance to see the interactive stands provided by Healthcare at Home, Arthritis Action, the British Acupuncture Council and a Bath Spa University research team, we continued with intriguing presentations on 'Diet and AS' from Martin Lau of Arthritis Action and an introduction to acupuncture from Adrian Lyster of the British Acupuncture Council.

The ever popular 'Friends and Family' session followed, led by Physiotherapy Manager Claire Jefferies, Rheumatology Matron Colin Beevor, Rheumatology Nurse Roneleeh Bungue-Tuble and NASS member Paul Curry. At the same time specialist physiotherapists Claire Harris and Amanda Thomas led a session with our members on Essential Exercise Tips.

After a delicious lunch in the Somerset sunshine we headed back into the lecture theatre to hear Dr Raj Sengupta deliver a presentation on the AS Rehabilitation Course at the Royal National Hospital for Rheumatic Diseases. Soon we were back outside to make the most of the picturesque Bath Spa university campus by getting stuck into the practical sessions of Tai Chi, and singing. The enthusiasm for the practical activities inspired by our session leaders Sue Gurden (Tai Chi) and Frances Bennett (Singing) was great to see, and hopefully some people found a new way to manage their AS.

After the exertion of the practical sessions, everyone made their way back inside for the final act of a fantastic day. NASS Chair Raj Mahapatra led the birthday celebration for NASS's 40th year with a toast to 40 more years and beyond.

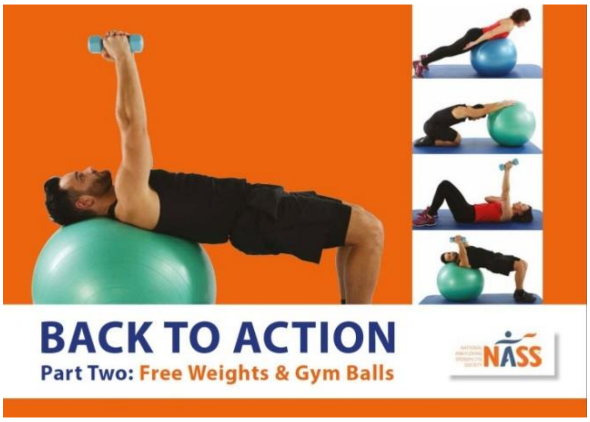
We would like to say thanks again to everyone who came, especially to our speakers, stand holders and volunteers without whom we wouldn't have been able to enjoy this landmark occasion. All of the presentations are on the NASS website.

*We would like to thank MSD who provided NASS with a grant towards the AS wellbeing project, including Members' Day. Thanks also to Bath Spa University for hosting the event, and Laura Richards for her wonderful photography skills capturing the day.*

## AS & You

Our information and discussion evenings for people newly diagnosed were held in four venues in 2016 – Norwich, Aberdeen, Plymouth and Leeds. The feedback we receive from attendees is always excellent; the opportunity to learn in depth about the condition combined with access to some of the top health professionals in the country always strikes a chord with everyone who comes along.

## Back to Action



In 2010 NASS developed our Back to Action guide to help people with AS exercise safely in the gym. This was developed into an iOS app in 2011 and an android app in 2012.

In 2016 a part two of the book was developed with 30 new exercises focusing on gym balls and free weights. The book was published in June and a copy was sent free of charge to every physiotherapy department in the UK (370).

Many thanks to Claire Harris, physiotherapist at North West London NHS Trust and Claire Jeffries, physiotherapist at Solent Healthcare NHS Trust for all their hard work on the book. A special thank you must also be given to NASS member Zoe Jones who kindly compiled the list of names and addresses for the mailing. The app is currently being updated and as such the updates should be available in early 2017.

## ASone

ASone
BRINGING young people
WITH AS together

ASone is a new NASS project, broadly aimed at 18 – 25 year olds with AS. In 2016 the brand was developed and a website built. The aim of the project is to allow interaction and shared experiences for people of that age group via the website and other channels, including in person. Due to limited resources the project was delayed but will be further progressed in 2017.

# Working with other organisations

NASS works on a number of initiatives with colleagues at organisations such as Arthritis Action, Arthritis Research UK (ARUK), the National Rheumatoid Arthritis Society, the British Society for Rheumatology (BSR) and the Chartered Society for Physiotherapists. I serve as a member of ARUK's Clinical Studies Group for Spondyloarthritis and am also a member of the BSR's Anti-TNF Guidelines Committee and the BSR-BR Ankylosing Spondylitis Registers Committee.

## National Institute for Health and Care Excellence (NICE )

### TNF-alpha inhibitors for ankylosing spondylitis and non-radiographic axial spondyloarthritis

### (TA383)

I reported on the NICE anti TNF Multiple Technology Appraisal fully in the 2015 Annual Report. I can confirm that the Final Appraisal Determination was published on 1 February 2016. The new guidance means:

- All the available anti TNF therapies are recommended as options for treating AS.
- Adalimumab (Humira), certolizumab pegol (Cimzia) and etanercept (Enbrel) are recommended, as options for treating severe non-radiographic axial spondyloarthritis.
- Treatment with another anti TNF is recommended for people who cannot tolerate, or whose disease has not responded to, treatment with the first anti TNF, or whose disease has stopped responding after an initial response.

### Secukinumab for active ankylosing spondylitis after treatment with non-steroidal anti-inflammatory drugs or TNF-alpha inhibitors (TA407)

In March 2015, Sally Dickinson attended the NICE Secukinumab Single Technology Appraisal Scoping meeting. In January 2016 the NICE Single Technology Appraisal started and we carried out a survey of NASS members to ascertain their views on the introduction of a new class of biologic medication. We submitted our evidence to the NICE appraisal process and attended the committee meeting to share the views of NASS Members.

On 28 September NICE published Technology Appraisal Guidance recommending secukinumab (Cosentyx®) as an option for treating active AS in adults whose disease has responded inadequately to conventional therapy (non-steroidal anti-inflammatory drugs or TNF-alpha inhibitors). This means there is now an alternative option on anti TNF therapy for people with AS.

### Spondyloarthritis Guideline Development Group

I have been a member of the Spondyloarthritis Guideline Development Group at NICE since 2014. The draft guideline was released for consultation and the final guideline was published in February 2017. I am incredibly proud of our campaign to secure this Guideline and indeed my contribution to the Guideline Development Group. I am hopeful that this Guideline will go some way to improving diagnosis times and indeed improving and seeing more consistent care. NASS will be actively promoting the Guideline in 2017 in various ways.

## Scottish Medicines Consortium

The role of the Scottish Medicines Consortium (SMC) is similar to that of NICE. It assesses newly licensed medicines to ensure they represent good value for money for NHS Scotland. The Consortium is made up of lead clinicians, pharmacists and health economists together with representatives of health boards, the pharmaceutical industry and the public.

The SMC approached NASS for a Patient Group Submission for new medicines associated with AS. In 2016 we provided Patient Group Submissions for both golimumab (Simponi®) for use in non radiographic axial spondyloarthritis and secukinumab (Cosentyx) in ankylosing spondylitis. In both cases the SMC gave a positive submission meaning the drugs can be used within their licensed indications within Scotland.

## All Wales Medicines Strategy Group (AWMSG)

The All Wales Medicines Strategy Group (AWMSG) provides advice on medicines management and prescribing to the Welsh Government’s Minister for Health and Social Services. Its role is similar to that of NICE and the SMC in that it aims to develop timely, independent and authoritative advice on new medicines.

In 2016 the AWMSG approached NASS to submit our views on golimumab (Simponi®) for use in non radiographic axial spondyloarthritis. In October 2016 the AWMSG decided in favour of golimumab for this licensed indication.

## British Society for Spondyloarthritis (BRITSpA)

NASS works in partnership with BRITSpA on a number of initiatives. In 2016 BRITSpA provided a £5000 grant to NASS to contribute towards the RCGP on-line learning modules. I was delighted to be asked to speak about the work of NASS and the patient perspective at the annual BRITSpA conference held in Birmingham in September. I look forward to NASS continuing to work closely with this organisation.

## Work Foundation

NASS continues to have a working relationship with the Work Foundation. I am a member of the Fit for Work UK Coalition.

## European League Against Rheumatism (EULAR)

NASS continues to work with EULAR. In June 2016 their annual conference was held in London where the Ankylosing Spondylitis International Federation (ASIF) was able to have an information stand which was staffed by NASS employees and trustees, as well as members of ASIF's Executive Committee. Copies of Back to Action (part 2) were distributed for free to any UK hospital who visited the stand and Jill Hamilton presented a scientific poster about Back to Action and its impact.

## Arthritis and Musculoskeletal Alliance (ARMA)

Jill and I continue to work with ARMA, attending policy and CEO meetings as well as feeding into their Clinical Networks project, including participating in a large event with many CCGs present at the beginning of the year.

## National Voices

NASS is a member of National Voices and continues to support and comment on their work around the NHS and healthcare for people with long term conditions, and as well as being members of special interest groups.

## Prescription Charge Coalition

NASS is a member of the Coalition which has called on the Government to extend exemption from prescription charges to all those with long-term conditions in England. The Coalition successfully campaigned for prescriptions to remain free in Northern Ireland in 2016.

## Disability Benefits Consortium (DBC)

The DBC is a national coalition of over 70 different charities and other organisations committed to working towards a fairer benefits system. Benefits are a hugely important issue to many people with AS, and we have actively supported the DBC's work accordingly. On 13 January NASS joined a mass lobby at Westminster Hall to campaign against proposed welfare cuts in the latest Welfare Reform Bill. The lobby was attended by over 130 campaigners from a range of charities, who met with MPs to discuss the impact cuts will have on disabled people. NASS Trustee Gillian Eames joined us to share her experiences about the impact on people with AS, and met with a number of MPs. Following on from our Parliamentary lobby the Disability Benefits Consortium (DBC) gained brilliant coverage of the proposed cuts. In a letter from DBC members including NASS, to Iain Duncan Smith MP, Secretary of State for Work and Pensions at the time, the DBC called for the government to scrap the plans, arguing that they would put the disabled under increased pressure and make it harder for them to find work. NASS will continue to work with the DBC in 2017.

# NASS Branches and Exercise

NASS currently has 95 branches operating around the UK and in 2016 we were delighted to open 4 new branches in Derry, Wrexham, Eastbourne and London Euston. It was a bumper year for branch visits with myself and Jill Hamilton attending many branch sessions. Special thanks to members of the team and trustees who also helped out with the branch visits – Sally, Amardeep, Matthew, Claire Harris and Raj Mahapatra . The full list of branches visited in 2016 is:

Bristol North, Grimsby, Woking & Weybridge, Cambridge, Swindon, Ashford, Abergavenny, Derry, Llandudno, Derby, Manchester, Glasgow (Gartnavel), Stoke Mandeville, Amersham, Stoke-on-Trent, Margate, Swansea, Colchester, Stockport, Northampton, Crewe, Carlisle, Harrogate, Bath, South Essex, Huddersfield, Bangor, Hereford, Tyne & Wear, Sunderland, Poole, Newport & Caerphilly, Burton on Trent, Haywards Heath and Wrexham.

Awareness events were also held in Crewe, Glasgow, Burton on Trent, Grimsby, Torbay and Sheffield. New branches will hopefully open in Sheffield and Torbay in 2017. Grants are available for newly formed branches.

## Branch Fundraising

We continue to encourage our branches to boost their funds with some local fundraising where possible. Amongst our successful branches in this area were Bognor Regis who received a grant from the Sussex Community Fund as well as holding their own fundraising events. Brighton were also beneficiaries of a collection at the Gay Men's Chorus and then Chair Sue Northeast gave a talk to the audience about AS and NASS. Edinburgh, Leeds, Portsmouth and others also held a variety of events to successfully help boost their funds.

## Branch Communication and Promotion

A monthly e-news is sent to all branch members that we have on record, updating them on relevant news and offering any help that might be needed. We also continue to produce posters and leaflets for branches to advertise their branch locally, and NASS also uses Facebook and Twitter to regularly advertise individual branches and the whole branch network.

DIAGNOSED WITH ANKYLOSING SPONDYLITIS (AS)?

NATIONAL ANKYLOSING SPONDYLITIS SOCIETY NASS

Come and exercise with NASS Bangor

xercising is one of the most important things you can do to help you self manage your AS and reduce your stiffness and pain

Exercise can help improve your flexibility, posture, range of movement and improves your sleeping pattern

NASS Bangor invites you to join friendly, welcoming and supportive fortnightly exercise sessions - supervised by qualified physiotherapists

2nd & 4th Monday of the month 7pm—8pm
Arfon Leisure Centre, Bethel Road, Caernarfon LL55 1HW

For more information contact:
Ann Hughes
01248 670 106
annhughes50@yahoo.co.uk

NASS Bangor
http://nass.co.uk/Bangor
www.nass.co.uk
Registered charity no: 272258.
Scotland 041987.

## Physiotherapy and AStretch

NASS has a strong relationship with AStretch, a group of physiotherapists who specialise in AS. Members of the committee often work with NASS on projects such as Back to Action and the Back Pain Plus campaign. NASS supports AStretch by hosting and contributing to committee meetings. I also spoke about NASS and our current projects at their bi-annual conference in Birmingham in December. AStretch held a two day training course in Ystrad Mynach in October which NASS was pleased to support, funding the course fees for two branch physiotherapists to attend.

## Hydrotherapy

The current financial pressures in the NHS means that a substantial amount of cost cutting appears to be in force. Sadly this has resulted in hydrotherapy being viewed as a service which is expendable in comparison to other services in some areas. We will continue to campaign with individual hospital trusts, health boards and CCGs to ensure that our voice is heard and that hydrotherapy is not seen as a luxury but rather a necessary service which helps to greatly improve quality of life for many people with AS and indeed other conditions.

# Research

## Research Fund

In 2016 we reopened the NASS Research Fund.  Two awards were made:

- Ms Debbie Chagadama £2,290.45 for the project 'Health-related Quality of Life Experiences of Bangladeshi Patients with ankylosing spondylitis'
- Dr Jon Packham, £29,536.00 for the project 'CLASP – Characterising Low back pain Associated with Skin Psoriasis'

## Educational Bursaries

Four educational bursaries were awarded in 2016 to:

- Katharine Arnold
- Chris Bellis
- Rebecca Dykes
- Nathan Pearson

## Genetic Research

We continued to support the genetic research at Oxford University led by Professor Paul Wordsworth, mailing 401 NASS members in June asking them to take part in the research by providing a saliva sample.

## Self-Management

When we undertook to find out what our members wanted from research into AS back in 2013, working with the University of Lancaster, one of the big areas you wanted us to address was a recognised self management programme which could be delivered consistently across the UK.  In the summer NASS funded a meeting to establish a Steering Group to take this forward.  In September Arthritis Research UK (ARUK) part-funded, with NASS,  a stakeholder engagement day in Birmingham to further develop this initiative.  I am delighted that the team at the University of Aberdeen has agreed to work with NASS to take this forward and make a formal application to ARUK for this much-needed piece of research.

## State of the Nation Survey

I believe that an important role of NASS is to give people living with AS a voice. We listen to patients informally through social media, the NASS Helpline, Members' Day and branch visits but we also listen more formally through surveys.  We aim to carry out a large scale survey of people living with AS in the UK every 3 years. Accordingly, in 2016 we ran our State of the Nation survey.

Our surveys are not just for NASS Members, our aim is to capture the views of people living in the UK with AS. In February 2016 all NASS members and supporters with registered email addresses (4,693) were sent a request to participate in an online survey. The survey link was also advertised via NASS E-News, Twitter, Facebook and a pop-up advertisement on the NASS website. Only one reply was accepted from an individual IP address and the first 2000 replies were analysed. The survey comprised 63 open and closed questions regarding aspects of care and service delivery.  The 2000 respondents came from across the UK and comprised 56% men and 44% women. 30% were under the age of 44, 48% were 45-64 and 22% were 65+. Additionally, 53% were employed full or part time.

The survey included questions on terminology; delays to diagnosis; whether people were under the care of a rheumatologist; satisfaction with AS care; access to physiotherapy; unmet needs; exercise levels; smoking; and working with AS. Important findings from the survey included:

- People with AS want to access advice and care from their rheumatology team, including their physiotherapist, during a flare but access is variable across the UK. Seeing a member of the team during a flare is considered more important than having more frequent follow up appointments.
- While people are satisfied with the level of information they have received from their rheumatology team, they wanted more information on coping with fatigue (51%), their long-term prognosis (45%), managing flares (38%) and coping with pain (36%).
- Only 12% of people have a written management plan for their AS.
- Less than half (46%) have seen a physiotherapist in the past 12 months and only 27% of those who have seen a physiotherapist were aware they could self-refer during a flare.

As referred to earlier, we have taken every opportunity over the year to highlight these results to health professionals and opinion leaders and will continue to use them throughout 2017 to bring positive change to AS care.

## Rheumatology Department survey

In 2016 we planned a joint survey with the British Society for Spondyloarthritis (BRITSpA). The survey aimed to discover what services rheumatology departments offer AS patients in the UK.

During February 2016, a validated web-based questionnaire was emailed to named NHS consultant rheumatologists at all acute trusts in the UK. The survey comprised 47 open and closed questions regarding professional views and service delivery relating to AS. A total of 83 different NHS Trusts took part in the research.

Important findings from the survey included:

- 61% of rheumatology departments have at least one clinician with a declared special interest in AS and 58% offered a dedicated AS Clinic.
- Patients were routinely reviewed 6-monthly by 61% of centres and annually by 23%.
- In 19% of centres there were combined clinics; 3 ophthalmology, 5 gastroenterology, 13 dermatology.
- Metrology is routine practice in 96% of centres
- The majority (94%) have a patient advice line, aiming to respond within same (25%) or next working day (63%).

We concluded that there remains wide variation in practice and services offered to AS patients in the UK. There is a need to develop a national framework for service delivery. We also identified a need for an easily accessible and searchable database of AS services in the UK.

# Fundraising

## Legacies

We are hugely grateful to all of our supporters who have chosen to leave a gift to NASS in their will. Legacies are an incredibly vital source of our funding.

We would like to acknowledge legacies in 2016 from:

- Michael J Leaman
- Audrey Smith
- Frank Hawley
- Tom E Corne
- Anthony Chubb

## Trusts

We would like to express our gratitude to the wide variety of trusts and grant-making organisations that provided vital support for our work in 2016:

- G C Gibson Charitable Settlement
- Hamilton Wallace Trust
- Neville Milner Charitable Trust
- Reuben Brother’s Foundation
- Stella Symons Charitable Trust
- Summers & May Charitable Trust
- Bernadette Charitable Trust
- Charles Fairweather Charitable Trust
- Mary Homfray Charitable Trust
- N & P Hartley Memorial Trust
- Simon Gibson Charitable Trust
- Vivienne & Sam Cohen Charitable Trust
- C M Keyser Charity Trust

## Companies

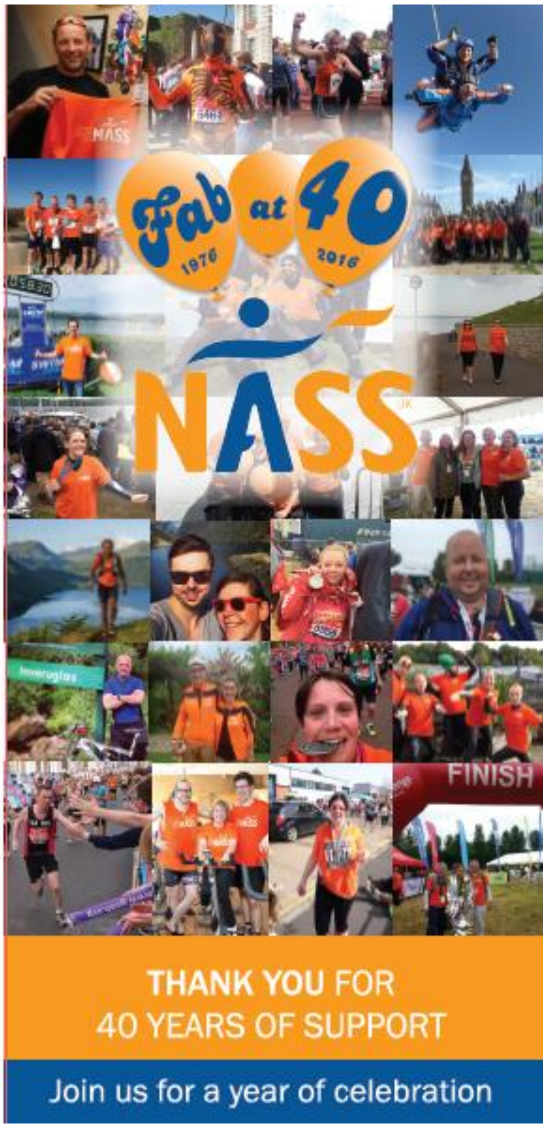
- Lloyd’s Bank
- Google
- OpenBet Technologie
- Wolseley Group UK
- Sainsbury’s (Bromley)
- Nationwide
- Equiniti Recruitment
- UCB Celltech
- AbbVie
- Novartis
- Merck Sharp & Dohme
- Pfizer

## Events

2016 marked the 40th anniversary of NASS. To mark the occasion, NASS planned a series of activities to engage members, non-members and supporters, whilst raising awareness of AS amongst the general public.

Below is a summary of each event.

## Fab At 40 Fortnight



During 1-15 May, we encouraged our members, branches and non-members to hold their own ‘Fab at 40’ fundraiser to celebrate our birthday. This support was wide and varied including coffee mornings, a charity football match and pub quizzes. These dates embraced World AS Day on 7 May and gave us a platform to raise as much awareness and money as possible.

We helped people host their own events by producing a fundraising pack consisting of posters, balloons and donation boxes. Alongside the packs, we had bespoke 40th birthday merchandise available to order, with new wristbands featuring our 40th birthday logo and limited edition pin badges available.

NASS members, supporters and partners across the UK organised a number of celebratory events, ranging from charity football matches, bake sales, runs and cycle rides.

Thank you to NASS trustee Dr Karl Gaffney, who cycled from London-Paris, raising over £5,300 (including Gift Aid) for NASS. Trustee Gillian Eames also hosted a Fab At 40 Fun Day in Newcastle, involving a charity football match, raffle, bake sale and children’s face-painting, and raised over £2,600 (including Gift Aid). I also took on my own challenge to celebrate our birthday, completing the Great North Run, my first ever half marathon and raising over £1,000 (including Gift Aid).

Our pharmaceutical partners Pfizer, AbbVie, and UCB held fundraising and awareness days, reaching hundreds of staff. Six national hospitals also hosted Fab At 40 information stands.

In total, our Fab At 40 Fortnight raised £18,000 (including Gift Aid) for NASS. Alongside this income, we raised vital awareness of AS amongst the public, whilst engaging with new and existing supporters. The campaign also provided a great opportunity to strengthen our pharmaceutical partnerships.

*Many thanks to NASS Member and volunteer Sabine Maerky who designed our Fab at 40 logo.*

## NASS 40th Birthday Tea

Held in Bath on 3 June, the day before our Members' Day, our Birthday Tea was a small way to say 'thank you' to those who have been involved with NASS from our early days, and in some cases, the very beginning of NASS. The event was attended by 25 rheumatologists, early members and supporters. It was a wonderful occasion, and I felt so privileged to attend and speak. It was a lovely event where old relationships were renewed and those who played a vital role in the formation of NASS came together.

## Fab At 40 Party

Our birthday celebrations culminated in the Fab At 40 Party, held in London on 15 October. The party was a great success, with 100 guests attending and tables being bought by branches from Edinburgh, Brighton, Portsmouth and Derby.

On the night, we recognised long-term supporters, and also held a raffle with prizes donated by members, trustees and local businesses. The raffle raised £933.20. Combined with ticket sales, the Fab At 40 Party raised £4,688.20, and provided a fantastic opportunity for members and supporters to engage even more with our work. It was great to see so many NASS supporters enjoying themselves in celebration of our great organisation and its milestone birthday year.

## Reactive fundraising

Our fundraisers had a fantastic 2016, with over 90 of our supporters taking on a huge variety of challenges to support NASS. People ran, walked, swam, cycled, baked, skipped, skydived and sang throughout the year, raising an amazing £61,476.

Each and every one of our fundraisers makes a huge difference to our charity and to the lives of thousands of people with AS. Not only do they raise essential funds to keep our services going, they also raise vital awareness of AS, and act as ambassadors for our work. We extend our sincere thanks again for all their efforts in aid of NASS.

## Working with the Pharmaceutical Industry

NASS receives some hands-off financial support from the pharmaceutical industry allowing us to deliver specific projects.  We set our priorities in advance in our 5-year strategic plan, which you can view on our website. The charity is not influenced by the agenda of the industry in any way. Our trustees also set a threshold to limit the amount of this type of funding that we can receive; no more than 25% of our overall income in a 3-year rolling period. We also work with colleagues in industry to deliver specific initiatives funded by them.

During 2016 I was invited to the Back in Focus Steering Group meeting in January and was then asked to speak about the work of NASS and the patient voice later in the year at the Back in Focus events held in London, Manchester and Birmingham.  Back in Focus is a great education initiative aimed at health professionals working in axial spondyloarthritis and is funded by Abbvie.  In September I was invited by MSD to speak at their YOU+RS nurses meeting and this was a great opportunity to address a room full of rheumatology nurses about NASS and our patient survey results.  UCB invited me to one of their global meetings in December where I was the only patient group representative, talking about the patient voice in a room full of eminent rheumatologists from across the globe; a great opportunity to raise awareness about NASS.

At the end of 2016, NASS was invited by Pfizer to deliver presentations about AS to staff at Homecare Delivery Companies to further enhance their understanding of the burden of disease.  Sally and I both attended and presented at homecare companies in 2016 and this work will continue into early 2017.

The amount of support received from the industry in 2016 was as follows:-

| | | | |
|---|---|---|---|
| - | £ 25,000 | AbbVie | Core funding |
| - | £ 20,000 | AbbVie | Patient Survey |
| - | £ 30,000 | AbbVie | Back Pain Plus |
| - | £ 10,000 | MSD | Members' Day |
| - | £ 10,000 | UCB | Back Pain Plus |
| - | £ 6,000 | UCB | InTune programme |

## Membership

The number of NASS Members at the end of 2016 was 3731, which is much lower than reported in last year's annual report (5886). We carried out a review of NASS membership in 2016. Several inconsistencies within the membership database and membership direct debit payments were identified.

The results of this review found membership figures had not been reported accurately for several years, over 650 direct debit members payments were not up to date and NASS membership was not covering its own costs. This led to drop in membership numbers (5586 to 3731) but should not been seen as sudden loss of 2000+ members but more of a realistic and accurate report of NASS membership numbers.

Clearly this was a much-needed piece of work to regularise the database inconsistencies dating back over many, many years and I am now satisfied that we have accurate data on which to build. Given that we report that there are 200,000 people in the UK, and given that NASS relies on its members to fund our vital work, we clearly have a lot of work to do to improve the number of members we have.

In response to this review our Council of Management recommended and NASS members subsequently agreed to a small increase membership fees at the AGM in June which will be implemented from 1 January 2017. In 2017 NASS will be looking to introduce a new fundraisers' membership.

As ever, NASS is extremely grateful to all our members for the fantastic support they continually show the charity. Being a member of NASS is about being a part of a community and contributing to the work that we do, working towards a better life for people with AS. Thank you to all our members, we appreciate and value your continued support. NASS actively listens to its members, seeking their views to inform our work.

# The NASS Team

People often tell me that they cannot believe all that NASS achieves, given that we are a small team of 6 people. I joined NASS in 2011 and inherited a team of 5. I still have a team of 5 but we have increased our profile and outputs year-on-year; this is purely down to the dedication and commitment of the team to the work of NASS and how they work together to make things happen for the AS community.

Since the early part of 2016, Jill Hamilton has been supporting all of our branches, in addition to undertaking her permanent role looking after our Projects and Policy work. Supporting our branch network is an essential and enjoyable part of what we do, but this post has on occasion proven difficult to recruit to and then sustain. I was so grateful to Jill for her flexibility and support. I am hopeful that in 2017 we can go back to having some permanent support for our branches thus allowing Jill to focus on our projects in particular.

I was incredibly sad to see Laura Garbari move on to a promotion at another charity in November 2016. Laura was a highly-valued and capable member of the NASS Team. Recruiting to her role of managing our finance and administrative duties also proved somewhat challenging and once again every member of the NASS Team stepped in to help absorb the duties until a replacement was found. Once again, I am incredibly grateful to all of the Team for their willingness to do what it takes to ensure that we continue to operate efficiently and effectively. I wish to put on record my thanks to Laura and indeed all of the NASS Team for their support particularly when there were gaps to fill.

My role at NASS, in addition to managing the charity and all of its functions is as an ambassador for our wonderful organisation. This means that at times my work is very much outward focussed; attending external events to secure funding, raise the profile of AS and NASS, represent the patient voice with a view to improving services being just a few examples. I can only be so outward focussed because I have the support of such a wonderful team. I never take for granted their support, hard work and dedication. I wish to thank them all for the commitment they show to NASS and for the support that they give to me both professionally and personally.

## The Future

2017 is shaping up to be another busy year for NASS. We continue to work on the priorities set out in our 5-year strategic plan with early diagnosis and raising awareness being very much at the forefront of our activities.

After serving on the NICE Spondyloarthritis Guideline Development Group for 2.5 years, I am personally delighted to see the launch of this Guideline scheduled for February 2017. This is a huge step forward in terms of improving diagnosis times and indeed, quality of care. NASS was instrumental in calling for and campaigning for the production of this Guideline and we will work hard to ensure that the recommendations contained within it are embraced. Never ones to rest on our laurels, it is likely that the next steps for NASS will be to call for NICE Standards of Care for axial spondyloarthritis; a further step to securing the best care for people with AS.

We have applied for funding for our major projects for 2017. Back Pain Plus is such an excellent initiative, aiming to reduce delays to diagnosis that it will continue into subsequent phases for 2017. I am excited about the development of our AS Clinic Near You project; a web based tool enabling you to search for your nearest rheumatologist and services specialising in AS. All of the branding and website for ASOne, our 18-25 year project was developed in 2016 but we are hoping to secure funding for some temporary and additional resource to now take this project to launch and to secure its further development.

In 2016, two of our MAB members, Dr Karl Gaffney and Dr Daniel Murphy worked incredibly hard writing two on-line learning modules for the Royal College of GPs platform. Mainly funded by NASS (with a £5000 grant from the British Society for Spondyloarthritis), these two learning modules have the potential to reach 50,000 GPs and Health Care Professionals. This is a much needed learning resource on diagnosis and management of AS and we eagerly await their launch in the Spring of 2017.

Our annual report can only scratch the surface and highlight just some of the main projects that NASS delivers on behalf of the AS community. I can assure you that we work tirelessly behind the scenes on projects, initiatives and campaigns to improve the quality of life for people with AS, their family and friends.

Our annual Members' Day will this year be held in Sheffield on 17 June. This year the conference will focus on 'flares' as this is something you've told us is an area where you need more support. NASS continues to listen to what the AS community tells us is important to them, aiming to deliver change and improvements where possible. Some of the work we do is not always visible but I am confident that we are delivering a huge amount of support given the small team that we have. I am though as ever, always happy to hear your views on what more you'd like support with, should we find ourselves in a position to be able to deliver additional initiatives.

NASS can only continue the work we do with the support of our members and supporters. Increasing the number of NASS members is one of the biggest challenges we face. Our costs are rising year-on-year and we will rely on the wonderful support of our fundraisers to help us with this. Our Mighty Orange Mashup Fundraising package planned for 2017 provides a fun way to get involved and help us meet these challenges.

Thank you from the bottom of my heart to all our supporters, volunteers, fundraisers, trustees, the NASS Team, MAB, branch physiotherapists, the list goes on and on; with your continued support 2017 will be another bumper year.

Debbie Cook, NASS Chief Executive
May 2017

# NASS' Trustees Report

The Trustees present their report and accounts for the year ended 31 December 2016, prepared in accordance with current statutory requirements, in accordance with the Charity Commission Statement of Recommended Practice.

## 1. Reference and administrative details

### a. Name, address and registration

The name of the charity is the National Ankylosing Spondylitis Society and its address is Unit 4, Albion Court, Galena Road, London W6 0QT. The charity is registered with the Charity Commissioners for England and Wales, registration number 272258, and with the Office of the Scottish Charity Regulator, registration number 041347.

### b. Trustees

The Trustees who served during the year were:

| | |
|---|---|
| *Honorary Officers* | Raj Mahapatra (Chairman)<br>Simon H Frost (Treasurer)<br>Dr Andrei Calin (Vice President)<br>Hedley Hamilton (Vice President)<br>Dr Richard Jacoby (Vice President) |
| *Ordinary Members* | Stephen Dean<br>Eric N C Eustance<br>Dr Karl Gaffney<br>Claire Harris<br>Ben Hoare<br>Dr Andrew Keat<br>Ruth Miller<br>Grant Poiner<br>Dr Raj Sengupta<br>Roger Stevens<br>Peter Wheatley-Price<br>Professor Paul Wordsworth |
| *Co-opted Members* | Gillian Eames<br>Jean Morton<br>Peter Townsend<br>Tim Warburton |

## 2. Structure, Governance and Management

### a. Constitution

The Society is an unincorporated society and was registered as a charity in August 1976. The rules and regulations of the Society are set out in its Constitution, adopted on 18 November 2000 and amended on 17 November 2007, approved by the Charity Commission.

### b. Appointment of Trustees

The governing body of the Society is a Council of Management consisting of elected and co-opted Trustees. Only members of the Society may be appointed as Trustees.

The Constitution permits the appointment of a Chairman, a Treasurer, a minimum of 8 and a maximum of 12 elected Trustees and a maximum of 4 co-opted Trustees.

The Chairman, the Treasurer and the elected Trustees are all appointed by election at the Society's Annual General Meeting. The Chairman and Treasurer are appointed for a term of one year and may put themselves forward for re-election if eligible. Other elected Trustees are appointed for a term of 3 years and may put themselves forward for re-election if eligible.

Co-opted Trustees are appointed by Council for a term of one year.

In advance of each AGM members of the Society 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 by the Chairman or Treasurer and to meet the Chief Executive, the staff and understand how the society works. Formal training is provided when required.

Vice Presidents are appointed by the Trustees in recognition of their contribution to the Society's affairs. Vice Presidents are invited to attend meetings of Trustees and to express their views on matters set before the Trustees. They are not entitled to vote at such meetings.

### c. Management

The Trustees meet quarterly to review matters of policy and to make appropriate judgements, directions and decisions on Society issues.

The Trustees have delegated the ongoing management of the Society to an Executive Committee of Trustees consisting of the Chairman, the Treasurer and 3 appointed Trustees. This Committee meets on a monthly basis. Day-to-day administration of the Society is undertaken by the Chief Executive and her staff.

None of the Trustees received any remuneration during the year. Eleven trustees received expenses, mainly relating to travel.

## 3. Objectives and Activities

### a. Objectives

The Society's vision is to advance the interests of people affected by ankylosing spondylitis and related conditions in the UK.

The Society's mission is threefold:

- To seek a cure for ankylosing spondylitis and related conditions, and improve their treatment in the UK;
- To promote awareness of these conditions in the UK; and
- To provide guidance, advice and information for people affected by these conditions including their families, their carers and their employers.

### b. Public benefit

The Trustees have paid due regard to the Charity Commission's guidance on public benefit in deciding on the activities the Society should undertake.

The Society provides public benefit in several ways:

- by promoting research into the management and cure of ankylosing spondylitis and related conditions and their causes;
- by disseminating the results of research related to these conditions;

- by working with statutory bodies and others that provide for the treatment and welfare of people affected by these conditions;
- by educating people affected by these conditions, as well as healthcare professionals and the public, on the problems related to these conditions; and
- by putting people affected by these conditions in contact with expert advisers on all aspects of these conditions.

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

The Society achieves these aims by developing and adopting relevant strategies and through establishing the necessary resources and an appropriate structure to deliver these strategies.

### c. Strategies adopted

In accordance with the provisions set out in its Constitution, the Trustees have adopted the following strategies to meet the Society's principal objects:

(i) Research into ankylosing spondylitis and related conditions:
  - to facilitate research through a variety of means including campaigning, cooperation with academic centres and with pharmaceutical companies, and PR;
  - to encourage members of the Society to co-operate in research programmes;
  - to set up a grants scheme for research;
  - to communicate to members and the wider public the results of research using the most appropriate media, including AS news, websites and conferences.

(ii) Campaigning on behalf of people with ankylosing spondylitis and related conditions:
  - to use a variety of means to increase awareness of these conditions among the public and within the healthcare profession, including such matters as early diagnosis and appropriate treatment;
  - to use a variety of means to improve access to the latest available treatments and care, in particular through lobbying elected representatives, healthcare professionals and statutory bodies;
  - to ensure that awareness of these conditions is raised with related charities and organisations so that concerted approaches can be made when appropriate including at international level.

(iii) Education of the public about ankylosing spondylitis and related conditions:
  - to provide an information service for people affected by these conditions, for the newly diagnosed, for families, for the wider public and for healthcare professionals;
  - to provide a support network for people with these conditions and their families through such means as a membership network, a branch network, advisory panels, casework support and welfare grants;
  - to facilitate and support training seminars and conferences for people with these conditions and for healthcare professionals.

## 4. <u>Achievements and Performance</u>

### a. Risk

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

(i) Loss of funds: Funds are held with various first-tier banks on a short-term basis and as a result there is little risk of loss in the short to medium term.

(ii) Loss of income: The Society seeks to broaden and expand its income from all sources. Nevertheless the Society is dependent upon voluntary income, both at branch level and at national level, and aims to continue to increase its membership locally and nationally.

(iii) Loss of reputation: The Society seeks at all times to maintain its independent viewpoint. Assistance received from external bodies, such as members of the pharmaceutical industry, is strictly controlled so as to ensure that independence is not compromised.

### b. Subscriptions

The Society charges subscriptions to its members at national and branch level. In addition the Society operates a local branch model for group exercise and most of the attendees are national members. At national level this income is used to fund the charitable activities of the Society and to defray the costs of running the Society. At branch level the income is used almost wholly to provide to members physiotherapy treatment over and above that available from the NHS. The Society has approximately 3,700 members at national level and around 800 attendees per week at branches. The Trustees actively encourage all those with AS and related conditions to join the Society.

### c. Branch network

The Society has 95 active branches throughout the UK. Each branch is managed by a committee comprising a Chairman, a Treasurer and a Secretary, each elected by branch members. Each appointee can hold office for an indefinite period. Branches are required to keep proper accounting records and to make annual returns to the Society each year.

The Trustees are keen to expand the branch network. During the year four new branches were opened and none closed down.

### d. Fundraising and Grants

The Society holds fund-raising events from time to time and also welcomes the efforts of individual members who undertake fund-raising activities on behalf of the Society. The Society also solicits grants from charitable trusts and from the pharmaceutical industry, subject to certain limits in order to protect the independence of the Society. In particular grants received from the pharmaceutical industry are limited to 25% of income of the average charity income over 3 consecutive years and must be made available for the support of the Society's charitable activities without restriction.
During the year the Society received an unrestricted grant of £25,000 (2014 - £25,000) from Abbvie UK. In addition grants totalling £118,080 (2015 - £68,000) were received for specific projects.

### e. Expenditure on Research

The Society incurred total costs of £62,048 (2015 - £109,860) on research activities during the year which included support costs of £28,318 (2015 - £31,083). The Trustees are keen to foster continued research into AS and related conditions, and the Society continues to operate a grant based system for funding research projects.

### f. Expenditure on Campaigning

The Society incurred total costs of £125,168 (2015 - £100,664) on campaigning activities during the year which included support costs of £84,954 (2015 - £93,249). This reflects the continuing emphasis placed by the Trustees on campaigning for wider recognition of the condition, speedier diagnosis and better treatment.

The Trustees expect to continue the Society's efforts to campaign on a wide range of issues on behalf of members concerning AS and related conditions.

### g. Expenditure on Education and Support

The Society incurred total central costs of £234,126 (2015 - £204,157) on education and support activities during the year which included support costs of £141,590 (2015 - £155,415). Education and support remains a vital part of the Society's activities and the Trustees continue to seek to broaden the Society's work in these areas.

In addition the Society incurred branch costs of £201,391 (2015 - £208,546) in support of these activities.

### h. Volunteers

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

### i. Organisational relationships

The Society is a member of the following organisations:

- The Arthritis and Musculoskeletal Alliance (ARMA)
- The Ankylosing Spondylitis International Federation (ASIF). The Society is also represented on its Executive Committee
- National Voices
- National Council for Voluntary Organization (NCVO)
- Helpline Partnership

### j. The Future

The Society has exciting prospects for the future. The very significant increase in the Society's resources, resulting from four major legacies received in 2014 and the uplift in value of the Society's investments in 2015, has enabled the Trustees to plan for growth in all areas of the society's charitable activities. Principal among these is the establishment of a continuing scheme to promote and fund research projects into many aspects of AS.

## 5. Financial Review

### a. Reserves

Free reserves, defined as the balance of unrestricted funds less tangible fixed assets, currently amount to £1,170,000 (2015 - £ 1,244,000). As reported last year, the Trustees have established a five year strategic plan to address the use of these reserves and substantial expenditure is planned on all of the Society's charitable objectives over this five year period.

At present the Society 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. The Trustees have therefore decided that Free Reserves should be maintained at least at a level sufficient to meet all anticipated outgoings of the Society for the next financial year.

### b. Investments

The Society has hitherto adopted a policy of maximising liquidity and therefore funds available have been held in interest-bearing bank accounts or equivalent short-term deposits at varying rates of interest placed with first-tier banks. The Trustees announced in 2009 their intention to review this policy. However the effect of the lengthy economic recession downturn after 2008 and related impact on investment performance had delayed this review. The review was further delayed by the significant increase in the Society's resources in both 2014 and 2015. The Trustees are currently updating the Society's strategic plan for the next 5 years which is expected to have a significant impact on investments.

As reported last year the Trustees converted the Society's former headquarters, in Richmond, into two residential apartments and have rented out these apartments to generate income for the Society. Conversion was completed in December 2015 and both flats continue to be let out on shorthold assured tenancies. In 2015 this asset was reclassified in the Society's accounts as an investment. The Society's investments also include four Elisabeth Frink statues also carried at market value.

### c. Summary of financial performance

As a whole, the Society reported a shortfall of income over expenditure of £71,210 (2015 – surplus of £2,863). A deficit of £78,837 (2015 – deficit £1,570) arose centrally and a surplus of £7,877 (2015 - £5,457) arose at branch level.

As a result of the increase in resources over the last two years the Trustees have adopted a five year strategic plan to apply these resources to all the Society's charitable activities. Therefore expenditure is set to continue to rise over the period of the five year strategic plan.

## 6. Statement of Trustees' responsibilities in respect of the accounts

The Society's trustees are responsible for preparing a trustees' annual report and 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 accounts for each financial year which give a true and fair view of the state of affairs of the Society and of the incoming resources and application of funds of the charity for that year. In preparing those accounts, the Trustees are required to:

- select suitable accounting policies and then apply them consistently;
- observe the methods and principles in the applicable Charities SORP
- make judgements and accounting estimates that are reasonable and prudent;
- state whether applicable accounting standards have been followed, subject to any material departures disclosed and explained in the accounts; and
- prepare the accounts on a going concern basis unless it is inappropriate to presume that the Charity will continue in operation.

The Trustees are responsible for keeping proper accounting records that are sufficient to show and explain the Society's transactions and disclose with reasonable accuracy at any time the financial position of the Society and to enable them to ensure that the accounts comply with the Charities Act 2011, the applicable Charity (Accounts and Reports) Regulations, the Charities Accounts (Scotland) Regulations 2006 and the provisions of the Trust deed. They are also responsible for safeguarding the assets of the Society and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

The trustees are responsible for the maintenance and integrity of the Society and of the financial information included on the Society's website. Legislation in the United Kingdom governing the preparation and dissemination of financial statements may differ from legislation in other jurisdictions.

## 7. **Auditors**

Feltons, Chartered Accountants, have expressed their willingness to continue as the charity's auditors.

Signed on behalf of the Trustees

Raj Mahapatra
Chairman

London
16 June 2017

# Auditors’ Report to the Trustees

We have audited the financial statements of The National Ankylosing Spondylitis Society for the year ended 31 December 2016 set out on pages 39 to 50. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice) including FRS102 “The Financial Reporting Standard applicable in the UK and Republic of Ireland”.

This report is made solely to the Charity's trustees, as a body, in accordance with section 154 of the Charities Act 2011 and section 44 (1c) of the Charities and Investment (Scotland) Act 2005 and regulation 10 of the Charities Accounts (Scotland) Regulations 2006 (as amended). 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 members, as a body, for our audit work, for this report, or for the opinions we have formed.

**Respective responsibilities of Trustees and auditor**

As explained more fully in the Statement of Trustees' responsibilities set out on page 10, the Trustees are responsible for the preparation of financial statements and for being satisfied that they give a true and fair view.

We have been appointed as auditor under section 44 (1c) of the Charities and Investment (Scotland) Act 2005 and under section 144 of the Charities Act 2011 and report to you in accordance with regulations made under those Acts. Our responsibility is to audit and express an opinion on the financial statements in accordance with applicable law and International Standards on Auditing (UK and Ireland). Those standards require us to comply with the Auditing Practices Board's Ethical Standards for Auditors.

**Scope of the audit of the financial statements**

An audit involves obtaining evidence about the amounts and disclosures in the financial statements sufficient to give reasonable assurance that the financial statements are free from material misstatement, whether caused by fraud or error. This includes an assessment of: whether the accounting policies are appropriate to the Charity's circumstances and have been consistently applied and adequately disclosed; the reasonableness of significant accounting estimates made by the Trustees; and the overall presentation of the financial statements.

In addition, we read all the financial and non-financial information in the Trustees' report to identify material inconsistencies with the audited financial statements and to identify any information that is apparently materially incorrect based on, or materially inconsistent with, the knowledge acquired by us in the course of performing the audit. If we become aware of any apparent material misstatements or inconsistencies we consider the implications for our report.

**Opinion on financial statements**

In our opinion the financial statements:

- give a true and fair view of the state of the Charity's affairs as at 31 December 2015 and of its incoming resources and application of resources 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 the requirements of the Charities Act 2011, the Charities and Trustee Investment (Scotland) Act 2005 and Regulation 8 of the Charities Accounts (Scotland) Regulations 2006.

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

We have nothing to report in respect of the following matters where the Charities Act 2011 or the Charities Accounts (Scotland) Regulations 2006 (as amended) requires us to report to you if, in our opinion:

- the information given in the Trustees' report is inconsistent in any material respect with the financial statements; or
- proper and sufficient accounting records have not been kept; or
- the financial statements are not in agreement with the accounting records and returns; or
- we have not received all the information and explanations we require for our audit.

Feltons

Feltons
Chartered Accountants & Statutory Auditors
1 The Green
Richmond
Surrey
TW9 1PL

Date: 12 September 2017

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

# NASS: Statement of Financial Activities

*For the year ended 31 December 2016*

| | | | Restricted Funds | | | | |
|---|---|---|---|---|---|---|---|
| | Note | Unrestricted Fund £ | Branch Funds £ | Branch Developt Fund £ | Fergus Rogers Fund £ | Total Year ended 31 Dec 2016 £ | Total Year ended 31 Dec 2015 £ |
| **Income from:** | | | | | | | |
| Donations and legacies | 2 | 307,189 | 212,562 | - | - | 519,751 | 534,575 |
| Charitable activities | 3 | 140,651 | - | - | - | 140,651 | 39,808 |
| Investments | 4 | 23,485 | 132 | - | - | 23,617 | 2,422 |
| | | - | - | - | - | - | - |
| Total income | | 471,325 | 212,694 | - | - | 684,019 | 576,805 |
| Expenditure on | | | | | | | |
| Raising funds | 5 | 122,615 | 917 | - | - | 123,532 | 130,486 |
| Charitable activities | 6 | 430,056 | 201,391 | - | 250 | 631,697 | 634,704 |
| Total expenditure | | 552,671 | 202,308 | - | 250 | 755,229 | 765,190 |
| **Net income (expenditure) from operations before transfers and investment gains** | | (81,346) | 10,386 | - | (250) | (71,210) | (188,385) |
| **Transfers between Funds** | | 2,509 | (2,509) | - | - | - | - |
| | | (78,837) | 7,877 | - | (250) | (71,210) | (188,385) |
| **Gains (losses) on revaluation of investments** | 10 | - | - | - | - | - | 191,248 |
| Net movement in funds | | (78,837) | 7,877 | - | (250) | (71,210) | 2,863 |
| Reconciliation of funds: | | | | | | | |
| Total funds brought forward | | 1,261,022 | 216,126 | 2,201 | 3,051 | 1,482,400 | 1,479,537 |
| Total funds carried forward | 18 | 1,182,185 | 224,003 | 2,201 | 2,801 | 1,411.190 | 1,482,400 |

The notes on pages 41 to 50 form part of these accounts.

# NASS: Balance Sheet

*31 December 2016*

| | Note | 31 December 2016<br>£ | 31 December 2015<br>£ |
|---|---|---|---|
| **FIXED ASSETS** | | | |
| Tangible assets | 9 | 12,131 | 16,907 |
| Investments | 10 | 792,513 | 747,540 |
| **Total Fixed Assets** | | 804,644 | 764,447 |
| **CURRENT ASSETS** | | | |
| Debtors and prepayments | 11 | 26,200 | 16,816 |
| Cash at bank and in hand | 12 | 658,117 | 759,033 |
| Total current assets | | 684,317 | 775,849 |
| **CREDITORS** | | | |
| Amounts falling due within one year | 13 | 77,771 | 57,896 |
| **NET CURRENT ASSETS** | | 606,546 | 717,953 |
| **TOTAL NET ASSETS** | | 1,411,190 | 1,482,400 |
| **CHARITABLE FUNDS** | | | |
| Unrestricted funds | 14 | 1,182,185 | 1,261,022 |
| Branch funds | 15 | 224,003 | 216,126 |
| Branch development fund | 16 | 2,201 | 2,201 |
| Fergus Rogers fund | 17 | 2,801 | 3,051 |
| **TOTAL CHARITABLE FUNDS** | 18 | 1,411,190 | 1,482,400 |

The accounts set out on pages 39 to 50 were approved by the Trustees on 17 June 2017.

**Raj Mahapatra**

*Chairman*

**Simon H Frost**

*Treasurer*

# NASS: Notes to the accounts

*For the year ended 31 December 2016*

## 1. ACCOUNTING POLICIES

(a) ***Accounting convention***: The accounts have been prepared in accordance with the Statement of Recommended Practice : Accounting and Reporting by Charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS102) issued on 16/07/2014, the Financial Reporting Standard applicable in the United Kingdom and Republic of Ireland (FRS102), the Charities and Investment (Scotland) Act 2005 and the Charities accounts (Scotland) Regulations 2006 (as amended, and the Charities Act 2011 and applicable regulations.

The accounts have been prepared under the historical cost convention with items recognised at cost or transaction value unless otherwise stated in the relevant note(s) to these accounts.

The Society constitutes a public benefit entity as defined in FRS102.

(b) ***Designation of funds***: Restricted Funds are maintained where the funds raised are to be used for specific purposes. Accumulated surplus income, which forms the Fund's reserves, is retained in Unrestricted Funds. Reserves are maintained to meet the Fund's continuing obligations and to cater for future needs and contingencies. Unrestricted funds comprise those funds which the trustees are free to use for any purpose in furtherance of the charitable objects.

(c) ***Investments***: The investments are a form of basic financial instrument and are initially recognised at their transaction value and subsequently measured at their fair value at the balance sheet date and unrealised investment gains or losses are reflected in the Statement of Financial Activities.

(d) ***Subscriptions, donations and legacies***: All income is recognised once the Society has entitlement to the income, it is probable that the income will be received and the amount of income receivable can be measured reliably. Subscriptions from members are included in the Statement of Financial Activities when received. Donations and legacies from private and other sources are included in the Statement of Financial Activities when received. Gifts-in-kind are valued by the Trustees and are included at that valuation in the Statement of Financial Activities when received.

(e) ***Grants received***: Grants received from charitable organisations towards shared costs are included in the Statement of Financial Activities when received or deferred to the extent that they relate to future accounting periods. Grants from pharmaceutical companies, which are restricted to an overall limit of 25% of charity income averaged over the last 3 years, are treated similarly.

(f) ***Expenditure and liabilities***: 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. All expenditure is accounted for on an accruals basis as a liability is incurred. Expenditure includes any VAT which cannot be recovered, and is reported as part of the expenditure to which it relates. Costs of generating funds comprise the costs associated with attracting voluntary income. Charitable expenditure comprises those costs incurred by the charity in the delivery of its activities and services for the beneficiaries. It includes both costs that can be allocated directly to such activities and those costs of an indirect nature necessary to support them. Governance costs include those costs associated with meeting the constitutional and statutory requirements of the Society and include the audit fees and fess linked to the strategic management of the Society. Support costs are allocated to charitable activities in proportion to the estimated time expended by the Society's staff on these activities.

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 Society 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.

## 1. ACCOUNTING POLICIES - continued

*(g)* ***Fixed assets***: Fixed assets are depreciated at 25% per annum on a straight line basis.

*(h)* ***Branch Funds***: Funds held by branches are treated as Restricted Funds as such funds are primarily for use by branch members to facilitate appropriate treatment. Transactions at branches are reflected in the Statement of Financial Activities.

*(i)* ***Pension contributions:*** The Society operates a defined contribution pension scheme and the pension charge represents the amounts payable to the fund in respect of the year.

## 2. INCOME FROM DONATIONS AND LEGACIES

This category comprises income from all sources where the income is provided on a voluntary basis. It includes subscriptions, donations, grants, legacies and income form fundraising events. Where relevant the income has been increased by any Gift Aid received.

| | **Year to 31 Dec 2016 £** | Year to 31 Dec 2015 £ |
|---|---:|---:|
| **Unrestricted funds** | | |
| Subscriptions | 72,140 | 69,419 |
| Donations and grants | 125,509 | 96,372 |
| Fundraising events | 61,554 | 74,521 |
| Annual Draws | 11,193 | 9,719 |
| Legacies | 36,793 | 69,290 |
| Total | 307,189 | 319,321 |
| **Branch funds** | | |
| Subscriptions | 173,775 | 179,538 |
| Donations | 23,005 | 19,467 |
| Fundraising events | 11,530 | 14,248 |
| Other income | 4,252 | 2,001 |
| Total | 212,562 | 215,254 |
| **Branch Development Fund** | | |
| Donations | - | - |
| Total | - | - |
| **Fergus Rogers Fund** | | |
| Donations | - | - |
| Total | - | - |
| **Total voluntary income** | 519,751 | 534,575 |

## 3. INCOME FROM CHARITABLE ACTIVITIES

Income in this category is primarily associated with grants received to fund specific charitable activities. It includes income from trading and merchandise sales.

| | Year to 31 Dec 2016 £ | Year to 31 Dec 2015 £ |
|---|---|---|
| **Unrestricted funds** | | |
| Grants for specific activities | 133,909 | 31,000 |
| Merchandise sales | 6,742 | 8,808 |
| Total | 140,651 | 39,808 |
| | | |
| **Total income from charitable activities** | 140,651 | 39.808 |

## 4. INVESTMENT INCOME

Income in this category comprises interest, dividends and rental income earned on the Society's investments and bank deposits.

| | Year to 31 Dec 2016 £ | Year to 31 Dec 2015 £ |
|---|---|---|
| **Unrestricted funds** | | |
| Rental income received | 22,813 | - |
| Dividends received | 8 | 19 |
| Interest received | 664 | 2,258 |
| Total | 23,485 | 2,277 |
| | | |
| **Branch funds** | | |
| Interest received | 132 | 145 |
| Total | 132 | 145 |
| | | |
| **Total investment income** | 23,617 | 2,422 |

## 5. EXPENDITURE ON RAISING FUNDS

Costs in this category comprise those costs associated with generating income from all sources. Certain costs are excluded where the source of the income is a charitable activity such as shop trading but the Society does not undertake any of these excluded activities.

| | Year to 31 Dec 2016 £ | Year to 31 Dec 2015 £ |
|---|---|---|
| **Unrestricted funds** | | |
| Annual draw prizes and expenses | 2,958 | 4,266 |
| Fundraising expenses | 20,544 | 16,452 |
| Support costs (note 8) | 99,113 | 108,790 |
| Total | 122,615 | 129,508 |
| **Branch funds** | | |
| Fundraising expenses | 917 | 978 |
| Total | 917 | 978 |
| **Total costs of generating funds** | 123,532 | 130,486 |

## 6. EXPENDITURE ON CHARITABLE ACTIVITIES

(a) Charitable expenditure comprises all of the costs incurred by the Society in meeting its charitable objectives. These costs are summarised into the 3 main areas of charitable activity: research, campaigning, and education and support.

| | | Year to 31 Dec 2016 £ | Year to 31 Dec 2015 £ |
|---|---|---|---|
| **Unrestricted funds** | | | |
| Research | [note 6(b)] | 62,048 | 109,860 |
| Campaigning | [note 6(c)] | 125,168 | 100,664 |
| Education and support | [note 6(d)] | 234,126 | 204,157 |
| Governance costs | [note 7] | 8,714 | 10,453 |
| Total | | 430,056 | 425,134 |
| **Branch funds** | | | |
| Campaigning | | - | - |
| Education and support | [note 6(e)] | 201,391 | 208,546 |
| Total | | 201,391 | 208,546 |
| **Branch development fund** | | | |
| Grants made | | - | - |
| Total | | - | - |
| **Fergus Rogers Fund** | | | |
| Welfare – grants made | | 250 | 1,024 |
| Total | | 250 | 1,024 |
| **Total resources expended on charitable activities** | | 631,697 | 634,704 |

## 6. EXPENDITURE ON CHARITABLE ACTIVITIES - continued

(b) Expenditure on research from the Society's unrestricted funds comprised the following:

| | Year to 31 Dec 2016 £ | Year to 31 Dec 2015 £ |
|---|---|---|
| Grants for research and related costs | 33,730 | 78,777 |
| Support costs (note 8) | 28,318 | 31,083 |
| **Total research expenditure** | 62,048 | 109,860 |

(c) Expenditure on campaigning from the Society's unrestricted funds comprised the following:

| | Year to 31 Dec 2016 £ | Year to 31 Dec 2015 £ |
|---|---|---|
| Advertising and campaigning | 40,215 | 7,415 |
| Support costs (note 8) | 84,953 | 93,249 |
| **Total campaigning expenditure** | 125,168 | 100,664 |

(d) Expenditure on education and support from the Society's unrestricted funds comprised the following:

| | Year to 31 Dec 2016 £ | Year to 31 Dec 2015 £ |
|---|---|---|
| AS News | 15,906 | 14,927 |
| Literature, brochures and information | 62,189 | 9,723 |
| Patient and member conferences | 9,271 | 21,579 |
| Branch conferences and support | 5,170 | 2,513 |
| Support costs (note 8) | 141,590 | 155,415 |
| **Total education & support expenditure** | 234,126 | 204,157 |

(e) Expenditure on education and support from the Society's branch funds comprised the following:

| | Year to 31 Dec 2016 £ | Year to 31 Dec 2015 £ |
|---|---|---|
| Treatment by healthcare professionals | 159,716 | 155,470 |
| Hire of venues and facilities | 29,318 | 36,279 |
| Grants payable | 2,544 | 2,687 |
| Support costs (note 8) | 9,813 | 14,110 |
| **Total branch education & support expenditure** | 201,391 | 208,546 |

## 7. GOVERNANCE COSTS

Governance costs relate to the general running of the Society as a legal entity.

| | **Year to 31 Dec 2016 £** | Year to 31 Dec 2015 £ |
|---|---|---|
| Expenses paid to Trustees | **2,133** | 3,389 |
| Trustees meetings | **1,661** | 1,064 |
| Auditors' remuneration | **4,920** | 6,000 |
| **Total governance costs** | **8,714** | 10,453 |

The Trustees received no remuneration during the year (2015 – nil). Eleven Trustees claimed expenses during the year.

## 8. SUPPORT COSTS

Support costs comprise all of the costs, except governance costs, associated with the administration of the Society and the implementation of its charitable objectives.

(a) Central support costs incurred in the year comprised the following:

| | **Year to 31 Dec 2016 £** | Year to 31 Dec 2015 £ |
|---|---|---|
| Staff costs (note 8c) | **248,931** | 256,923 |
| Premises costs | **50,487** | 67,043 |
| Travel expenses | **9,607** | 12,599 |
| IT and Communications | **26,066** | 26,344 |
| Office costs | **10,426** | 12,525 |
| Insurance, legal and professional | **8,457** | 13,103 |
| **Total support costs** | **353,974** | 388,537 |

(b) Support costs are allocated to the Society's activities on the basis of the estimated time spent by the Society's paid staff on each activity. The allocation for the year is set out below:

| Charitable activities | **Year to 31 Dec 2016 £** | Year to 31 Dec 2015 £ |
|---|---|---|
| Research | **28,318** | 31,083 |
| Campaigning | **84,953** | 93,249 |
| Education and support | **141,590** | 155,415 |
| Fundraising activities | **99,113** | 108,790 |
| | **353,974** | 388,537 |

Branch support costs incurred in the year amounted to £9,813 (2015 - £14,110), and are wholly attributable to education and support.

## 8. SUPPORT COSTS - continued

c) Staff costs incurred during the year consisted of:

| | **Year to 31 Dec 2016 £** | Year to 31 Dec 2015 £ |
|---|---|---|
| Wages and salaries | **214,846** | 227,665 |
| Social security contributions | **19,656** | 21,726 |
| Pension contributions | **7,629** | 5,713 |
| Recruitment, training and other costs | **6,800** | 1,819 |
| **Total staff costs** | **248,931** | 256,923 |

d) Information about employees:

| | **Year to 31 Dec 2016** | Year to 31 Dec 2015 |
|---|---|---|
| Average number of employees during the year | **6** | 6 |
| Number of employees for whom pension contributions have been made | **4** | 4 |
| Number of employees whose emoluments exceeded £60,000 per annum | | |
| £70,000 to £80,000 | **1** | 1 |

## 9. TANGIBLE FIXED ASSETS

| | **Office Equipment £** | **Total £** |
|---|---|---|
| Cost at 31 December 2015 | 22,649 | 22,649 |
| Additions in the year | - | - |
| Disposal in the year | - | - |
| **Cost at 31 December 2016** | **22,649** | **22,649** |
| Depreciation at 31 December 2015 | 5,742 | 5,742 |
| Depreciation charge for the year | 4,776 | 4,776 |
| Disposal in the year | - | - |
| **Depreciation at 31 December 2016** | **10,518** | **10,518** |
| Net book value at 31 December 2015 | 16,907 | 16,907 |
| **Net book value at 31 December 2016** | **12,131** | **12,131** |

## 10. INVESTMENTS AND INVESTMENT GAINS

| **Investments** | **31 Dec 2016** | 31 Dec 2015 |
|---|---|---|
| | **£** | £ |
| **Leasehold property at valuation** | | |
| Balance at the start of the year | 675,000 | 351,000 |
| Additions in the year (conversion costs) | 45,513 | 202,587 |
| Revaluation Surplus | - | 121,413 |
| | **720,513** | 675,000 |
| **Bronze statues, at valuation** | **72,000** | 72,000 |
| **Listed shares, at valuation** | - | 540 |
| | **792,513** | 747,540 |

| **Investment gains** | **31 Dec 2016** | 31 Dec 2015 |
|---|---|---|
| | **£** | £ |
| Leasehold property at valuation | - | 179,248 |
| Bronze statues, at valuation | - | 12,000 |
| Listed shares, at valuation | - | - |
| | - | 191,248 |

In 2015 the Society completed the conversion of its former office in Richmond in to two residential flats and these were reclassified as investments in the Society's accounts. The flats have been professionally valued at a combined amount of £715,000. A final payment of £42,500 in relation to the conversion work and certain legal costs were paid during the year. Because the Society is an unincorporated association, title to these two properties are registered in the name of two trustees.

The bronze statues, by Elizabeth Frink, were acquired at a cost of £2,156 in 2009. These were revalued in September 2010 and the unrealized gain of £59,844 was reflected in the Statement of Financial Activity for that period. A further valuation was obtained in December 2015 and an additional unrealized gain of £12,000 was reported.

The listed shares were sold in February 2016 and a small loss was incurred.

## 11. DEBTORS AND PREPAYMENTS

| | **31 Dec 2016** | 31 Dec 2015 |
|---|---|---|
| | **£** | £ |
| Office lease deposit | **8,100** | 8,100 |
| Prepayments | **8,100** | 8,100 |
| Sundry debtors | **10,000** | 616 |
| | **26,200** | 16,816 |

## 12. CASH AT BANK AND IN HAND

| | **31 Dec 2016** | 31 Dec 2015 |
|---|---|---|
| | **£** | £ |
| Deposit account balances held centrally | **350,290** | 449,651 |
| Deposit account balances held by branches | **219,110** | 215,661 |
| Current account balances | **81,725** | 87,755 |
| Cash in hand | **6,992** | 5,966 |
| | **658,117** | 759,033 |

## 13. CREDITORS: Amounts falling due within one year

| | 31 Dec 2016<br>£ | 31 Dec 2015<br>£ |
|---|---|---|
| Taxes and Social Security | 7,236 | - |
| Sundry creditors | 10,199 | 8,543 |
| Deferred income | 52,401 | 37,000 |
| Accrued expenses | 7,935 | 12,353 |
| | 77,771 | 57,896 |

There are no creditors falling due after more than one year (2015 – nil).

## 14. UNRESTRICTED FUNDS

Unrestricted Funds represent the accumulated surplus income of the Society and form the Society's Reserves. These funds are expendable on the Society's charitable activities without restriction. The Society's policy on Reserves is explained in the Trustees' Report.

## 15. BRANCH FUNDS

Funds held by the Society's branches are treated as restricted funds. The use of these funds is limited to the furtherance of branch activities in support of the Society's charitable activities. Amounts held by branches in excess of 2 years' normal expenditure are required to be transferred to the Society's Unrestricted Funds. No such transfers were made in the year nor in the previous year.

During the year grants totalling £390 (2015 - £550) were paid to branches from Unrestricted Funds and donations totalling £2,899 (2015 - £968) were made by branches to Unrestricted Funds.

## 16. BRANCH DEVELOPMENT FUND

Funds held in the Branch Development Fund have been raised to support the development of the Society's branch network. During the year £nil (2015 - £nil) was transferred from branch funds for this purpose.

## 17. FERGUS ROGERS FUND

Funds held in the Fergus Rogers Fund have been raised to support 2 areas of the Society's charitable activities: research and welfare into AS and related conditions. During the year £250 (2015 – £1,024) was expended on welfare.

## 18. RECONCILIATION OF CHARITABLE FUNDS

| | **Unrestricted Fund £** | **Branch Funds £** | **Branch Dev Fund £** | **Fergus Rogers Fund £** | **Total Funds £** |
|---|---|---|---|---|---|
| Tangible assets | 12,131 | - | - | - | 12,131 |
| Investments | 792,513 | - | - | - | 792,513 |
| Debtors and prepayments | 26,200 | - | - | - | 26,200 |
| Cash at bank and in hand | 427,177 | 225,938 | 2,201 | 2,801 | 658,117 |
| Less creditors | (75,836) | (1,935) | - | - | (77,771) |
| **Total charitable funds** | **1,182,185** | **224,003** | **2,201** | **2,801** | **1,411,190** |

For the year ended 31 December 2015, all Tangible assets, investments and debtors related to unrestricted funds. Of the cash at bank and in hand balance of £759,033, an amount of £226,832 related to restricted funds. Of the creditors balance of £52,442, an amount of £5,454 related to restricted funds.

## 19. FIRST TIME ADOPTION OF FRS102

It is the first year that the Society has presented its financial statements under SORP 2015 and FRS 102 and the following disclosures are required in the year of transition. The last financial statements prepared under previous UK GAAP were for the year ended 31 December 2015 and the date of transition to FRS 102 and SORP 2015 was therefore 1 January 2015. As a consequence of adopting FRS 102 and SORP 2015, a number of accounting policies have changed to comply with those standards.

The policies applied under the Society's previous accounting framework are not materially different to FRS 102 and have not impacted on funds or net income/expenditure.

## 20. RELATED PARTY TRANSACTIONS

There were no related party transactions in the year.

## 21. FINANCIAL COMMITMENTS

At 31 December 2016 the Society had future minimum lease payments under non-cancellable operating leases totalling £89,100 which represents payments up to September 2019.